VIGILANCE EXPERIENCES: CANCER PATIENTS, FAMILIES, AND NURSES

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DEDICATION

This dissertation is dedicated to patients with cancer, who like heroes from mythology begin their epic journey, to family members of cancer patients who endure the storm to shield their loved ones, and to oncology nurses, who create balance from chaos through their dedication.

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ABSTRACT

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Cancer disease, treatment, and errors in health care put patients at increased risk for poor outcomes. To improve outcomes and protect patients, researchers recommend increased vigilance; yet, research on vigilance in health care is minimal. There are even fewer studies on patients, family members, and nurses' experiences of vigilance, although such studies could contribute to understanding mechanisms that foster vigilance within and across groups.

The purpose of this study was twofold: Aim 1 was to describe the experiences of vigilance as perceived at the individual levels of patients receiving treatment for cancer, family members of a patient with cancer, and oncology nurses. Aim 2 was to evaluate commonalities in the lived experience of vigilance as described by patients receiving treatment for cancer, one of their family members, and a nurse caring for them.

A qualitative, empirical phenomenological method guided this research. The sample consisted of 7 cancer patients, 6 family members of cancer patients, and 7 oncology nurses. Broad, data generating questions were constructed to elicit rich, narrative descriptions of participants' experiences with vigilance, which were audio-taped and transcribed.

Each participant group data were individually analyzed, using Colaizzi's method. Significant statements from each participant were identified, restated in the language of science, and interpreted for formulated meanings. From formulated meanings, theme categories were constructed and merged across participants within the groups. A narrative of the commonalities of the experience within each group was developed. The across group commonalities were analyzed in a matrix.

A total of 5,272 total significant statements were derived from three participant groups. Eleven themes were derived from patient data, ten from family member data, and ten from nurses' data. Vigilance appeared as a complex, multidimensional phenomenon, which is implicitly shared within and across these three groups. Common vigilance themes found across all 3 groups included: identification of threats, the key importance of knowledge, trust, hope and connectedness, the beyond the call of duty nature of vigilance, ways vigilance takes energy and effort, what promotes and interferes with vigilance, and vigilance as a shared phenomenon. Implications were found for the healthcare system and nursing care.

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CHAPTER I

Vigilance Experiences: Cancer Patients, Families, and Nurses

Cancer patients are at increased risk for poor outcomes from two sources: their disease and treatment process and from errors in health care. Cancer patients are at risk for many complications related to their treatment. For example, up to 40% of cancer patients develop infections which progress to life-threatening sepsis [1]. Of those cancer patients that develop sepsis, the mortality rate is high, from 50 to 80% depending on the type of cancer [1, 2]. Other possible side effects of treatment include fatigue, cognitive effects, nausea, constipation, and oncologic emergencies such as tumor lysis syndrome [3-8]. Patients already at risk for poor outcomes are further at risk from healthcare system errors. In 2000, the Institute of Medicine (IOM) released its report, “To Err is Human” [9]. This report was a result of an investigation performed by the Committee on the Quality of Health Care in America. The focus of the investigation was on errors in healthcare. The estimates of deaths related to healthcare errors ranged from 44, 000 to 98, 000 deaths per year. There have been investigations into the roles that nurses have in medication errors as well as errors related to lack of nursing experience [10, 11].

To decrease error potential, the Joint Commission on Accreditation of Healthcare Organizations has increased its focus on safety [11] and the IOM has recommended improvements to the healthcare system. The IOMs recommendations include the use of the Complex Adaptive Systems (CAS) framework to understand the system complexity involved in errors and patient safety [9]. CAS function in unpredictable and surprising ways, which creates the need for members within such systems to be alert and adaptable. A major consideration in examining CAS and errors is an understanding of how system components and their interrelationships contribute to errors. For example, if a drug company switches packaging of a medication to an unfamiliar design, and the pharmacist puts the wrong medication dosage in the medication bin, and the nurse gives

the wrong dosage of medication, it is not just the nurse alone at fault for the wrong medication dosage being delivered. In this example, multiple system interactions led to one medication error. In order to prevent future error, more than one area in the system needs to be improved. One way to improve individual, as well as system performance related to patient safety and quality of life outcomes (patient sense of well-being, satisfaction, and safe passage through complex healthcare systems) may be through the study of vigilance. Although vigilance is often discussed as a necessary, watchful behavior of healthcare providers, there is virtually no research in healthcare defining what vigilance is or how it is used to promote positive patient outcomes.

For example, lack of vigilance is often identified as a theme in error reports. Error reporting instruments designed to measure incidents in health care use lack of vigilance as a common category in classifying errors [12-14]. Despite researchers indicating a relationship between vigilance and healthcare error, little is known about the experiences of vigilance and how, if at all, they are connected to patient outcomes. Since vigilance remains undefined and vigilance behaviors in health care have not been identified, it is difficult to draw any substantial conclusions from error reporting forms about the role of vigilance or lack thereof in healthcare incidents. What is known about vigilance in health care is that healthcare professionals and the patients and families they care for seem to have divergent views of what vigilance is. Healthcare professionals have measured vigilance in terms of task performance (e.g., number of minutes to answer a patient call light), yet evidence suggests that patients and families view vigilance as being on a continuum [15-19].

No studies have been done to identify the commonalities of individual experiences of vigilance from key perspectives of patients, family members, and healthcare professionals, particularly nurses. Understanding the individual's experience is a necessary first step in a planned research program aimed at understanding vigilance at

different levels, within complex healthcare environments. Ultimately, such understanding should contribute to the development of interventions to increase vigilance and appropriate means to measure vigilance. The purpose of this first study was to explore vigilance as a lived experience from three perspectives: the patient, the patient's family, and the nurse.

Problem Statement

Numerous studies recommend vigilance as a way to prevent negative outcome [see Appendix A]. In oncology, vigilance is presented as useful to decrease mortality, through early cancer detection and to decrease morbidity by being watchful for early signs and symptoms of treatment-related side effects [20, 21]. Despite such numerous recommendations several issues regarding vigilance are not understood. First, vigilance has been studied from limited perspectives. In the past vigilance was conceptualized as a physiological response to signals, and therefore has been investigated quantitatively as a measurement of individual's response times to signals [22-24]. Few studies have qualitatively examined vigilance experiences of patients, their family members, or nurses [18]. Although the literature implies that vigilance occurs between persons, nowhere has vigilance been studied as a shared process. Moreover, research studies in health care have not used a consistent population or methodology in order to examine vigilance. Therefore, limited conclusions can be reached about the true nature of vigilance from previous research studies. Second, the context of Complex Adaptive Systems has not been considered in previous studies on vigilance. In order to begin to be able to explicate vigilance, it must be examined from more than one perspective and within the context of Complex Adaptive Systems. Third, vigilance is an implicit and assumed action in health care. The way in which persons, whether they are patients, families, or nurses, are supposed to exhibit vigilance is taken for granted. Until a more comprehensive understanding of vigilance is developed and what people recognize as vigilance is

identified, recommendations to use vigilance as a means to increase patient safety and sense of well-being are ineffective.

One way to begin to understand implicit phenomenon is to investigate it from an existential-phenomenological perspective. This perspective is useful to reveal the extraordinary in the everyday ways that vigilance is experienced [25]. The phenomenological study proposed for this dissertation was to understand how vigilance is experienced by patients, families, and nurses and was a necessary first step to develop a program of research on vigilance. Future focus will be on vigilance as a multidimensional, interactive process as it occurs in the complex healthcare environment. Ultimately the goal is to develop interventions to encourage vigilance partnerships as a way to prevent negative outcomes.

Specific Aims

Specific Aim 1

Describe the experiences of vigilance as perceived at the individual levels of patients receiving treatment for cancer, a family member of a patient with cancer, and a nurse providing care to patients experiencing cancer.

1.1 What is the lived experience of vigilance from the perspectives of patients receiving treatment for cancer?

1.2 What is the lived experience of vigilance as perceived by family members of patients receiving treatment for cancer?

1.3 What is the lived experience of vigilance as perceived by nurses caring for patients receiving treatment for cancer?

Specific Aim 2

Evaluate commonalities in the lived experience of vigilance as described by patients receiving treatment for cancer, one of their family members, and a nurse caring for them. By examining themes for commonalities, any differences will also be likely to emerge.

2.1 What are commonalities in the experience of vigilance across the three groups?

CHAPTER II

Review of the Literature

In past research, vigilance has been conceptualized in different ways. In the defense industry, psychological studies, and some healthcare studies, vigilance has been conceptualized as a response to stimulus [22-24, 26]. However, in qualitative studies examining families' experiences or patients' experiences with vigilance, vigilance is presented as a very complex phenomenon [15-19]. A review of the historical research concerning vigilance as well as the way in which vigilance has been examined in healthcare research will provide an overview of the current conceptual underpinnings of vigilance.

Conceptual Issues Related to Vigilance

To better understand the historical underpinnings of vigilance and its current conceptualizations in health care, literature was reviewed in the following areas: 1) Historical studies of vigilance from a task performance perspective; 2) Vigilance in health care-task performance versus complex phenomenon; 3) Healthcare providers' perspectives vigilance; 4) Patients' perspectives on vigilance; 5) Family members' perspectives on vigilance; 6) Cancer-representative of the best case for vigilance; and 7) Complex Adaptive Systems and vigilance.

In addition to the review of literature, vigilance was further analyzed using concept analysis techniques. These techniques allowed for discovery of more in depth knowledge related to vigilance. Analysis presented includes: 1) Vigilance clarification and the consideration of meta synthesis; 2) Terms closely related to vigilance; 3) Vigilance definitions; 4) Determining adequacy of definitions of vigilance; 5) Attributes, antecedents, and consequences of vigilance; and 6) Derivation of an adequate definition of vigilance.

Vigilance Conceptualized as Task Performance: Historical Studies

Vigilance as a concept emerged in the defense industry [23]. Vigilance was used in detecting radar signals of approaching enemies. World War II was an impetus to develop more knowledge about vigilance, in order to better train radar operators. In response to this need, Mackworth performed the first sound research studies related to vigilance [26]. The Clock Test, in which participants watched a clock-like machine with a rotating clock hand, was constructed to simulate the task of stimuli detection by radar operators. Participants were to identify points at which the clock hand suddenly moved faster than it previously had been moving. In addition to the Clock Test, Mackworth carried out several experiments, while controlling for extraneous variables, to examine how rest, interruptions, incentives, knowledge, medications, environmental temperature, and signal intervals affected the ability to maintain a state of vigilance [24]. Mackworth essentially concluded that vigilance performance was a state-of-being and a matter of stimulus-response conditioning [23]. From such studies, detractors and contributors to vigilance performance were defined. Detractors from vigilance included 1) Long tasks; 2) Boredom; 3) Increased number of false alarms; 4) Isolated work environment; 5) No evaluation of efficiency; 6) Difficult tasks; and 7) Long response times [23]. Contributors to vigilance were things that were oppositional to the detractor list, such as short tasks and varied environment to stave off boredom.

Implicit in the view of vigilance as task performance are the assumptions that vigilance is a knowledgeable response, in that vigilance as task performance requires the ability to be both physiologically responsive, mentally alert, or aware and knowledgeable about a situation. Mackworth's landmark studies of vigilance led to the development of several vigilance theories, including Inhibition Theory, Reinforcement Theory, Filter Theory, Expectancy Theory, Arousal Theory, and Signal Detection

Theory [22, 26]. Table 1 provides brief descriptions for each of these early vigilance theories. The commonality among these theories is that vigilance was viewed as a task and measured by physiological responses to signals [26]. Critiques of these vigilance theories included a lack of both conceptual clarity and operationalization of associated terms, such as the definition of stimulus [22].

Table 1. Summary of Early Vigilance Theories

Inhibition Theory	• A decrease in signal detection is similar to extinction that occurs related to non-reinforced responses-often related to fatigue. Signal detection is thought to be related to "classical conditioning".
Reinforcement Theory	• Similar to "operant conditioning". Detection of the signal is believed to be the reinforcement-Although a plausible theory, not much attention has been given to this.
Filter Theory	• Vigilance is viewed as data-processing which occurs in the human perceptual system. Decreased human perceptual capacity leads to filtered information in order to decrease perceptual overload.
Expectancy Theory	• Previous signals determine the observer predictions about future occurrences; this expectancy determines performance level.
Arousal Theory	• Both signals and non-signals are used to maintain alertness.
Signal Detection Theory	• Mathematically-based theory of decision processes in visual detection. It is not just the overall ability to detect signals that decreases, but that weak signals are missed more often. This theory allows for data collection on false alarms. Only percentages of detections are recorded, so detection is not either / or.

Vigilance Conceptualized as a Complex Phenomenon: Healthcare Studies

Vigilance research is most commonly found related to the defense industry; a very limited number of studies have focused directly on vigilance in the context of health care. Rather than directly studying vigilance in the context of healthcare, vigilance has generally emerged as one of several themes in studies examining qualitative

experiences in a variety of healthcare situations. Studies in which vigilance emerged as a theme are discussed in the following sections. Studies in which vigilance was the direct focus were reviewed in relation to the purposes of the study, the method, sample, theoretical perspectives, and findings and then critiqued [see Table 2].

Table 2. Summary of Studies Directly Examining Vigilance in the Context of Healthcare

Author	Purpose	Sample	Methods	Theoretical Perspective& Measures	Findings	Critique
Meyer, [18]	To explore, describe, and analyze the process of vigilance in women who had migraine headaches to develop a substantive theory of the phenomenon	22 women with migraine headaches	Qualitative-grounded theory	None a priori	Vigilance is a process used by women experiencing migraines in order to maximize social functioning. Several themes were revealed including: Watching out, Making the Connections, and Calculating the risk.	• Sample all moderate SES status and highly educated-All had health insurance • No understanding of vigilance in the context of complex systems nor interactions with healthcare providers
Carr [15]	To examine vigilance or families' close protective involvement with their hospitalized relatives	8 relatives of patients in acute care neurological units	Qualitative-ethnography	Leininger's Cultural Care Diversity / Universality	Vigilance is a caring phenomenon expressed by families of hospitalized patients in the context of culture as framed by Leininger's theory: Themes included: Commitment to care, Emotional upheaval, Resilience.	• Theory seemed to be 'force fit' to examination of vigilance. • The actual number of interviews performed is unclear.
Mahoney [27]	To obtain descriptions of the caregiving phenomenon from family caregivers of individuals with Alzheimer's disease	Sample size not provided Family caregivers of patients with Alzheimer's disease	Qualitative-no specific method identified	Atheoretical Subsequent development of the Caregiver Vigilance Scale	Vigilance is a way caregivers ensure the unique needs of the patient are recognized. Themes included: Watchful supervision, Protective intervening, and On duty.	• Subjective reports of "hours on duty". • Vigilance was conceptualized as a task performance-No literature review of vigilance. • Actual size of sample unclear. Messages posted on Internet by caregivers were analyzed per message not per participant.
Howard et al. [28]	To examine effects of sleep deprivation on clinical performance of anesthesia residents (implied)	12 Anesthesia residents	Quantitative	Atheoretical Sleep Disorders & Owl and Lark Questionnaires Actigraphy recordings Psychomotor tests related to simulated cases	No significant difference in number of errors related to clinical performance between sleep deprived versus sleep extended groups during simulated anesthesia administration.	• Limited Statistical Power. • Vigilance narrowly conceptualized as task performance. • Simulated setting.

Perspectives on Vigilance

Healthcare providers' perspectives on vigilance. Similar to the defense industry, the limited perspective of vigilance-as-task is commonly found in literature relating to health professionals. The vigilance-as-task view has been adopted particularly in the field of anesthesia. One quantitative study focused on healthcare professionals and vigilance was found [28]. In this study vigilance was viewed as a physiologic response to stimuli that could be impaired by lack of sleep. Two different groups of anesthesia residents were exposed to two different sleep conditions: extra time to sleep versus sleep deprivation. During a videotaped, simulated operation, the responses of the participants were scored through task analysis. Prior to the simulation, participants completed questionnaires (The Sleep Disorders Questionnaire and the Owl and Lark Questionnaire) to determine preexisting conditions, which may have predisposed the participants to decreased levels of vigilance, even before being sleep deprived. During the simulation, tests of vigilance pertained to measurement of psychomotor responses such as reaction times, memory recall, mood analysis, and measurement of sleepiness. Level of vigilance was determined based on scores on test measurements. Findings from this study indicated that there was progressive task performance impairment after sleep deprivation; however, the differences between errors made in the two sleep conditions were not significant. Major limitations of the study are that it was conducted as a simulation of a clinical environment. The authors noted that the measures were not reflective of actual work skills and did not capture the complexity of the real work environment.

The conceptual and methodological underpinnings of the Howard et al. [28] study suggest that vigilance was conceived as a task performance, with similar detractors and contributors as found in the earlier studies performed within the defense industry. However, this view, as noted by the authors, did not reflect the complexities of the work environment. The authors' conclusion implies that vigilance-as-task performance is

actually one dimension of a larger phenomenon of vigilance. Vigilance described as a lived experience may address complex elements of the phenomenon that vigilance viewed as a task performance does not address.

Patients' perspectives on vigilance. Unlike health professionals, patients' and family members' descriptions of vigilance indicate it is a multidimensional phenomenon. One qualitative study examined dimensions of vigilance described by patients. Meyer [18] conducted semi-structured interviews, guided by grounded theory, to elicit responses regarding the presence of vigilance. Meyer interviewed women who had a medical diagnosis of migraine headache, and found that women used vigilance as a process of watching out to ultimately inform decision-making regarding their migraine headaches. Morse and O'Brien [29] also conducted a qualitative study of trauma patients who were interviewed regarding their experiences pre-, during, and post-trauma. Although the authors did not set out to study vigilance, vigilance ultimately emerged as a process that allowed preservation of self. In addition, trust was an influencing variable in this study. If patients felt they could not trust someone to take over vigilance for their condition, the patient continued to use his or her own energies to maintain vigilance. Only when patients felt they could trust a healthcare provider would they allow the provider to become vigilant on their behalf.

Family members' perspectives on vigilance. Studies of family member vigilance also suggest that vigilance is a complex phenomenon. One study examined vigilance directly, and in other family studies vigilance emerged as a part of caregiving. Carr [15] conducted an ethnographic study using informal, semi-structured interviews and participant observation to inductively examine vigilance as perceived by family members of hospitalized patients. Although Carr noted that dynamism influenced level of vigilance, the presence of vigilance and how family members expressed vigilance was the focus of

this study. Vigilance was interpreted as a caring pattern exhibited by families during patients' hospital stays.

Being in the position of caregiver seems related to vigilance. Mahoney [30] conducted a qualitative study of caregivers of patients with Alzheimer's. Five categories reflective of vigilance were discovered: "watchful supervision, protective intervening, anticipating, on duty, and being there" (p. 26). Mahoney indicated that family vigilance over time is tiring for the family caregiver. Implications of becoming fatigued when a person is a caregiver and needs to remain vigilant, requires more study. Subsequent to studying caregivers vigilance for patients with Alzheimer's Disease, Mahoney et al. [27] developed and tested the Caregiver Vigilance Scale. Internal consistency of the 4-item scale was determined using Cronbach's alpha which was reported at 0.66. Ultimately the researchers concluded that the scale should be used primarily in conjunction with other caregiving measures to capture time spent supervising or performing care-related activities. The suggestion that the Caregiver Vigilance Scale be used with other scales in order to capture time-on-task suggests that Mahoney subscribed to the view of vigilance as a task, despite derived categories from participants which seem to indicate vigilance was more than just a time-related task. Mahoney et al. focused the development of the Caregiver Vigilance Scale on fatigue related to caregiving based off the themes from the initial study, *Being there and On duty*, but did not address the other three categories (*Watchful supervision, Protective intervening, Anticipating*) that emerged from the initial study on caregiver vigilance. It is unclear why the researchers did not take the remaining three categories into account as they developed the Caregiver Vigilance Scale.

Unlike Mahoney's conclusion of vigilance as a task performed by family caregivers, studies conducted with cancer patients and their families about their experiences revealed vigilance to be a complex phenomenon. Wilson and Morse [19] conducted a qualitative study examining the experiences of husbands living with wives undergoing

chemotherapy. Husbands described vigilance as allowing them to care for and protect their wives. Krumwiede et al. [17] and Eggenberger, Krumwiede, Meiers, Bliesmer, and Earle [16] described a grounded theory study of how rural family members understand experiences of caring for neutropenic cancer patients. Family vigilance emerged as a process used to protect the neutropenic cancer patient [17]. Behaviors associated with family vigilance were described as "monitoring symptoms, protecting the patient from infection, and advocating for effective management of neutropenia" [16] (p. 618). Perhaps vigilance emerged as a theme in these studies in part because of the high need to be vigilant when people have cancer or are caring for people with cancer. The possibility that cancer populations may experience the phenomenon of vigilance more often than other populations led to a review of cancer-specific healthcare literature.

Oncology perspectives on vigilance. In the oncology literature, the use of vigilance is alluded to as a way to decrease morbidity and mortality. Cancer patients have a particular need to be vigilant and to be supported through family members and nurses. The threats for cancer patients are many and complex. Further, the experience of cancer and its subsequent treatment is often dynamic, with both acute and chronic presence of threats. A review of the cancer literature revealed the many threats that cancer patients and their families experience [6, 8, 31-33] with the need for vigilance being frequently implied [16, 17, 34-37]. Cancer patients experience threats from the symptoms associated with their disease. Some of the common symptoms associated with cancers are bleeding, bruising, fatigue, fevers, and infections [21]. Besides the symptoms associated with disease, side effects from treatment are potential threats. Treatment-related side effects include risk for infections, bleeding, nausea and vomiting, diarrhea or constipation, and central nervous system effects to name a few [20, 21]. The need for vigilance in cancer patients and their family members does not end when treatment for the cancer ends. Instead, cancer is more and more being considered a chronic illness with the need for

lifelong vigilance. Cancer patients risks do not end once the cancer is removed or in remission. Post-treatment risks may include lingering effects from the disease and treatment. Treatment for cancer may produce toxicity for certain organs including the heart, the renal system, the nervous system, and the immunologic system, to name a few [20]. Cancer survivors are at increased risk for a recurrence of cancer and need to remain vigilant for symptoms that the cancer may have returned [20]. The risky nature of cancer and its treatment, as well as an ongoing need for effective vigilance post treatment indicates that cancer is a case which gives rise to the phenomenon of vigilance. Patients experiencing cancer provide representation of vigilance through their experiences with the disease and treatment. However, the literature indicated that family members, as well as nurses participate in vigilance experiences which may be inextricably linked with the cancer patient's own experiences of vigilance.

The oncology literature indirectly indicates that vigilance occurs between persons. Cancer is a family disease with patient and family quality of life reflective of one another [38]. Nurses play a significant role in the support of the patient and therefore, family member, especially in the hospital environment. Nurses, because they give direct patient care, are the healthcare providers who most often identify subtle changes in the patient condition which have the potential to lead to serious complications [21]. A picture emerges that indicates that cancer patients rely on families for support, and cancer patients' families seek support from healthcare providers [17]. Vigilance seems to contribute to a sense of support. Vigilant nursing care has been linked with patient comfort and patient satisfaction. Patients recognize nurses' vigilance on their behalf, which leads to patients feeling safe [39] and comforted [40-42]. On the other hand, the oncology literature implies that, when vigilant behaviors are not demonstrated by healthcare providers, there are negative outcomes. A lack of knowledge, particularly regarding diagnosis and treatment of cancer [36, 37], and inattention and inaction on the

part of the healthcare provider [34] lead to patient and family distress [37], patient and family dissatisfaction [35], a decreased sense of well-being on behalf of the family of the cancer patient [34], conflict between family members of cancer patients and the patients themselves [16], and mortality of cancer patients [35]. The aforementioned aspects of vigilance are embedded in the literature and have not been studied directly as vigilance experiences. What seems implied in this body of literature is the presence, or perhaps need for vigilance partnerships or triads among patients, family members, and healthcare providers. However, what is not presented in the literature is how patients, families, and nurses experience vigilance within complex healthcare systems and what patterns, if any, may be found across these three experiences.

Complex Adaptive Systems and Vigilance

The literature indicates that vigilance is a complex, multidimensional phenomenon. The complexity inherent in healthcare environments further increases the complexity of vigilance. There are many factors in complex environments that may impede the use of vigilance [43]. Therefore, compelling reasons exist to consider Complex Adaptive Systems (CAS) in the study of vigilance. The IOM has recommended that healthcare systems adopt Complexity Science as a theoretical way to improve performance in CAS such as hospitals. In contrast to the linear causal models of thought, where A leads to B, complex adaptive systems are characterized by many different agents that interact and mutually affect one another [44]. CAS are inherently associated with high risk, which increases the chance of errors. Vigilance is a necessary response to risk (threat) within complex adaptive systems and vigilance is important to prevent errors [43, 45]. Nurses work in CAS characterized by ever-changing environments and interactions with many disciplines, patients, and families. Uncertainty and risk increases as changes in environment and interactions increase [11]. The complexity of nurses' work with patients is further increased by complex disease processes, such as those exemplified with

cancer [44]. Therefore, vigilance is a necessary response by nurses to their environments and to the patients and families with whom they work. Because CAS are always changing and unpredictable, the focus of evaluation should be on the process of establishing quality relationships among nurses, patients, and families, instead of on predicting linearly derived outcomes [44]. In CAS, learning takes place when persons with diverse points of view enter into meaningful relationships with one another [46-54]. What is learned from persons in such relationships allows them to better adapt to the complex, ever changing environment, disease, and treatment process. When the focus is on establishing relationships among individuals, quality care is reflected by the ways in which nurses, patients, and family members work together and learn from each other [55]. Outcomes such as patient safety then become byproducts of these relationships [11].

One way to establish quality relationships among nurses, patients, and families may be through shared vigilance, or the establishment of vigilance partnerships / triads. The principles of Complexity Science note that diversity, mutuality, and open communication will lead to a healthier system [44]. Nurses, patients, and families experience vigilance from a diversity of perspectives, but there were no discussions in the literature of vigilance as a mutual, openly shared experience among nurses, patients, and families. Therefore, we do not know if or how vigilance may influence patient safety or quality of relationships between nurses, patients, and families, particularly as it is experienced in the context of CAS.

In summary, the literature review thus far indicates a need for further clarification of the concept of vigilance as it is used in healthcare environments. What has been discovered indicates that historical underpinnings have influenced some of the views of vigilance in healthcare. However, vigilance as a task, as conceptualized historically is not the only way vigilance is viewed in health care. Results of qualitative studies indicate vigilance in health care is a complex phenomenon. Further, cancer specifically seems to

be a disease that promotes vigilance experiences for several reasons. Last, vigilance is experienced within complex healthcare environments, and yet environment has not emerged or been considered as a factor in previous studies.

Based on the review of literature it appears that vigilance in the healthcare literature is an ambiguous concept lacking boundaries and clarity. In order to reach a further understanding of vigilance for this dissertation research, a concept analysis was conducted. The following sections address this analysis and results.

Clarification of the Concept of Vigilance

Several methods exist that are useful to clarify a concept. In order to clarify the concept of vigilance the uses of the concept of vigilance and previous research were examined. First, meta-synthesis of existing qualitative research on vigilance was considered. Second, terms closely related to vigilance or used interchangeably with vigilance were examined. Third, previously used definitions of vigilance were compared and examined for adequacy. Next, attributes, antecedents, and consequences of vigilance were determined. Finally, a definition of vigilance was derived, based on the sum of the analysis of the concept.

Vigilance Clarification and the Consideration of Meta-Synthesis

One way to begin to clarify a concept is to combine results of previous research studies through a meta-synthesis, in order to identify constructs that emerge in the research findings. Meta-synthesis [56] is a growing trend in qualitative research which lends to the generalizability of qualitative research studies. The largest bodies of research in healthcare related to vigilance are qualitative in nature. Because the interest of this dissertation research is in the vigilance experiences of patients, families, and nurses, it seemed prudent to consider the possibility of using meta-synthesis to further clarify the concept of vigilance from any of these perspectives. Researchers have provided examples of the usefulness of aggregating qualitative data [57, 58]. Criteria for

aggregating qualitative study data includes examining studies that focus on similar populations and use similar research approaches [59, 60]. As can be seen from the previous discussion of healthcare research on vigilance [see Table 2], the research populations and methods have not been consistent, or even similar. Studies reviewed for this dissertation research used different samples; therefore it is difficult to draw conclusions about the phenomenon of vigilance. Aggregation of data from previous qualitative studies, which could lead to an understanding or identification of a theoretical construct of vigilance, has not been possible because those studies have not met the above criteria for aggregating qualitative research. In making population choices for the purposes of understanding and explicating a phenomenon, it is recommended that researchers consider what types of cases best represent the phenomenon. Samples can then be chosen carefully as representatives of the particular phenomenon [61].

Terms Closely Related to Vigilance

To date, the concept of vigilance has been presented in the literature ambiguously. Sometimes vigilance is viewed as a task performance and sometimes vigilance is presented as a complex process that entails more than just simply responding to a stimulus. One way to explore a concept for the purposes of clarification is to examine all the terms that have been used to describe the concept being analyzed, as well as to examine closely related terms. Of importance is the identification of antecedents, attributes, and consequences of the concept under study [62-64]. Confusion has surrounded the study of vigilance as many terms have been used to describe the concept of vigilance and no common definition of vigilance has been established.

In order to identify the attributes of vigilance and examine definitions related to vigilance, for this concept analysis, literature was reviewed that had a direct connection with the concept. In other words, sources were reviewed if they identified vigilance as a keyword when describing ways people were watchful. However, it was found that there

exist many uses and variations of the term, vigilance. A broader review of the literature led to the discovery that many terms are used to describe vigilance or vigilant actions, leading to lack of conceptual clarity and difficulty in identifying literature that addresses the study of vigilance [see Table 3].

Table 3. Terms Related to Vigilance

Acutely aware of one's surroundings
Alertness
Attention
-conscious attention
-watchful attention
Attentive
Awareness
-heightened awareness
-conscious awareness
Consciousness
Expectation
-expecting a threat
Intensity
Looking for something
Mindfulness
Monitoring
Subliminal perception
Watchfulness
-watching closely
Vigilance
-constant vigilance

19, 23, 29, 39, 65-78

In general, within the defense industry and other and related industries, such as airlines, the term vigilance was consistently used to refer to stimulus recognition and response. However, outside of these industries, vigilance has many labels. For example, in psychology and sociology literature vigilance is called consciousness [65, 72, 73], attention [69, 75, 76], vigilance [23, 69], monitoring [69], expectation [23], and "looking for something" [77]. In health care, terms used to describe vigilance have been both consistent and inconsistent with the previously stated terms. Several authors used the term awareness or some variation of it [29, 67, 74]. Other terms used within healthcare to describe vigilance were alertness, watchfulness [18, 68, 71], constant vigilance [19], and "expecting a threat" [39]. A lack of conceptual clarity exists, in part, because many terms have been used to describe

vigilance. Using many different terms leads to confusion about vigilance and ways to define it.

Definitions of Vigilance

In the literature, there is a lack of conceptual clarity regaridng vigilance. Definitions have lacked precision and many terms have been used to describe vigilance. Hinds [78] noted that conceptual clarity and precise definitions are important because they may lead to a better understanding of the concept and help in development of theoretical constructs, as well as influence clinical decision-making. In other words, when definitions lack precision, the concept is difficult to understand, identify, measure, or use to provide good patient care. There is no common definition or description of vigilance. In order to better understand the concept of vigilance, an analysis of previously used definitions is an important step in the concept clarification of vigilance.

Vigilance has been defined in two broad ways. One way implies that vigilance is a stimulus-response state as indicated by definitions such as “maintenance of wakefulness and performance” [28] or “a state of readiness to detect and respond to certain specified small changes occurring at random time intervals in the environment” [23]. Such definitions imply that vigilance is being viewed as a task performance. Another way vigilance is defined is as a process, such as a “process of watching out” [18]. Definitions similar to this one imply that vigilance is a complex phenomenon and perhaps is more complicated than responding to a stimulus or performing a task. A literature review led to further analysis of vigilance definitions.

Determining adequacy of definitions of vigilance. Definitions of vigilance were evaluated in two ways to determine definition adequacy. First, definitions of vigilance were evaluated for adequacy according to rules for definitions proposed by Cohen, Nagel, and Hamblin [78]. According to these definition rules, in order for a definition to be considered adequate, the definition should not be circular, should be stated in positive

terms, should not use obscure or figurative language, should imply some type of continuum, and contain some context within which the concept is embedded [78].

Each criteria suggested by Cohen, Nagel, and Hamblin [78] was used to determine definition adequacy. Application of these criteria revealed vigilance had not been adequately defined. The criteria as they applied to each definition will be briefly reviewed. All definitions of vigilance were found to be stated in positive terms. Interestingly, the definitions mirrored how the concept was viewed as either a task performance or a complex phenomenon. No definition merged components of vigilance as both task performance and complex phenomenon. No definitions were circular, meaning no definitions used the word vigilance within the definition itself. Weis and Fine's [77] definition was the only one in which figurative language was used, making the definition very difficult to understand. Some obscure language was used by Hirter and Van Nest [68] such as "myriad" and also used by Meyer [18] with the use of "watching out".

Another way the definitions demonstrated the philosophical split according to task performance versus complex phenomenon was related to whether vigilance was something stable or whether vigilance could be measured on a continuum. The only author who indicated vigilance was on a continuum was Meyer [18] who indicated that vigilance was a "process". Indicating vigilance was a process was reflective of Meyer's presentation of vigilance as a complex phenomenon. When vigilance is viewed as a complex phenomenon, it is presented as having levels or degrees of intensity. In the three articles in which authors focused on vigilance tasks, vigilance was viewed as stable, meaning either persons are vigilant or they are not vigilant. Vigilance was not viewed as having levels or degrees of intensity. Authors used words such as state of [23], continual [68], and maintenance of [28] to describe vigilance as continually present at one level. Indicating that vigilance was stable mirrored the philosophical perspective of vigilance as task performance.

Two of the reviewed authors used a healthcare setting as the context within which vigilance would be present [15, 68]. Two authors did not define contextual space [18, 28]. Davies and Tune [23] identified a generic environment as the place in which vigilance would be exercised. Finally, Weis and Fine [77] indicated vigilance was evident in the presence of a "shell". According to the analysis conducted, none of the definitions reviewed met all the criteria for adequacy per the definition rules [78].

Attributes, antecedents, and consequences of vigilance. The second way in which vigilance definitions were evaluated for adequacy was to assess whether essential attributes of vigilance were included in the definition. In order to develop a definition that adequately meets the criteria for definition construction according to Hinds [78], attributes of the concept must first be identified. In other words, the key elements of the concept as currently described in the literature must be identified and included in the definition. Articles were reviewed to identify previously used definitions, as well as to identify antecedents, attributes, and consequences of vigilance. Essential attributes were used to further evaluate definition adequacy. In other words, a definition could not be considered accurate if it did not meet all the criteria for adequacy, or if it did not contain a majority of the essential attributes in the definition. Essential attributes of vigilance included: knowledge, watchfulness, interaction, and responsiveness. A key antecedent of vigilance was the presence of threat. Of all reviewed definitions Hirter and Van Nest [68] had the most concise definition, yet the essential attributes of knowledge and interaction were still missing from their definition. All reviewed definitions of vigilance were lacking some essential attributes. To construct an adequate definition, literature was reviewed regarding the primary antecedent of threat, and the identified attributes of vigilance were examined within the context of health care.

The stress and coping literature indicates that vigilance is a response demonstrated through thoughts and actions that occur related to threat. Threat is defined as an

anticipated harm [72]. Other literature on threat further classifies it as potential, actual, or perceived harm [29, 67, 70, 74-77]. Potential threats are harms that may possibly occur, such as the side effect of chemotherapy. An actual threat is a harm that is certain to occur if there is not an intervention, such as receiving a large overdose of medication. A perceived threat is one is which a person is suspicious that something may be harmful even though there may be no logical support for this perception. An example would be someone who refuses to take a medication because he or she perceives it could cause nausea, even though nausea is not a known side effect of the drug.

The literature represents vigilance as behaviors or responses that occur both within and between persons. In addition, vigilance is described as a process in that it is strategic, planned, thoughtful, and occurs over a period of time. Vigilance is a knowledgeable, interactive, responsive process of action. Knowledge is an important attribute in vigilance. Knowledge is needed in order to recognize threats, to effectively analyze threats, and to assess vulnerability to threats. In order to be vigilant, one must be watchful or observant in a knowledgeable way. Therefore, vigilance is not characterized by inaction, indecisiveness, ignorance, or isolation.

The literature review also indicated that vigilance was influenced by two variables, dynamism and trust. Dynamism is characterized by fluctuating environments [15]. Too little dynamism, such as similar routines repeated over time, may decrease vigilance. An example would be a patient who has been in the hospital for several days and assessments of the patient have become so routine that no one (nurse or physician) notices an eye infection that is very obvious to another nurse, who has not previously seen the patient. Too much dynamism, such as a situation reeling out of control, may also decrease or cause vigilance to be ineffective. Dynamism as a potential moderator speaks to the influence Complex Adaptive Systems may have on vigilance. Another variable which may moderate vigilance, trust, may influence vigilance in that one's own

vigilance may increase or decrease depending on whether or not a belief exists that one person will indeed be vigilant on behalf of another. For example, in order for patients to relinquish their care to a nurse, they must trust that the nurse will watch out for them [29]. Trust would likely moderate the interactive aspect of vigilance between nurses, patients, and families. In addition to identification of antecedents, attributes, and consequences of vigilance, the literature review informed assumptions about vigilance. A major assumption about vigilance is that persons must be physically and psychologically capable of responding to threats. People in a state of coma, or persons with uncontrolled, major mood disorders, may not be able to be vigilant in response to threats.

Consequences of vigilance were also discovered. The consequences reflected whether vigilance had been conceptualized as a task performance or a complex phenomenon. When vigilance was conceptualized as a task performance, safe patient care, professional satisfaction, and ability to perform duty were outcomes of appropriately responding to stimuli [28, 68]. Outcomes of vigilance as a complex phenomenon included effective decision-making, optimal functioning [18], resilience, patient satisfaction [15], and freedom [77]. Overall, from the task performance perspective, vigilance is represented as preventing patient morbidity and mortality. From the complex phenomenon perspective vigilance is used to promote quality of life and patient satisfaction.

Derivation of an adequate definition of vigilance. Based on the analysis of definitions and identified attributes of vigilance, a definition of vigilance was derived that met Hind's criteria for definition construction [78]. Vigilance is the degree to which an interactive (between persons) process of knowledgeable watchfulness exists in healthcare in response to threats [79]. Interactive knowledgeable watchfulness is influenced by

physiological and psychological abilities to respond to threats and is further influenced by environment and trust.

Summary of Conceptual Issues

Vigilance was found to be a concept lacking in clarity. In healthcare literature, vigilance is presented two ways; 1) As the performance of a task as a response to stimuli; and 2) As a complex phenomenon that is shared among persons. Clarification of vigilance is difficult for several reasons. Many terms are used to describe vigilance. There is no common definition of vigilance. Research of vigilance has been inconsistent in use of cases, samples, methods, and context. Therefore, there are three broad recommendations related to further clarifying the concept of vigilance. First, researchers must begin to use a consistent philosophy, case, sample, and context determined to be the best representatives of the phenomenon. Second, consistent use of methods will allow for the possibility of meta-analysis of qualitative studies, which will allow for greater generalizability of research findings and generation of a theory of vigilance. Third, research findings need to be used to further clarify the definition, antecedents, attributes, and consequences as they relate to vigilance.

First, determining what case and sample best represents the phenomenon of vigilance is an important consideration. Philosophy about the concept informs what case may best represent vigilance. If researchers consider vigilance a task performance, they would likely choose a different case to represent vigilance than researchers who view vigilance as a complex phenomenon. Further, the conditions under which vigilance is thought to emerge must be considered. Conditions such as migraine headaches, being the family member of a hospitalized patient, administering anesthesia, or being a caregiver of Alzheimer's patients may encourage the use of vigilance. However, when little is known about a phenomenon or there is a lack of conceptual clarity, the best case must be chosen to represent the phenomenon. Cancer is an excellent context to

examine vigilance for several reasons. The disease and treatment of cancer exposes people to many threats. Threat is an antecedent of vigilance. Cancer is generally considered a chronic disease, with the need for continuing vigilance over a lifetime. Cancer is a family disease, in which family and nursing support are paramount. Cancer patients rely on family members to be vigilant, family members rely on nurses to be vigilant, and nurses rely on patients to share their knowledge and concerns about their condition and, to some extent, self-manage their symptoms. Such interactions and knowledgeable watchfulness are attributes of vigilance. Cancer patients who are hospitalized, their family members, and nurses represent an excellent sample to represent vigilance relative to the context of the hospital as a Complex Adaptive System. Research has indicated that environments influence vigilance. Because Complex Adaptive Systems are ever changing, persons exposed to hospitalization should exhibit a wide range of vigilance experiences and responsiveness to the changes in the environment. Responsiveness is an attribute of vigilance.

Second, consistent use of research methods will allow research results to be aggregated, allowing the ability to produce more powerful results, discover deeper relationships of vigilance as a construct, and lead to the development of a theory of vigilance. Combining alternate kinds of qualitative inquiry may not provide a clearer picture of concepts, such as vigilance because the philosophical assumptions underlying different types of qualitative methods seek different types of information about concepts under study; thus they would more likely confound information about vigilance than clarify it. For the purposes of the current research, empirical phenomenology was used to gain an understanding of cancer patients, family members, and nurses' experiences with vigilance.

Third, research findings must be used to further clarify the definition, antecedents, attributes, and consequences of vigilance. The derived definition of vigilance meets all

the prescribed rules for developing an adequate definition. Consistent use and evaluation of the derived definition will help to guide and clarify vigilance research. In particular, consequences of vigilance that were identified were confusing and inconsistent as they were dependent on whether vigilance had been researched as a task performance or as a complex phenomenon. A consistent program of research will allow for clarification of vigilance outcomes. In other words, what happens when persons are vigilant is unclear. Identification of vigilance outcomes is extremely important in considering the efficacy of being vigilant.

The concept of vigilance needs to continue to be refined. A program of research should be planned aimed at understanding the concept, and confirming or identifying additional antecedents, attributes, and consequences of vigilance. Consistent use of the best case and sample to represent vigilance will contribute to the ability to further clarify vigilance. Further, vigilance needs to be consistently researched from one philosophical perspective. From the literature review, it is believed that vigilance as a task performance represents vigilance at its lowest level of responsiveness. Investigating vigilance as a complex phenomenon will lead to the maturation of vigilance as a concept and clarify its role in health care, particularly in relation to consequences of vigilance.

Methodological Issues Related to Vigilance

A concise definition allows researchers the ability to measure concepts under study. In turn, once measurements are established, the quantitative analysis of the concept will allow for further clarification and precision in defining and describing the concept [78]. A primary issue in measurement is the concern of whether there is accurate measurement of the concept under study-which is a concern of validity of the measures [80]. Many challenges exist in measurement of complex phenomenon [81]. Vigilance is a complex phenomenon with a history of conceptual ambiguity. Thus, there has been a lack of precision in measuring the concept of vigilance. Two methods have been used to

measure vigilance; qualitative and quantitative methods. Further, ways to measure vigilance varied greatly, according to viewpoint of vigilance as a task performance or vigilance as a complex phenomenon. In reviewed articles, the presence of vigilance was measured through analysis of skill performance, through interviews, through interpretation of poetry, or through completion of instruments designed to measure vigilance.

Qualitative Measures of Vigilance

Qualitative methods are generally used to measure phenomenon when little is known about the phenomenon related to little previous research or the phenomenon has evolved and previously established beliefs or theories no longer are applicable to the phenomenon [82]. Qualitative methods are also used to investigate complex or sensitive phenomenon and construct detailed information about the phenomenon [83]. Three qualitative methods were used to measure vigilance. One study examined family members of hospitalized patients using ethnography, one study examined the experiences of women who got migraine headaches using grounded theory, and one investigation examined vigilance through an analysis of poetry written by inner city youth.

Carr [15] conducted informal, semi-structured interviews, combined with participant observation and guided by ethnographic methods, in order to determine vigilance as perceived by family members of hospitalized patients. Vigilance themes derived included commitment to care, emotional upheaval, dynamic nexus, transition, and resilience. Although Carr noted that dynamism, as an environmental factor, influenced level of vigilance, it was more the presence of vigilance and how family members expressed vigilance that was measured through this study. Carr used Leininger's Theory of Cultural Care Diversity and Universality as a means to contextualize analysis of the data. Many

of the conclusions Carr made about the nature of vigilance and its links were found to be illogical when diagrammed as relational statements.

Like Carr, Meyer [18] conducted semi-structured interviews, however grounded theory was the methodology used to elicit responses regarding the presence of vigilance. Meyer, however, interviewed women who had a medical diagnosis of migraine headache. Meyer, therefore, gained a patient perspective of what it meant to be vigilant. Themes included *Owning the Label, Making the Connections, Watching Out, Deciding What to Do, and Maximizing Function*. Watching Out, the theme category most closely associated with vigilance included several subthemes; Assigning meaning to what is, calculating the risk, staying ready, and monitoring the results. Meyer has subsequently developed a preliminary model of nursing vigilance based on this qualitative study [84]. However, Meyer conducted the grounded theory study for the theory of nursing vigilance with a population of women with migraine headaches, not with a population of nurses. In other words, Meyer took what was learned qualitatively from one population, and without further reported testing, made it into a theory for another population. Additional critiques of Meyer's work in regards to the definition of vigilance derived for this dissertation research; Meyer's definition of vigilance lacks interaction as an attribute of vigilance and lacks consideration of the healthcare environment.

Lastly, regarding the qualitative measurement of vigilance, Weis and Fine [77] examined the presence of vigilance as seen through the experiences of urban youth, expressed through poetry. Vigilance was described as "watching others" (p. 188) as a means of self-protection, and "watching out for others" (p. 188) was a way to describe guarding others. Watching is a way to protect self as expressed by "Do you see it too?" (p. 189), asking a young girl to see her situation as an abused child. Watching was also a way to prey on others expressed by "She followed you to where she is not watched" (p. 189), illustrating the mother's attempt to abuse and not be caught. Finally, watching is

a way of escape. If the little girl can answer “yes” to the question “Do you see it too?” she may be able to extricate herself from the abuse. Vigilance is obviously present in the lives of the young people who wrote this poetry. Vigilance was expressed as metaphor, which needed to be examined and explored in order to understand what form vigilance took and how vigilance was used. Although the analysis of the poetry written was interesting and informative, the use of metaphor makes it difficult to derive explicit knowledge about vigilance. As the concept of vigilance to date has been ambiguous, more explicit representation of it needs to be sought.

The measurement of vigilance from qualitative data presented vigilance as a complex phenomenon that is used as a means of self protection [18, 77] and a means to protect others [15, 77]. Beyond these findings, it is difficult to make generalizations about vigilance, which could be used to construct measures, as the studies used different cases, samples, methods, and settings. According to guidelines for meta-analysis, qualitative studies that use different methods, cases, and samples should not be used as a means of clarifying a concept in order to consequently produce measurements [59].

Quantitative Measurements of Vigilance

Quantitative studies have also been conducted to measure vigilance. Quantitative studies are conducted to empirically measure the phenomenon through the use of instrumentation. Statistical analyses are then conducted to examine relationships, prediction, effectiveness, or explanations surrounding the phenomenon being measured [81]. Difficulties arise in quantitative measurement when instruments do not exist to measure the phenomenon under study. When instruments do not exist to measure the phenomenon, researchers may choose to develop instruments or choose to use instruments that closely approximate a measurement of the phenomenon under study [80]. Difficulties may arise related to either of these options. Developing an instrument is time-consuming and slows the pace of research progress. Use of pre-

existing instruments may measure an approximation of the concept of interest, but unless the instrument was developed from a similar philosophical perspective, based on sound research, and used with a similar population, validity may be an issue.

Vigilance has been measured quantitatively by Howard et al. [28] and Mackworth [24]. Howard et al. viewed vigilance as a physiologic response to stimuli that could be impaired by lack of sleep. Researchers used instruments (The Sleep Disorders Questionnaire and the Owl and Lark Questionnaire) to measure the presence of preexisting sleep conditions that may have interfered with anesthesia residents' ability to be vigilant. Further measurements were conducted during an operating room simulation. Tests of vigilance pertained to measurement of psychomotor responses such as reaction times, memory recall, mood analysis, and measurement of sleepiness. Level of vigilance was determined based on scores related to test measurements. Howard et al.'s research reflected the philosophical perspective of the historical vigilance studies conducted by Mackworth in measuring radar operators' responses to stimuli. Therefore, the Howard et al. study measured vigilance as the performance of a task. Ultimately, quantitative measures of vigilance collected on physiologic response to stimuli are measuring the physiologic responses related to vigilance, rather than direct measures of vigilance. Caspi and Burelson [81] described measuring changes in physiology as confounding since many variables can influence changes in physiological responses, particularly when researching a complex phenomenon.

Two instruments were located that were constructed to more directly measure vigilance [see Table 4]. One scale was developed for measuring the vigilance of caregiver's of Alzheimer's patients [27]. The instrument, The Caregiver Vigilance Scale was developed from a perspective of vigilance as a task and time-on-duty was measured as impacting the ability to be vigilant. The Caregiver Vigilance Scale was described as measurement of tangible and non-tangible tasks of caregiving. In other

words the researchers assumed that the more hours spent caregiving, the more hours caregivers were considered vigilant. The usefulness of this scale is extremely limited. The scale was designed to measure caregivers' perspectives on time spent caring for family members with Alzheimer's. Specifics about how persons are vigilant and what they are vigilant about are not addressed in this 4-item scale.

The second instrument evaluated was the Vigilance to the Condition subscale for a larger scale, The Acceptance of Asthma Questionnaire [85]. Items seemed to reflect vigilance as a more complex phenomenon as opposed to a task. Vigilance in this subscale is related to response to threats. This subscale was developed from a rigorous, qualitative study and used a theoretical framework as a guide. However, the population this subscale was derived from was school-age children and not adults. Great care would need to be taken in applying this scale to an adult population, as perceptions of vigilance may vary greatly based on age and life experience.

No gold standard exists for measuring vigilance of patients, families, or nurses. Previous qualitative work has informed some parameters of vigilance, but cannot be used to make theoretical connections as the research was inconsistent in method, case, sample, and context. The majority of quantitative studies have examined vigilance as a task, with fatigue being the primary variable that may interfere with the ability to respond to stimuli. One developed subscale approximates vigilance as a complex phenomenon, responsive to threats, yet, does not include statements that are reflective of the derived definition of vigilance as an interactive process [85]. The vigilance subscale also was designed to measure children's vigilance, which may be qualitatively different than vigilance exhibited by adults

Instruments needed to measure vigilance and role in error. The construction of measurements of vigilance is warranted. No gold standard measurement of vigilance exists. Yet, lack of vigilance is a documented problem in healthcare errors. In the

majority of error reporting forms, lack of vigilance is cited as a reason for healthcare errors. Despite the recognition that lack of vigilance contributes to error, there is no standardized way to measure what is meant by vigilance or lacking vigilance. Because vigilance is not a phenomenon that has been defined, described, or made explicit knowledge, it is not surprising to note that healthcare providers seem to have a general lack of ability to identify events surrounding potential errors [86]. In a study conducted to see if providers (nurses, physicians, and pharmacists) could identify close calls presented in scenarios which could lead to error, only 40% of participants could identify close calls. This means that 60% of participants missed signals that may have allowed them to identify a close call, and thus have the potential to prevent later error from occurring. Research such as this provides even greater insight when coupled with findings from other research. Preventing errors from occurring, when possible, has a more positive impact on patient outcomes than detecting errors after they have occurred The failure to rescue patients from potential errors (such as not detecting symptoms that a patient is deteriorating) may lead to negative patient outcomes [87].

Table 4. Analysis of Instruments Measuring Vigilance

Researcher	Method of scale development	Name of Scale	Theoretical underpinning	Number of items	Sample	Analyses	Results
Mahoney et al.[27]	Qualitative-non specific methodology	The Caregiver Vigilance Scale	None	4-item fill-in the blank scale	1,229 caregivers of Alzheimer's patients	Spearman's rank correlation, Cronbach's alpha, Exploratory Factor analysis	• Non-normal distribution. • internal consistency 0.66. • PCA-first eigenvalue (2.00) greater than second (0.96) and accounted for 50% shared variance among vigilance items.
Kintner[85]	Qualitative-empirical phenomenology-Colaizzi method	The Vigilance to Condition Subscale	Lifespan Development Framework	6-item Likert-type scale	150 school age children ages 9-14	Cronbach's alpha Factor Analysis of ten original items	• .77 reliability. • 4 items eliminated (loaded on more than one factor). • 6 items retained with factor loadings ranging from .55 to 78.

The lack of vigilance is noted as a common contributor to errors. More recent investigations into healthcare errors have focused on the role of the complex system and the interrelationships within it and the contribution to errors the whole system has as opposed to simply blaming the individual for making errors. However, error reporting instruments seem to have not taken into account many of the environmental variables that contribute to error. Since vigilance behaviors have not been identified in healthcare, it would seem difficult to categorize contributors to incidents as lack of vigilance. As an error category, lack of vigilance has been labeled without research to support what is first meant as vigilance in healthcare. The following section demonstrates that in current healthcare error reporting instruments, lack of vigilance is a common category attributing to error.

In well known error reporting instruments, categories of error are often included which reflect lack of vigilance as contributory to healthcare errors. In an older Australian study, 2000 anesthetic mishaps were classified related to human performance factors. The 12 most common factors leading to such mishaps were classified. Inattention emerged as an important factor in anesthetic mishaps and played a role in 12% of the reported anesthetic errors [12].

Another classification system developed in 1989, the Edinburgh WGH ICU incident reporting scheme, accrued data on 710 reports of critical incidents occurring in an intensive care unit during a ten-year period of time (1/89-2/99). The Edinburgh scale combines human performance factors identified by Rasmussen with behavioral categories, in order to classify human errors. About 28% of the incidents that occurred were attributed to inattention or thoughtlessness. On further examination of the classification systems in this instrument two other categories, inexperience and failure to check equipment, could be related to lack of vigilance when compared to the derived definition of vigilance for this dissertation research. Inexperience is reflective of the

importance that knowledge plays in ability to be vigilant. In the classification of contributing factors to critical incidents in the Edinburgh incident reporting scheme, 25% of contributing factors were linked to inexperience. Failure to check equipment seems an obvious link to vigilance and the need to identify threat (potential, perceived, or actual) in order to enact the continuum of vigilance. About 15% of the incidents reported in the Edinburgh incident reporting scheme were related to failure to check equipment.

One classification system was examined in which errors nurses are likely to make were classified. A taxonomy of nursing errors was created in order to try and give nurses a better ability to more immediately detect and identify errors [13]. Nurses were chosen as the focus of this investigation as nurses are the persons most often present with patients on a continuous basis. The taxonomy of errors was developed from an examination of disciplinary case files from 9 State Boards of Nursing. Cases were identified (n=21) in which nurses had committed errors involving clinical judgment and competency issues, and in which patient harm had occurred or had the potential to occur. From these 21 cases, 8 categories of nursing error were identified. Categories ranged from medication error to lack of intervention of the nurse on behalf of the patient.

The end result of this study was the development of an instrument which authors noted may be used by healthcare organizations or State Boards of Nursing to accrue data and classify errors made by nurses. Data collection such as this was purported to allow the development of recommendations and interventions to decrease nursing error. Since nurses are the healthcare providers most involved in patient care, they have a greater burden than other providers to detect and intervene in incidents that may produce error and lead to patient harm. One of the 8 categories of factors contributing to nursing error was *lack of attentiveness*. Lack of attentiveness contained information concerning a wide range of nursing errors related to nursing care such as assessment, daily activities such as vitals or treatment monitoring, and lack of supervision by

managers or experienced nurses. Other considerations in classifying errors in this category were things such as whether patient complications were predictable or unpredictable and the influence the environment has on nurses' abilities to remain vigilant.

While error classification systems may lead to evidence regarding error occurrence, many ways to deal with error in healthcare are antiquated, anecdotal, and not evidence-based [88]. One ineffective way to try and prevent error is by suggesting that persons increase their vigilance. Although it is understood that many tasks in nursing require persons to be vigilant in order to carry the task out safely and things such as distraction and being tired interfere with nurses' abilities to maintain high levels of vigilance [89, 90], there is no sound evidence from which to inform persons of how to be vigilant. General suggestions are found related to decreasing error related to vigilance. Things such as: identifying threats, balancing attention to different aspects of work, understanding the basic tenets of vigilance (e.g., familiarity leads to decreased vigilance), recognizing that human performance has limitations, and fatigue contributes to decreased performance are commonly found as suggestions of ways to improve vigilance [91].

While such general suggestions given by Hughes may be helpful, they may be difficult to enact. Few studies in health care have examined vigilance, and none have analyzed vigilance within the context of complex systems. Perhaps, the identification of vigilant behaviors and the impact the complex environment may have on those behaviors is one way to begin to recognize that individuals are not solely at fault for errors related to lack of vigilance. It is possible that vigilance, as it appears in complex environments, is very different from the vigilance or lack thereof identified in error reporting instruments constructed from after the fact, or case study data. Further, in other healthcare research, vigilance is rarely presented as related to error prevention and previous healthcare research has not linked vigilance to errors made by persons.

Before vigilance or lack of vigilance can be measured as a means of improving care, measurements need to be developed to assess the presence or absence of vigilance, and under what conditions such behavior is likely to occur. In order to do this, a careful plan of research needs to be designed in which the ways to best develop measures are considered.

Developing a Meaning-based Model of Vigilance

To design more precise ways to measure vigilance as a step in the process towards developing interventions, an entire program of research must be developed that is aimed at the study of vigilance. Haase, Heiney, Ruccione, and Stutzer [92] have outlined ways to use both qualitative and quantitative research methods to generate models and develop meaning-based measures of experiences. Haase's Adolescent Resilience Model (ARM) was derived from 6 qualitative studies and 4 quantitative studies. Qualitative studies were used to generate, validate, and clarify the ARM. The qualitative studies were further used to gain perspectives of adolescents, parents, and healthcare providers and to more clearly understand antecedents, attributes, and consequences of the ARM. The quantitative studies were used to test psychometric properties of instruments designed to measure ARM factors as well as to begin to test the structure of the ARM.

Strategies such as those outlined by these researchers are believed to lead to interventions that are more meaningful and more effective, based on models and instruments derived directly from patient, family, and healthcare provider experiences. The methods used for developing the ARM and ARM factor measurements provide a framework from which to design research of other complex phenomenon, such as vigilance. Several steps must be taken to begin a research program focused on vigilance. First, an understanding of vigilance must be gained. Understanding may be gained through qualitative interviews and observations. Second, a preliminary model of vigilance must be constructed. Nunnally and Bernstein [93] noted that instrument

development must be guided by a theory and closely adhere to associated definitions and construct interrelations. Third, vigilance must be researched from differing levels of analysis. Vigilance may not be assumed to be the same construct at the individual, group, and organizational levels. In other words, how an individual exhibits vigilance, may not be how groups or organizations manifest vigilance. Instruments need to be developed that measure vigilance at the desired level of analysis.

Gaining a Deeper Understanding of Vigilance

Based on the identified issues pertaining to the measurement of vigilance, there are several recommendations for research which may lead to more precise measurements of vigilance. First, a deeper understanding of what vigilance is must be gained. Qualitative methods are recommended as the methods to use in order to derive a deeper and richer understanding of phenomenon. An essential attribute of vigilance is interaction. In order to understand vigilance as an interactive or shared process, it seems logical to first understand the individual experience of vigilance. Giorgi [94] stated that “care given has to be responsive to the other’s entire situation in the world and not just the medical and technical aspects of a person’s body” (p. 82). Vigilance partnerships among patients, families, or nurses may be strengthened by striving to understand each other’s situation in the world. Empirical phenomenology and observation are two qualitative methods which may be used to create this understanding.

Previous qualitative vigilance studies have examined vigilance as either cultural or procedural, not as lived experiences aimed at creating partnerships. Careful attention needs to be given to the case, sample, method, and context in order to gain a precise and meaningful way to describe the phenomenon. Consistent use of a particular case, such as cancer and a sample, such as hospitalized patients who are being treated for cancer, one of their family members, and nurses who care for them is a consideration when performing studies in which meta-analysis of the studies is desired. Use of meta-

analysis strategies in qualitative studies allows for the possibility of discovering theoretical constructs and the ability to explicate more precisely what vigilance is. From a thorough understanding of a phenomenon, adequate instruments and item pools may be developed [95].

Development of a Vigilance Model

Once the interactive natures of the three perspectives are obtained, a preliminary specification of a model of vigilance would be a logical second step. Model generation gives form to the phenomenon being studied. Hall, Stevens, and Melies noted that some phenomenon are deeply embedded, accepted, and used in health care, yet are not used at a conscious level [62]. Allee has described the benefits of bringing knowledge to levels higher than the unconscious. To bring a phenomenon to a conscious level, enough needs to be known about it to allow for intelligent conversation. Allee [48] classifies this kind of information at the level of knowledge. As persons become knowledgeable about a phenomenon, they can begin to understand how it is connected to the greater world around them. Allee classifies such understanding of connections as understanding meaning. Knowledge about a phenomenon and its meaning allows people to share what they know, and it is precisely this kind of sharing that leads to learning.

As previously discussed, in Complex Adaptive Systems, learning is what allows persons to become flexible and responsive to the environment and to others. The ability to be responsive to others and the environment is an essential attribute of vigilance. Therefore, constructing a model will help bring to consciousness vigilance and the way vigilance is explicitly used. In other words, a model will help make vigilance an observable phenomenon. From a measurement perspective, models are used to guide the development of instruments used to measure factors associated with the phenomenon [92, 93].

Levels of Analysis and Measurement Precision

Thirdly, vigilance must be researched from different levels of analysis. In disciplines outside of health care, such as business and organizational behavior, researchers have become aware of the need to carefully consider the level at which a concept is being evaluated. In both critiquing existing research and designing research studies, the level of analysis used is a careful consideration. Analysis needs to be thought of from the perspectives of the individual or group (known as micro levels of analysis), and organization (known as macro level of analysis) [96, 97]. An additional matter is to take into account how each of these levels interacts between one another (known as meso level of analysis) [98].

Individuals may be vigilant and we may even have a good idea about what makes persons appear vigilant, however, how an individual is vigilant may not be the same as how groups, such as patients, families, and nurses are vigilant together. From a measurement perspective, the level of analysis informs the development of the item pool [99]. Since interaction is an essential attribute of vigilance, items developed to measure vigilance must be constructed in such a way as to measure interactive vigilance. If the interest is in how vigilance is created and maintained by groups of nurses, patients, and family members, instruments must be worded in such a way to capture the interactive perspectives of vigilance. For example, instead of such statements as “I know what kinds of things are threats to my health” which would measure the individual’s own ability to be vigilant, other statements should be added to measure the level of interactive vigilance perceived by the patient. The statement to reflect measurement of an interactive vigilance would include two additional statements such as “My family members know what kind of things are threats to my health” and “My nurse knows what kinds of things are threats to my health”. Additional statements such as these allow a baseline from which to begin to measure vigilance as defined as an interactive

phenomenon. Morse noted, researchers must be knowledgeable about more than one research method in order to appropriately measure a complex phenomenon at different levels of analysis [100].

No gold standard measure of vigilance exists. The perspectives of vigilance measured have been limited to individuals. Yet, the literature indicated vigilance was an interactive process. Measuring a complex phenomenon from one level of analysis, the individual level, is a limited way to measure a phenomenon. In order for complicated phenomenon to be able to be effectively used by individuals, groups, or organizations, research must be predicated on analyzing the phenomenon at the appropriate level of analysis.

Vigilance Research and Implications for Clinical Practice

In order for vigilance to be effectively recognized and used in clinical practice, it must first be understood what vigilance is and what behaviors are exhibited when someone is being vigilant. Furthermore, how vigilance is created and maintained as part of interactions between persons needs a particular research focus. Qualitative research studies are a means to identify the essences, or the real meaning of what it is to be vigilant. Qualitative phenomenological interviews are a way to elicit experiences of vigilance as lived by persons. Through such methods, a deeper and more meaningful understanding of vigilance can be constructed.

Advancing the concept of vigilance through a program of research is thought to be useful for application in clinical practice in several ways. First, the ways in which cancer patients, families, and nurses view vigilance similarly and differently will impact interactions. Understanding what others view as being vigilant, especially if it is different among cancer patients, families, and nurses has the potential to influence patient quality of life, patient safety, and patient satisfaction. Understanding what a patient or family member views as vigilance could be very important for nurses to know. For example, a

nurse may exhibit high levels of vigilance in monitoring vital signs or checking intravenous lines. However if patients view vigilance as nurses sharing information about the disease process or nurses taking time to straighten patients' beds, and nurses do not take the actions the patient views as being vigilant, then the patient will not view the nurse as vigilant. Real implications exist in relation to patients and their families feeling safe and comforted because they view their nurse as being vigilant.

Second, vigilant behaviors need to be clarified. Actions such as checking intravenous lines or sharing information about disease or treatment are examples of behaviors that may be interpreted as acts of vigilance. Qualitative interviews are used as a way to identify vigilant behaviors. Additionally, other research methods such as ethology or ethnography provide frameworks for recording and analyzing what has been observed. Only when we can identify how people behave in a vigilant way can we then recognize the absence of vigilant behaviors. Such information is important in clinical practice as it informs the relationship between nurses, families, and patients.

Of further importance is the implication of being able to identify vigilant behaviors in relation to healthcare errors. Nurses have been expected to be vigilant or behave in vigilant ways without explicit knowledge of how to perform in that manner. Vigilance, as a concept, is not mature enough to have had its behaviors made explicit. Instead, in health care the lack of vigilance has been retroactively determined related to healthcare errors. In other words, in a large majority of cases when an error is made, it is often attributed to a lack of vigilance, or inattention. In these cases, vigilance has been determined to be missing, even though there is not yet a way to classify or measure vigilant behaviors. Being able to make vigilant behaviors observable, thus teachable, has the potential to change nursing education and clinical practice. The potential exists to use vigilance in a knowledgeable way to decrease morbidity and mortality related to

healthcare errors. As it stands now, it is counterproductive and ineffective to tell nurses and other healthcare providers they can avoid errors by increasing their vigilance.

Third, developing interventions to create vigilance partnerships among cancer patients, families, and nurses will allow a way for groups of persons to create and maintain vigilance. Vigilance is defined as the degree to which an interactive (between persons) process of knowledgeable watchfulness exists in healthcare in response to threats [79]. Vigilance does not occur solely within individuals. More so, vigilance is likely to be dependent on members of a group sharing knowledge, communication, and responsibility with one another in order to create vigilance partnerships. Measuring group phenomenon will require attention to group level analysis. Ways in which groups communicate their experiences as a group, are often different than the ways the same individuals would communicate individual experiences. Instruments designed to measure group vigilance will have to elicit responses from persons as they pertain to the group and not the individual. Ways to measure group vigilance are very important because such measures must be in place before interventions can be studied as a way to create and sustain vigilance partnerships among patients, families, and nurses.

Vigilance has been revealed to be a concept that needs further clarification. To this point, vigilance has been researched from two perspectives, as a task performance and as a complex phenomenon. Vigilance as a task performance is one dimension of a larger phenomenon of vigilance. Identification of antecedents, attributes, and consequences of vigilance and the establishment of an adequate definition of vigilance have allowed clarification of this concept. A carefully planned program of research using a consistent case and sample will lead to new information and understanding of vigilance and its role in healthcare.

Preliminary Pilot Study

In order to determine feasibility of the dissertation study, a pilot was conducted from July of 2006 to August of 2006. The focus of the pilot study was to examine practical issues related to recruitment, interviewing procedures, including participants' abilities to understand the questions and provide meaningful data, and gain a preliminary sense of performing data analysis.

Recruitment for Pilot Study

Per procedures approved by the Internal Review Board (IRB) of Indiana University-Purdue University, recruitment proceeded. A physician specializing in hematology-oncology and his nurse manager, were the main recruitment contacts. The physician's nurse manager approached patients and family members on the Hematology-Oncology unit at a Midwestern hospital to inquire about participation in this study. If patients or family members expressed interest, the physician's nurse manager referred the researcher to them and the researcher talked with the patient or family member at length about the study. If at that point, persons were interested in participating in the study, they were given consents to read through, an appointment time was set, and the participants were then given the data-generating questions so they had time to reflect on the phenomenon of vigilance.

Nurse recruitment proceeded differently than patient or family recruitment. After interviews with patients or family members, they were asked to identify a nurse who had been vigilant with them, or whom they considered to be vigilant. Without hesitation, participants named nurses who they felt exhibited vigilance. The nurse manager for the unit, had previously instructed nurses about the vigilance study and the possibility of being approached by the researcher. No nurses indicated they would not want to be approached about being in the study. The nurse manager was not notified whether nurses identified as vigilant chose to participate or not in the study.

Recruitment of participants worked well, however some potential challenges were identified. One challenge was the accrual of family members. The researcher needed to make herself available in evening hours when family members were more likely to be present. The other challenge identified was the instability of the population's health. If a patient participant was identified, it was more likely that the interview could be conducted with the patient and family member, when both interviews were on the same day participants were identified and consented. Otherwise, if a patient's condition worsened, both the patient and the family member were more likely to not be able to participate in the research.

Sample for Pilot Study

Eight interviews were conducted for the pilot study including 3 patients, one family member, and 3 nurses. The pilot sample was incorporated into the sample for the larger study and is fully described in the findings for the larger study.

Interviewing Procedures for Pilot Study

Part of the purpose of the pilot study was to determine feasibility and to examine whether or not the interviewing procedures worked in eliciting rich descriptions of the phenomenon of interest, vigilance. The pilot interviews indicated that participants were able to articulate their experiences of vigilance and the data generating questions produced a rich description of vigilance experiences across all three groups. Lengths of interviews ranged from around 40 minutes to over 1 hour.

Of importance was evaluation of the method, empirical phenomenology, and the questions constructed from that philosophical perspective and whether or not the method produced results that were theoretically congruent with empirical phenomenology. Questions asked in empirical phenomenology are thought to bring about a consciousness of the pre-reflective life world so that upon reflection, narratives can be given of the experience of interest [101]. Such transitions should occur in interviews

in order for the phenomenon to emerge. The following exemplar provides support that the questions proposed in this study elicited consciousness of the pre-reflective life world and thus a narrative of the experiences contained within that life world.

An exemplar from the pilot study [102] for the dissertation research helps to further illustrate the process of pre-reflection leading into consciousness and reflection. At first, the nurse I was interviewing had difficulty being aware of experiences with vigilance. "Well, I don't know. I think that to me vigilance is a really big word for something that we just do all the time and don't even think about it. Um, trying to take that apart and figure out exactly what that is…I don't know, it's kinda hard to do" (Nurse 001 C). However, as the interview progressed, the nurse began to become more descriptive and the pre-reflective life world could be expressed at the reflective level [103]: "I think that it's a combination of things …that just all come together in caring about this patient, or these patients..it's just wanting to try to pick up on any little problems…listening has a lot to do with it…asking questions is a big part of it because a lot times patients don't know that this is something that could be a problem…you pick up on it, and then start questioning them about it and then you come to find out more, and that yes that could be a potential for a complication or problem" (Nurse 001C). As this nurse continued her reflection, she gave detailed descriptions of her lived experiences with vigilance.

Data Analysis for the Pilot Study

For the pilot study, Colaizzi's [104] method of data analysis was used, as described in the Methods section of Chapter III. These procedures for analysis were found to be effective to identify emerging themes and, thus, were not changed for the full study. In addition, the data obtained and analyzed for the pilot were subsumed into the larger dissertation study.

Preliminary Results of the Pilot Study

Three preliminary themes emerged from the pilot data; *Knock Wood-The Spiritual Aspect of Vigilance, Vigilance is that Little Extra, and Vigilance is a Way to Focus Energies.* These preliminary themes were bracketed when analyzing data for the entire research study. Pilot participant data were subsumed in data, themes, and outlines derived from the entire study.

Summary of Pilot Discussion

The feasibility pilot study provided experience and the identification of potential challenges, although minor, that could have been encountered in continued dissertation research. Changes in the original proposal were not warranted. The data from the pilot study were added to the additional data collected in the dissertation study.

CHAPTER III

Methods

Design

The design for this dissertation study was a qualitative method, empirical phenomenology. Qualitative research is the preferred method when little is known about a concept or there has been a lack of conceptual clarity surrounding the concept. Phenomenological research is used to describe commonalities of meaning in the lived experiences of people in similar life situations [105, 106]. In qualitative research, questions are used to elicit rich narratives of a particular experience, in this case vigilance. Narratives are examined in order to derive essential structures (or common meanings) of the experience [107]. The identification of universal essences results in a generalized, yet as precise as possible, description of the phenomenon [108, 109]. Thus, phenomenology is used to clarify meanings that lead to understanding or generalizable descriptions of human experience [94].

Empirical phenomenology is derived from the philosophy of Husserl, who believed the expression of consciousness related to an experience was a scientific way to understand how people live or are situated in the world. Husserl theorized that persons were free agents who influenced their environment and culture and this was part of the lived experience of a phenomenon [108]. Empirical phenomenology was Husserl's response to traditional scientists, who felt investigations of human experiences did not constitute rigorous research [104]. However, other researchers felt human experience was a valuable and necessary area to investigate. Colaizzi [104] outlined several assumptions regarding the scientific significance for researching human experience. Assumptions included: 1) experiences are real to self and others; 2) experiences are not just felt internally, but are a way of being in the world; and 3) being in the world is existentially significant which justifies the research of human experience (p. 52). The

phenomenological perspective recognized that “the life world is not a realm of variables” [110], (¶ 59). Without such investigations, it is unlikely that an understanding would be developed of human psychological perspectives. While human experiences may be examined in a number of ways, empirical phenomenologists adhere to certain philosophical beliefs about the conditions under which phenomenon may appear. The underlying philosophies are what separate differing kinds of phenomenology from each other, as well as from other types of qualitative inquiry. Specific philosophies about consciousness, intentionality, bracketing, and phenomenological reduction guide investigations using empirical phenomenology. Each of these principles is examined in the following sections.

Consciousness and phenomenology. Being conscious of something is a necessary condition in order for a phenomenon to be explained. Consciousness contributes to meaning of the phenomenon [101]. “Consciousness introduces new types of relationships into the world” [94] (p. 76). Because vigilance is defined as an interactive watchfulness, the need for relationships among persons, in order to be vigilant, is implied. In empirical phenomenology, the articulation of consciousness of the experience is obtained through narrative stories. These stories provide the source of both meaning and knowledge regarding a phenomenon [111].

Husserl proposed empirical phenomenology as a way to maintain rigorous scientific standards when conducting philosophical inquiries into people’s conscious experiences. In order to be aware of a phenomenon, a person must be conscious of the phenomenon. For example, it is sometimes difficult for participants to describe their experiences with everyday phenomenon, because they have not consciously thought about the phenomenon, but rather experienced it as an everyday occurrence. In other words, “consciousness is the forum in which things show themselves or are revealed” [103],

(p. 12). Phenomenology is one method which allows for reflections of the conscious world. One of the reasons it may be so difficult to explain everyday experiences with phenomena is related to the relationship between the subject (the experiencer [noesis]) and the object (that which is experienced [noema]) [103]. Husserl called this relationship intentionality. Intentionality is another important underlying belief in empirical phenomenology [101].

Intentionality and phenomenology. An understanding of intentionality is an essential feature of phenomenological investigations. Intentionality is a belief that humans and the world together are inseparable and that human reality and the existence of the world cannot subsist without each other [104]. In other words, humans and the world exist together reciprocally and that each makes the other who or what they are [104]. The experience of humans interacting with their world cannot be separated into subject (noesis) and object (noema) because the mind and the world are correlated with one another [112]. It is both subject and object together that create the meaning of experiences. Experiences are the result of the subject directing their consciousness towards an object [101].

Intentionality, then, in phenomenology is about the mindful connection one has with another [112] or the reaching out of a person, in a mindful, conscious way towards the phenomenon [113]. Oftentimes, persons may experience the presence of a phenomenon, but the presence of the phenomenon has not been made explicit in such a way that everyone can see the phenomenon as it exists [101]. Phenomenology is used to sort out the relationship between the experiencer and the object they are experiencing [112] in such a way that the existence of the phenomenon and experiences with it become clear [101]. The perspective taken which allows phenomenological researchers access to consciousness and intentionalities is called phenomenological reduction.

Phenomenological reduction and bracketing. Phenomenological reduction is a philosophical stance taken in which the researcher does not just make links between things and events, as in natural science, but begins to try and understand "why there are things or events at all" [101] (¶ 12). Phenomenologists adopt a transcendental attitude, whereby they step back and do not just say that an object exists, but rather wants to understand why people say the object exists [101]. Stepping back from the natural attitude, helps phenomenologists maintain a skeptical attitude in order to refrain from judgment until the evidence is clear [112] (p. 49). In phenomenology this kind of stepping back is known as epoche. In order to take the action that needs to be taken to suspend judgment, empirical phenomenologists practice what is known as bracketing.

Bracketing, an important concept in empirical phenomenology, is a setting aside that which is previously known or understood about a phenomenon [114]. Assumptions and preconceived ideas about the phenomenon are clearly stated so that the researcher, as well as others, have awareness at the reflective level what those assumptions are. It is believed that as the researcher makes assumptions clear, more links to other assumptions, previously hidden will emerge. Each assumption or preconception then is held aside, so as to influence the appearance of the phenomenon as little as humanly possible in the analysis of narratives [101, 103]. Bracketing may include an accounting of knowledge gained from literature reviews, written accounts of personal and professional assumptions about the phenomenon, and reflection on the presuppositions or assumptions that may otherwise cloud the researcher's judgment [113]. Phenomenologists believe that thoughts, in the form of theories, assumptions, and preconceived ideas are "quieted" when the researcher is aware of their presence [113]. Bracketing is a rigorous, conscious, and constant state of assessment for the researcher using empirical phenomenology [115].

Bracketing is performed in order to separate the object from its appearance [112]. Separating objects from their appearance is what allows a description of the object through thematic expression. Researchers consciously separate themselves from both the objective perspective (such as looking for a cause of the phenomenon) and the subjective perspective (looking at how a person feels about the phenomenon). In bracketing, the researchers' version of the "truth" must be suspended in order to describe as accurately as possible the phenomenon as it appears through the experiences of the participants [114]. Empirical phenomenologists believe that without bracketing, the phenomenon will not appear as experienced by the participants, but only through the preconceived ideals of the researcher. (Bracketing strategies are further addressed in the section on trustworthiness and credibility strategies.)

Empirical phenomenology was the preferred method for this research because the literature indicated the experience of being vigilant in the context of health care was not well described or understood for any of the targeted populations. Giorgi [94] stated that "care given has to be responsive to the other's entire situation in the world and not just the medical and technical aspects of a person's body" (p. 82). In order for patients, families, or nurses to enter into vigilance partnerships, the other's situation in the world must first be understood. Empirical phenomenology provided a method to create this understanding.

Human Subjects Approval

Human subjects were recruited for the proposed research. In keeping with the policies of the Health Insurance Portability and Accountability Act (HIPAA) and Indiana University, all research was reviewed and approved by both the Institutional Review Board (IRB) and Scientific Review Committee (SRC) [see Appendices B & C]. The IRB approval was contingent on approval from the SRC. Approval was also received for consents for all participants and authorization for release of medical information was

received for patients [see Appendices D & E]. Risks, benefits, and precautions were identified for this proposal [116, 117].

Risks

The risks for participation in this study were minimal. The risks of completing the interview for participants included feeling uncomfortable answering the questions, or feeling too tired to complete an interview. No participants asked for interviews to prematurely end. No participant refused to answer any questions; In fact, participants fully engaged in responding to questions and provided rich descriptions of vigilance experiences. Another risk was the possibility of the loss of confidentiality. No identifying information was left in transcripts. Names of participants and physicians, as well as names of healthcare facilities, and cities' and states' names were removed. Signed consent forms were kept separate from the interview information. All study related information was kept in locked file cabinets or in password protected computer, with only investigators having access.

Benefits

The benefits of participation were minimal for participants. One unexpected benefit that arose was a family member indicating that time spent with the researcher allowed that family member to see the patient in a new light and take the time to appreciate some things about the patient that the stress of the cancer had interfered with [see Appendix F]. The research may benefit patients in the future through deepening an understanding of the vigilance process and how nurses and family members may best participate in that process with the patient. This information will be used to develop and clarify the understanding of vigilance. The risks associated with participation in this study were believed to be uncommon or relatively minor in severity; therefore it was reasonable to ask persons to participate in this study. Due to limited risk involved with

participation in the study the knowledge gained regarding vigilance experiences of cancer patients, families, and nurses outweighed the risks involved.

Protection

I personally conducted all interviews. Precautions, such as privacy and a relaxed atmosphere were carefully implemented in order to reduce any associated anxiety. Participants were reminded that they could refuse to answer any question and could end the interview at any point in time.

Efforts were made to keep information confidential. The risks to breach of confidentiality were minimal as names and identifying information were removed from the recorded and transcribed data. Code numbers were assigned to a name and identifying information was kept separate from data in a locked file cabinet. Additionally, data were grouped and narrative quotes were kept gender-neutral to protect nurse participants' identities. The nurse manager was not informed which nurses consented or not to participate in the study. Although nurses were told that a patient or family member had identified them as a vigilant nurse, they were not informed which patients or family member identified them as such.

There were slight emotional or psychological risks involved in this study. Precautions were taken to minimize these risks through: 1) thorough explanation of the study initially and obtaining informed consent; 2) reminding participants that participation in the study was voluntary and they could withdraw at any time; 3) reminding the participant that they could refuse to answer any questions and end the interview at any time; and 4) telling participants that precautions would be taken to maintain confidentiality.

Further privacy considerations included: Participants were only contacted after they agreed to receive more information regarding the study. Participants decided preferred time and place for interviews to occur. Options for place of interview were in the home or

in a private room in the clinic, hospital, or school of nursing. Six interviews took place in patients' rooms; 12 interviews were conducted in a private room on the unit; one took place in the school of nursing, and one interview took place in the participant's home. Seven participants indicated an interest in findings from the study.

Sample

Sampling Method and Sample Inclusion / Exclusion Criteria

A purposive sample of twenty participants (n= 7 patients, 6 family members, and 7 nurses) was enrolled. The targeted sample was triads consisting of one patient, one family member, and one nurse identified as vigilant by the patient or family member. This preferred triad configuration could not be achieved because in some cases the patient was too ill to participate, a family member was unavailable, or in two cases a member of the triad did not consent to participate. When a triad was not available, participants were sought from the same groups, but not connected with a given triad, and were recruited until redundancy was reached for the specific group. For example, one patient had no family member to participate; therefore a family member unrelated to the patient was recruited. Because phenomenology was used to identify common experiences even among diverse samples, no effort was made to control for the following variables: gender, education, age, religious preference, socioeconomic status, marital status, cultural background, type of cancer, type of treatment, length of time since diagnosis, length of time as a nurse, and education level. However, demographic data was collected on these variables to fully describe the sample.

The criterion of theme redundancy [118] was used to judge the adequacy of the sample. Redundancy was indicated as analysis proceeded and no new theme categories emerged as analysis of the last participants' data were completed. The adequacy of qualitative sample size is best judged by an expert in qualitative research [119]. Dr. Haase, an expert in empirical phenomenology, concurred as data analysis was

completed for each group that redundancy was reached. Criteria for inclusion and exclusion are described in Table 5.

Table 5. Inclusion and Exclusion Criteria

Inclusion criteria for the patients included:

1. currently being treated, or has completed treatment for cancer within the last 6 months;
2. child or adult 18 years and over;
3. able to speak and understand English;
4. can identify having an experience of vigilance for self

Exclusion criteria for the patient were:

1. any diagnosis of cancer without subsequent therapeutic follow-up;
2. having any diagnosed major mood disorder, such as bipolar disorder or schizophrenia that would preclude providing a full and accurate description of their experience;

Inclusion criteria for the family member included:

1. identified by the patient who is being treated, or has completed treatment for cancer within the last 6 months;
2. child or adult18 years and over;
3. able to speak and understand English;
4. can identify having an experience of vigilance for the patient
5. willing to spend time to provide a full description of the experience.

Exclusion criteria for the family member were:

1. having any diagnosed major mood disorder, such as bipolar disorder or schizophrenia that would preclude providing a full and accurate description of their experience;

Inclusion criteria for the nurse included:

1. registered nurse;
2. having provided care to patients with cancer;
3. identified by a patient who is currently being treated or who has completed treatment for cancer within the last 6 months; or,
4. if nurse identified by a patient is already in study, the nurse identified by the patient will be asked to identify another nurse who was involved in the care for the patient
5. child or adult 18 years and over;
6. able to speak and understand English;
7. can identify having experiences of vigilance for patients
6. willing to spend time to provide a full description of the experience.

Exclusion Criteria for the nurse included:

There were no exclusion criteria for nurses.

Setting and Sample Recruitment

Recruitment began after receiving approval of the Scientific Review Committee for cancer patients, the Institutional Review Board (IRB) at Indiana University-Clarian. Recruitment procedures were the same as they were in the pilot study. The sample was recruited from a cancer center affiliated with a university health science center in the Midwest. Participants for this study were recruited following the Health Insurance Portability and Accountability Act (HIPAA) guidelines. Healthcare providers, including a physician specializing in hematology / oncology from a Midwestern city, registered nurses, and clinical nurse specialists within an oncology unit in a Midwestern hospital approached patients and their family members and discussed the study and ascertained interest in participation. Potential registered nurse participants were told about the study through their nurse manager prior to recruiting patients or family members. After receiving initial and general information from their nurse manager, no nurses indicated they would prefer not to receive more information about the study, if identified by a patient as being vigilant. The nurse manager was not notified by the researcher if nurses who were contacted chose to participate or not in the study.

If a patient or family member expressed interest and gave permission, the referring provider contacted the researcher with the patient's preferred means of initial contact. The initial preferred contact for all patients and family members was in person. For the majority of nurses, the preferred initial contact was by telephone.

At the initial visit with the potential participant, the study specifics were discussed. In order to participate, patients had to be currently receiving or had received (within 6 months) chemotherapy or radiation for treatment of cancer. The family member, (as defined and identified by the patient) had to have a relationship with the patient during the time period of cancer treatment. If a patient and family member were interested in participating, a consent form was reviewed. Once adequately informed, the patient and

family member were asked to sign the consent. The consent included a release of clinical information from the patient record regarding clinical characteristics of their disease process and subsequent treatment. Further, it was noted in the consent that participants could withdraw at any time from the research study and withdrawal would not affect their healthcare or employment in any way. After completion of an interview, patients or family members were asked to identify a nurse who cared for them during their treatment for cancer, whom they felt was vigilant with them. Designated nurses were contacted for interest in participation of the study. Nurses were not informed which patients or families named them as a vigilant nurse. Registered nurses were also asked to sign consents to participate, with the same kinds of information included in the patient / family consents, including refusal to participate at any time with no consequences.

Data Collection Procedure

I conducted all interviews, which were audiotape-recorded. Interviews were conducted at a time and place that was convenient for the participant. Patient and family data were collected in the unit and nurse data was collected in the unit or school of nursing, with one additional nurse interview taking place at the nurse's home. Regardless of location, the settings were quiet, comfortable, private and free from distraction (notice on the door of interview taking place, telephones forwarded and televisions turned off).

To facilitate a rich description of the experience of being vigilant, a written copy of the data-generating questions was given to the participants ahead of time. Patients and family members generally received questions from 3 to 24 hours prior to the interview. Because patients' conditions were not stable, opportunities were taken to interview patients and family members when patients felt well enough to be interviewed. This often necessitated same day interviews. When given at least 3 hours to prepare, patients and families seemed ready, interested, and fully engaged during interviews. Descriptions of vigilance were rich and detailed. Giving participants' time to reflect on experiences has proven

effective in obtaining full descriptions of an experience in previous studies [120-122] and seemed supported by the detailed narratives obtained in this dissertation study.

Each triad member was interviewed separately, with the exception of one couple who chose to be together during the interviews, but each answered questions separately, as if they were being individually interviewed. Patient interviews lasted between 17 and 57 (m= 42.8) minutes. Family members interviews lasted between 17 and 66 (m=45.6) minutes. Nurse interviews lasted between 26 and 50 (m=38.8) minutes.

Participants were told that confidentiality would be maintained by keeping identifying information separate from data and using pseudonyms in place of names during tape-recorded interviews, analysis, and in reports of findings. Participants were told their participation was voluntary and that they could stop at any time.

Measures (Methods of Questioning)

In phenomenological studies, participants' narrative descriptions of their experience are sought. The participants, through their subjective experience of the phenomena, give direction to the interview [94]. Open-ended, audio-taped interviews were completed. In phenomenology, rich and full descriptions are elicited through broad data-generating questions. Questions were submitted to the participants in advance so they had time to think about the descriptions of their experiences with vigilance. Questions were constructed to elicit the lived experiences and the meaning of those for the patient in relation to specific phenomena [123]. Interviews were continued until the participants felt the experience was fully described. Clarification of the word vigilance was provided, modeled after previous research on complex phenomenon. Clarification was provided so the focus of the participant's description was on the experience and not the technical knowledge of the term used to represent the concept [124]. In this instance, "being watchful" was another term used for vigilance by participants in previous research [18]. For this study, the following questions were used [see Appendices G, H, & I].

Questions for Patient Participants:

1) Please describe to me your experiences of vigilance. Vigilance is sometimes called “being watchful.” You may have another word that also fits this experience. We are interested in your stories and experiences of being watchful for yourself during your hospitalization and treatments for cancer. Please describe all you can remember about how you stayed vigilant or “watchful” for yourself—all your thoughts, feelings and actions. You might begin by telling a story about a specific time when you needed to be vigilant or “watchful” for yourself.

2) Please describe to me your experience of vigilance or being watched over by family members or nurses. Please describe all you can remember about how it was for you to be watched for by others—all your thoughts, feelings and actions about how others were watchful for you. Again, you might begin by telling a story about a specific time family members or nurses were vigilant or “watchful” for you.

Questions for the Family Member Participants:

1) Please describe to me your experiences of vigilance. Vigilance is sometimes called “being watchful”. You may have another word that also fits this experience. We are interested in your stories and experiences of being watchful for your family member during his or her hospitalization and treatments for cancer. Please describe all you can remember about how you stayed vigilant or “watchful” for your family member—all your thoughts, feelings and actions. You might begin by telling a story about a specific time when you needed to be vigilant or “watchful” for your family member.

2) Please describe to me your experience of nurses being vigilant for your family member. Please describe all you can remember about how it was for you to see nurses watching over your family member—all your thoughts, feelings and actions about how others were watchful for your family member. Again, you might begin by telling a story about a specific time nurses were vigilant or “watchful” for your family member.

Questions for the Nurse Participants:

1) Please describe to me your experiences of vigilance that is sometimes called "being watchful" for your patients during their hospitalization and treatments for cancer. You may have another word that also fits this experience. Please describe all you can remember about how you stayed vigilant or "watchful" for your patient—all your thoughts, feelings and actions. You might begin by telling a story about a specific time when you needed to be vigilant or "watchful" for your patient.

2) Please describe to me your experience of vigilance or of family members or patients being watchful. Please describe all you can remember about how it was for families or patients to be watchful—all your thoughts, feelings and actions about how they were watchful. Again, you might begin by telling a story about a specific time family members or patients were vigilant or "watchful".

Data Analyses and Interpretation

All audiotape-recorded data from participants were transcribed verbatim by trained personnel who passed the National Institutes of Health test for Use of Human Subjects. I checked the transcription for accuracy. Demographic data were analyzed through SPSS descriptive statistics. Descriptive statistics were used to describe the sample. The transcribed qualitative data were managed using features of Microsoft Word, including tables for steps of transforming raw data to formulated meanings within each interview (protocol) and using MSWord Outline for organizing themes across protocols.

Analysis of Study Aim 1

Qualitative interview data from each participant (patient, family member and nurse) were examined separately using Colaizzi's method of analysis [104]. For an example of the analysis method, see Table 6. The specific steps for analysis were: 1) The interviews were listened to several times and transcribed to get a sense of the experience as a whole; 2) Significant statements in each protocol were identified; 3) The significant

statements were restated in general terms to reflect the general language of science; 4) Meanings of statements were formulated; 5) The full protocol, significant statements and formulated meanings were reviewed in collaboration with an expert in phenomenology, Dr. Joan Haase, to assure fidelity to the participants statements and to identify any additional deeper layers of meaning; 6) Common themes across all the participants' protocols were identified and organized into theme clusters and larger theme categories; and, 7) a full narrative description of the common themes of the experience was developed; and 8) the essential elements of the experience were described in narrative form. Colaizzi suggested that an additional strategy to support the trustworthiness of analysis was for essential elements to be validated by participants. Validation of this dissertation study's findings is a strategy planned for post-doctoral studies. After the data were fully analyzed, through these steps, the findings were examined in light of existing literature as part of the discussion of findings.

Table 6. Example of Analysis Using Colaizzi's Method

Significant Statement	Restatement	Formulated Meaning	Theme Category
6.328A but in the interim, you may have gained information, or knowledge that you didn't have that changes your position on certain things.	6.328A but in the interim, patient may have gained information, or knowledge that patient didn't have that changes position on certain things.	6.328A Knowledge and information are things that change the way patients are vigilant.	Knowledgeable Vigilance: Supplies for the Journey.

Analysis of Study Aim 2

The method of matrix analysis was completed to identify similarities in themes among the groups. A matrix was constructed across groups after themes were identified. Matrices may be used to examine dimensions and look for interaction of those dimensions [125]. Matrices may also be used to identify relationships and for a search for tentative propositions regarding relations between categories of information [126]. In this instance, a

matrix was constructed to identify commonalities of vigilance experiences across three participant groups.

Trustworthiness and Credibility Strategies

In qualitative research it is important to have criteria for evaluation of trustworthiness and credibility of the research findings, as noted by several authors [127-130]. Trustworthiness refers to the study findings' applicability, truth value, consistency, and neutrality and these were established by creating adequate material for an audit trail and an adherence to the methodology used to examine the data [130, 131]. Trustworthiness and credibility were established in the following ways:

1) A rigorous self-examination of biases and presuppositions were bracketed during conduct of the interviews and analysis of the data [101, 110, 112, 113]; 2) Rigorous adherence to the Colaizzi method of analysis [104]; 3) "Peer review" of steps of analysis after formulated meanings was done with my advisor who has expertise in phenomenology and additional peer review of de-identified and aggregated data were reviewed by pre and post-doctoral students enrolled in Dr. Haase's empirical phenomenology course; 4) Maintenance of an audit trail which assured each step of analysis could be traced back to the original protocol; and, 5) Provision of a full and rich description of the sample in dissemination of findings.

Summary of Methods

Research of vigilance was a necessary first step to investigate the merit of developing it as a means of decreasing morbidity and mortality, as well as using it to improve patient quality of life through increased patient satisfaction and sense of well-being. Vigilance has only been examined at the individual level of analysis previously, and the proposal to continue its investigation through identifying common experiences may provide a way to conceptualize vigilance as a phenomenon which is shared among persons. The context of this study was innovative, as experiences of vigilance had not

been examined in Complex Adaptive Systems, which influenced the experiences expressed by patients, families, and nurses. The analysis of vigilance may help meet the suggestions from the IOM related to both patient-centered care and the use of Complex Adaptive Systems as a framework to reduce healthcare errors.

CHAPTER IV

Results

Results are presented in the following ways. First, a description of the sample is provided. Second, narrative descriptions of the experiences of vigilance were written from the theme outlines. Third, a description of the essential structure of the vigilance experience for the specific participant group is provided. Lastly, there is a listing of key findings, extracted from the narratives which will guide the discussion section for each participant group.

A total of 5272 significant statements were extracted from the three participant groups. Statements from each participant group were placed in an outline corresponding to each group, which was then used to identify theme categories relevant to each group's vigilance experiences. Eleven theme categories were identified for patient participants, ten theme categories were identified for family member participants, and ten theme categories were identified for nurse participants. The presentation of findings is organized by these resultant theme categories and each theme category and its subsequent theme clusters are used to present findings from each participant group. Included under each theme category are the theme clusters and themes which give detail to the narrative descriptions. Theme categories and theme clusters were described through metaphor. Such metaphorical descriptions can serve to enhance the vivid description of participants' experiences. Using metaphors to describe experiences such as these has been employed before in relaying other research findings [132]. Additionally, exemplary quotes are used to support narratives of theme categories and clusters.

Patient Results

Description of Patient Sample

In many qualitative research reports, participants are usually described in detail. Because patients and family members in the sample for this dissertation study had long term hospitalizations, nurses and other healthcare professionals became very familiar with them. Families and patients were likewise familiar with the nurses. In order to protect participants' confidentiality, the sample is described minimally.

Seven patients participated in this dissertation research. Four patients were males and three were female. Five patients declared ethnic identities of Caucasian, one Hispanic, and one specifically declared Native American / Mexican ethnicity. All patients but one were currently married. Five patients had advanced cancer with poor prognoses. Four patients were being treated for relapsed Acute Myelogenous Leukemia (AML), one with relapsed Acute Lymphocytic Leukemia, one newly diagnosed with AML, and one patient had B cell lymphoma. Patients ranged in age from 26 to 68 (m=46; SD 14.3). On average, this was an educated group of patients with a range of education from 13 to 25 years (m=15.57; SD 4.27). All patients were currently being treated as inpatients for their cancers through a variety of protocols matched to their specific cancer and condition. For the majority of patients this meant a hospitalization lasting an average of 30 days.

Narrative of Patient Findings

The overall experience of vigilance for cancer patients is like an epic journey. Patients revealed an overwhelming sense of trying to accomplish a task similar to stories from mythology, where heroes set out to accomplish tasks that seemed humanly impossible. Osborn [133] commented that "The hero's journey always begins with the call…When one thinks of some reason for not going or has fear and remains…because its safe, the results are radically different from what happens when one follows the call. If you refuse to go, then you are someone else's servant" (p. 78). Patients in this

dissertation study answered the hero's call. Eleven theme categories were identified related to patient participants' journeys. The theme categories and clusters derived from patient participant data are identified in Table 7.

Table 7. Overview of Patient Theme Clusters and Theme Categories

Theme Category	Theme Cluster
Describing Vigilance is Like Trying to Perform a Seemingly Impossible Task of Mythological Proportions	• Vigilance is Adaptive and Unique to the Person / Situation / Provider • There Are Many Things That One Needs to be Vigilant About • What Vigilance Is Not About
Circumstances Under Which Vigilance Shows Up-Summoning Forth Vigilance	• Getting or dealing with a serious illness summons vigilance • Vigilance is summoned when there is fear • To Avoid injuries / detrimental decisions • In order to have some control • Vigilance is summoned in order to stay alive and not die • Vigilance is summoned by having someone else to be vigilant for
Mythological Proportions of the Energy, Effort, and Thought it Takes to be Vigilant	• There are so many things to be vigilant about-It takes a concerted effort • Beliefs in one's own capability and responsibility to watch out • Maintaining me-ness an effortful strategy to maintain power and vigilance over self • Vigilant people are not easily deterred • Asking about potential errors / things that are unexpected takes effort, thought, and energy • Prioritizing where to focus vigilance • Identifying threats is essential to vigilance • A map of the dangers on the journey-Detectable signals of something wrong • Identifying and Sidestepping potential risks-Preventive vigilance through lifestyle adjustments • Help in the mythological journey: maintaining the effort and energy needed for vigilance
Like using a string to find the way out of a maze-Vigilance is a way to focus / conserve energy	• Who helps conserve energy • Ways patients save energy
Knowledgeable Vigilance: Supplies for the journey	• Knowledge must be sought • Being familiar with the route • Captain of the ship-Effective vigilance requires discernment and knowledge • knowledgeable vigilance must be understood and experienced • Lack of knowledge impedes ability to be effective in vigilance • Knowledge is needed to be successful • Knowledge Needs to be at the appropriate level / amount for the person • Knowledge is about sensemaking • Ways to learn how to be vigilant
Companions for the journey: A house of vigilance	• Family shield-Patients see Family Members Use Vigilance • Legacies (being close to family) • Lean on me–the kinds of things patients expect from or rely on family for

	• Lean all you want-family's gifts to the patient • Family sacrifices on behalf of patient are overwhelming to patients • Patient roles in families • Extended family-Siblings and their role in patient vigilance • When things interfere with families being watchful • When things interfere with families being watchful • Too much of a good thing-Family presence can lack optimal benefits • Kindness of others and being remembered is a way to be watched over • Patient's watching over the journey's companions
Half out of my mind: the complexity of cancer detracts from vigilance	• Vigilance detractors • Navigating with Visibility Zero-It is difficult to be vigilant when signs are hard or impossible to detect • Like a third world country-When what is perceived as the best healthcare and providers in the world do not meet patient minimum expectations • Doing what's right and doing what's wrong and still getting cancer: A sense of blame for failing to be vigilant at some level for one's health
Metamorphosis-the life changing forever events of having getting cancer	• The beginning of the end of the way things used to be • Negotiating the change-things are not the way they used to be • Strategies to remain positive • A noticeable day's work-Recognizing the changes in the journey of cancer • Changes occur in doing / thinking / being related to cancer • The Quest for the Holy Grail of Remission
Rising Spirits and the Yoke of Hope and Vigilance	• Knock Wood, appeasing the gods: The spiritual aspect of vigilance
What the Treasure Looks Like: The Patient Need / Awareness for Vigilance	• The need for vigilance is highlighted by the absence of it • The downside of HCP vigilance-responses from healthcare providers can be paradoxically appreciated and frightening / frustrating • A bevy of vigilance-a shared group phenomenon • 360 degree view of the system
The Meaningfulness of Vigilance: Like a Treasure Hidden Within the Seemingly Insignificant Little Extras	• The vigilance test-Determining which healthcare providers give that little extra • Insignificant significance-actions of healthcare providers that demonstrate that little extra of vigilance • Trust is requisite for sharing vigilance-patient healthcare provider trust • The patient benefits when nurses have / do that little extra • Nurses minus the little extra-no treasure to be found • The minimum isn't enough

Seven participants provided detailed narratives about their experiences with vigilance, both how others watched over the patients and how the patients watched over themselves. Participants who were patients with cancer were assigned a code beginning with a number and ending with A. Therefore, when it is noted after a quotation 6.234A,

one can interpret that the statement was made by participant 6, significant statement number 234, and this was a patient participant, as designated by the letter A. Because this research accrued data from three different samples, patients, families, and nurses, these terms will be used instead of participant, in order to avoid confusion over which sample is being discussed.

Theme Category 1. Describing Vigilance-

Like Trying to Perform a Seemingly Impossible Task of Mythological Proportions

Patients struggle to understand and grasp vigilance and almost by default shared experiences classified as NOT vigilance. Vigilance seems somewhat mysterious to the point that patients are uncertain how or from where it appears: [Spouse stated] “Mom is to do no dusting, no laundry, no cleaning, no cat box. She is not to be bothered. And I’ll kind of like look at him, I’m kind of like honey, where did this come from?” 4.210-4.212A. Three theme clusters related to Theme Category 1 were identified [see Table 8].

Table 8. Patient Theme Category 1

Theme Category	Theme Clusters	Themes
Describing vigilance is like trying to perform a seemingly impossible mythological task	Vigilance is Adaptive and Unique to the Person / Situation / Provider	
	There Are Many Things That One Needs to be Vigilant About	
	What Vigilance Is Not About	• Vigilance is not about letting others decide • Vigilance is not about poor judgments • Vigilance is Not about being helpless / powerless • Vigilance is not necessarily gentle or comforting • Vigilance is not about avoiding healthcare • Vigilance is not a cureall • Vigilance is not about chaos • Vigilance is not about hypervigilance • Vigilance is not about micromanagement • Not about being passive

Theme Cluster 1.1. Vigilance Is Adaptive and Unique to the Person / Situation / Provider

One of the reasons vigilance is difficult to recognize and describe is that it is adaptive and unique to the person, situation, and healthcare provider. Additionally, each person is affected by situations and treatments for cancer in different ways, making it hard to pin down a standard or one-size fits all vigilance "If somebody else [another patient] wants to venture beyond that [basic knowledge], they can. I think they're in trouble when they do that. Because first of all, they're way out of they're field of expertise" 6.322A-6.32A.

Theme Cluster 1.2. There Are Many Things that One Needs to Be Vigilant About &

Theme Cluster 1.3. What Vigilance Is Not About

Patients experience additional confusion about vigilance because there are so many things about which they, as cancer patients, need to be vigilant about. "But then there are more-some layers [to vigilance] like putting that guy with VRE [antibiotic resistant bacteria] in there with me when I would've been neutropenic" 9.020A-9.021A. In order to figure vigilance out, it seems that patients use trial and error methods to learn what vigilance is NOT. Descriptors of what vigilance is not about include: poor judgments, being powerless or helpless, avoiding healthcare, a cureall, micromanagement, being hypervigilant, chaos or being passive, or letting others decide. Participants perceive being vigilant is a choice that allows one to not feel helpless: "As opposed to this powerless guy, or helpless guy laying there on that bed and they're just taking care of you, and you're passive" 9.126A, describing what vigilance is not.

Theme Category 2. Summoning Forth Vigilance-

Circumstances Under Which Vigilance Shows Up

In mythology, special circumstances or special powers are required to summon forth assistance or conditions which allow heroes to complete the task they have been given. Much like mythological heroes that begin their journeys having had no reason before the

present to summon forth vigilance, patients suddenly are faced with the need to become highly vigilant. This theme category had seven theme clusters [see Table 9].

Table 9. Patient Theme Category 2

Theme Category	Theme Clusters	Themes
Circumstances Under Which Vigilance Shows Up-Summoning Forth Vigilance	Getting or dealing with a serious illness summons vigilance	
	Vigilance is summoned when there is fear	
	When Things Do Not Make Sense or Are Unexpected	
	To Avoid injuries / detrimental decisions	
	In order to have some control	
	Vigilance is summoned in order to stay alive and not die	• Vigilance is sparked because patient wants to live to see family
	Vigilance is summoned by having someone else to be vigilant for	• Having others to watch out for / Feeling responsible for others summons vigilance • Being a parent / pregnant vigilance calls personal

Theme Cluster 2.1. Vigilance Is Summoned When Someone Is Getting or Dealing with a Serious Illness

Participants describe vigilance as being summoned by getting cancer, in essence likening the beginning of the journey to the onset of the cancer. “Well, if we go back to the beginning of [the vigilance journey] which…was when I was first diagnosed with AML [leukemia]” 6.00A. Patients clearly contrast life with cancer to life when patients and their family members did not have to be as watchful: “…it scared us both because we both lived pretty, pretty carefree lives…” 8.071A.

Theme Cluster 2.2. Vigilance Is Summoned: When There Is Fear, Theme Cluster 2.3 When Things Do Not Make Sense or Are Unexpected, Theme Cluster 2.4 To Avoid Injuries / Detrimental Decisions Calls Vigilance, & Theme Cluster 2.5 In Order to Have Some Control

Being scared, or feeling fearful, seemed to summon vigilance from some unknown place. Vigilance appears to be a protective phenomenon brought forth to deal with fear, used to avoid pain, injuries, and detrimental decisions, and further used to make sense of or understand what is happening. Fear seemed an impetus to pay close attention to multiple things, including participants' health: "… then I was joking about cancer, and I was like yeah okay I scared myself. Now I gotta go [to the doctor]" 8.341A. Fearfulness is closely associated with things not making sense, or not having an understanding of a situation. It is necessary for things to make sense to patients. When patients are surprised by unexpected things or they could not make sense of what was going on around them, they respond by becoming very watchful in order to try and figure out or make sense of the situation: "Oh my God! You know…what's going on? I started looking at myself…" [to check where pool of blood had come from] *1.43A.*

Additionally, patients became especially watchful in order to avoid injury and pain. "I walked around with my toes sticking out, just so I wouldn't stub my toes it hurt so bad" [because toes were so bruised from bleeds related to cancer] 8.029A. Vigilance allows patients to perceive a control over their disease and treatment, a sort of extra insurance for having the best chance of recovering. "I know when the nurse came in this morning, and she had my chemo, I knew what it was and I was expecting it, and I know how long it's gonna run and I knew what's going on" 5.334A-5.337A.

Theme Cluster 2.6. Vigilance Is Summoned in Order to Stay Alive and Not Die

The primary reason patients relayed for watching out for themselves was to survive the cancer and the treatment: "I said this is my life, and as far as I'm concerned, I come first" 6.47A. Being able to stay alive held deeper meaning because it meant not having to relinquish life with family: "…'cause I'm not ready to leave my husband and children" 4.157A.

Theme Cluster 2.7. Vigilance Is Summoned by Having Someone Else to Be Vigilant For

Finally, as patients struggle to understand and use vigilance, they realize that vigilance has a sense of familiarity. Patients relay that vigilance in the present is similar to vigilance patients use to watch over family members and children. Having others' health or safety to watch over seems to be a way vigilance is summoned. Vigilance associated with watching out for family and children might be as benign as being watchful over the children's dietary habits: "My husband and I always used to think, well when the children were home, no soda, no koolaid…" 2.103A. Alternately, patients may have experience being seriously watchful over family members, who also have life-threatening illnesses: "…with my husband he has a disorder [one that produces spontaneous aneurysms] that causes us to be very, very vigilant. Everything he does, we have to watch out, every pain, pinch, or poke…we have to decide whether or not it's an emergency run" 8.006A-8.008A.

Theme Category 3. Mythological Proportions of the Energy, Effort, and Thought it Takes to Be Vigilant

Although there are many things that summon patients' vigilance, working to learn about vigilance and remain effectively watchful cost the patient energy. Vigilance is not optional; it is a necessary and difficult process: "When I say [to others] you have to [be flexible in my vigilance], I'm not lecturing. Everything I'm saying here is my feeling. This is what I've gotta do, and sometimes it's difficult" 6.333A. Ten theme clusters illustrate various ways in which vigilance required patients' energy, thoughts, and effort [see Table 10].

Table 10. Patient Theme Category 3

Theme Category	Theme Clusters	Themes
Mythological Proportions of the Energy, Effort, and Thought it Takes to be Vigilant.	There are so many things to be vigilant about-It takes a concerted effort	• Takes vigilant effort to preserve life • Many things to watch out for • Special things to watch out for-It takes a vigilant effort to watch over children
	Beliefs in one's own capability and responsibility to watch out	• Vigilancespeak-the patient's responsibility to speak up when they need answers • Vigilancespeak with care-A cautious and gentle approach invites others to be vigilant
	Maintaining me-ness an effortful strategy to maintain power and vigilance over self	
	Vigilant people are not easily deterred	
	Asking about potential errors / things that are unexpected takes effort, thought, and energy	
	Prioritizing where to focus vigilance	
	Identifying threats is essential to vigilance	• Awareness of the degree of danger informs how vigilant one should be • Degree of risk is weighed to determine where to focus energy • There are places where the danger factor is higher-Work is a place of danger • Awareness that a lack in vigilance (identifying dangers or threats) can lead to negative consequences • Not seeing the threat • Yielding to the expertise of healthcare providers-Trusting others to identify and deal with threats • Others need help recognizing danger
	A map of the dangers on the journey-Detectable signals of something wrong	• The physical symptoms of leukemia • Stubborn infections • Legs stuck in concrete • Overwhelming fatigue • Pounding Heart • Short of Breath • Bruises as a symptom • Bleeding / nose bleeds • Swollen lymph glands • Headache • Lack of appetite • Becoming experts of keeping track of the illness and response to treatment • Blood tests are a measurable way to be vigilant

	• Charts with counts are like a radar screen for detecting danger coming and going • Watching neutrophils peaking their heads up • Real peculiarities how people stay on guard for their bodies • Bone marrow biopsies and other tests • Night Sweats-can't miss them • Temperature monitoring • There is a limit to how much one can pay attention or wants to pay attention to visible / knowable signs
Identifying and Sidestepping potential risks-Preventive vigilance through lifestyle adjustments	• Lifestyle choices • Preventative vigilance • The futility of sidestepping-Too little, too late • Never walking down that path • Hindsight is 20/20 (noticing and changing habits when you have cancer) • Vigilance comebacks-The responses people have to recognizing something is wrong
Help in the mythological journey: maintaining the effort and energy needed for vigilance	• Food from the gods-the importance of sustenance on the journey • Staying connected with healthcare providers on the journey • Exercise / watching weight and nutrition on the journey • Companions in the journey • Even the gods take breaks so they can be vigilant • Family and their support for the journey • Remaining present-paying close attention to where one is and how the journey is going

Theme Cluster 3.1. There Are So Many Things to Be Vigilant About-It Takes a Concerted Effort, Theme Cluster 3.2. Beliefs in One's Own Capability and Responsibility to Watch Out & Theme Cluster 3.3. Maintaining Me-Ness: An Effortful Strategy to Maintain Power and Vigilance over Self

Although vigilance costs the patient energy, it is seen as energy well spent because vigilance is viewed as a path through which patients might save their own lives. One participant commented on his relapse "And this time, it'll probably require a great deal of more vigilance because this time, I've got to find something" [a way to get into remission]

6.282A. Vigilance is viewed by patients as something the patient themselves are responsible to do. It is a serious undertaking, for which patients believe they are capable of taking on: “Make sure that you follow up and stay on top of it because…this isn’t a hangman [game] we’re talking about, this is your life” 4.161A. It is important for patients to maintain the appearance of having the energy or power to be vigilant for themselves. Patients purposely expend energy to present themselves as normal and capable: “I think it was actually helpful for my dad to realize, not that it’s not a serious situation, but realize that maybe I am going to be okay. So I think for him to come in and see me in my t-shirt and shorts watching [TV], sitting in the recliner” [was important] 5.139A-5.138A.

Theme Cluster 3.4. Vigilant People Are Not Easily Deterred, Theme Cluster 3.5. Asking About Potential Errors / Things that Are Unexpected Takes Effort, Thought, and Energy, & Theme Cluster 3.6. Prioritizing Where to Focus Vigilance

Patients were determined to remain watchful for themselves and others. Very little interfered with the patients’ sense of needing to be watchful and speak up to remind others that they are being watchful and expect the other also to be watchful. That is, vigilance is not considered optional for self or others: “Even if I know them, I always ask them if they’re washing their hands” 9.026A. Patients did not like having to speak up, because it exacted a payout of energy, but as this patient puts it: “I would certainly say something if I felt that I wasn’t [being kept safe], just like I said something about that guy” [with antibiotic resistant bacteria] 9.029A. While vigilance for one’s self was very important, patients clearly understood they cannot be vigilant about everything. Since it takes such effort and energy to be vigilant, patients carefully choose what to spend vigilant energy on: “I don’t check the doses or the calculations they make and assume those are correct. That’s just typical to do that. I check my lab work” 9.007A-9.008A.

Theme Cluster 3.7 Identifying Threats Is Essential to Vigilance

Identifying and classifying things that were threatening uses a lot of patients' energies. Without expending energy to identify potential threats, patients sense they can be left open to harm. Patients determine how vigilant to be based on the degree of the threat in order to mete out how much energy to spend being vigilant. In other words, the higher the threat-the more energy expended on vigilance. Additionally, patients indicate an awareness of the dangers associated with not identifying or incorrectly identifying threats. "If I hadn't told them, [then] I'd go home and get VRE [antibiotic resistant bacteria] right when I'm neutropenic and I'd die" 9.109A.

Theme Cluster 3.8 A Map of the Dangers on the Journey-Detectable Signals of Something Wrong

One thing that is helpful to patients in identifying threats is whether or not the threat or danger can be detected or seen in some way. Patients rely on concrete clues as much as possible in order to conserve energy and focus on confirmed concerns. Participants look for both physical symptoms, such as fatigue, shortness of breath, and bruising, and medical tests, such as blood tests, charts indicating lab results-in particular neutrophil counts, and bone marrow biopsies as ways to monitor their condition. "I think this last time that it reoccurred, I was looking more for the bruising [more] than anything. Especially when I was getting a shower" 1.00A-1.01A.

Theme Cluster 3.9. Identifying and Sidestepping Potential Risks-Preventive Vigilance Through Lifestyle Adjustments

Patients are very aware that lifestyle choices, unhealthy or high risk behaviors, are commonly associated with whether people get cancer or recover from cancer or not. They are aware of the possibilities of preventing cancer by being vigilant about lifestyle choices. Unhealthy lifestyle choices are seen as threats that are controllable to some degree. Patients indicate that they often changed their lifestyles after getting cancer, but

at times, the change seems too late to hope for a cure from cancer. Patients feel as if some of their own lifestyle choices contributed to their cancer: “I…was always one of those…burned the candle at both ends. And I did it for so long, for so many years, that I think that that’s what triggered my cancer” 4.143A.

Theme Cluster 3.10. Help in the Mythological Journey: Maintaining the Effort and Energy Needed for Vigilance

While vigilance cost patients energy, patients clearly express the things they do in order to maintain the energy to remain vigilant. Patients perceive that things like food, exercise, taking breaks, using humor, and being connected with both family and healthcare providers helps to renew and maintain the energy needed to continue to be vigilant: “They’re [healthcare providers] not strict…I mean they want you to have, I don’t want to use the word fun-but at the same time, they don’t want you to let it [cancer] consume you” 4.27A.

Theme Category 4. Like Using a String to Find the Way Out of a Maze-Vigilance Is a Way to Focus and Conserve Energy

Vigilance appears to be a paradoxical concept on many levels; while vigilance is reported to cost energy or effort, using vigilance is also described as a way to save energy. Instead of blindly stumbling around, as if in a dark cave, patients are aware of certain vigilant people and practices that, like having a string to follow back out of a maze, saves incredible amounts of energy. Two theme clusters were identified [see Table 11].

Table 11. Patient Theme Category 4

Theme Category	Theme Clusters	Themes
Like using a string to find the way out of a maze- Vigilance is a way to focus / conserve energy	Who helps conserve energy	• Healthcare providers and energy saving actions • Family members and energy saving actions
	Ways patients save energy	• Not worrying about inconsequential or imaginary things • Weighing what is too much in order to conserve energy • Must have a balance to conserve energy

Theme Cluster 4.1. Who Helps Conserve Energy

Patients seem aware of the ways in which both healthcare providers and family members watching over them help conserve patients' energies. Patients seem to understand that to remain vigilant oneself, yet allow others to be vigilant for oneself is a necessary paradox: "And again, not to be contradicting, but there's a time when proactivism has to stop from your standpoint, and you have to relinquish some of that to somebody else" 6.69A. Patients relate that vigilant others recognize a need to conserve the patients' energy: "When I was asleep this weekend, they [nurses made the effort and] really didn't bother me" 8.225A.

Theme Cluster 4.2. Ways Patients Save Energy

Patients do not just rely on healthcare providers or family members to do things in order to conserve patient energy. Patients actively participate in energy conserving and energy renewing activities. Particularly, patients consciously work to not worry about things that are not important, understanding that focusing too much on any one issue could lead to hypervigilance, an energy-wasting kind of ineffective vigilance. Instead, patients put effort into having a balanced sort of vigilance that is neither over nor under the amount of watchfulness required for the situation. Whereas before the cancer and treatment participants may have exerted energy for non-essential tasks, after the cancer diagnosis, participants make changes specifically designed to save energy: "Cause kids

will just take them and throw them [socks] all over the house. And before I know it, I've got 59 unmatched pair. So I told my husband…I think I'm just gonna go buy each of them a pack [of socks] a week. It seems like that's what we need to do" 4.221A-4.222A.

Theme Category 5. Knowledgeable Vigilance: Supplies for the Journey

Knowledge is described by patients as crucial to being able to be vigilant. Just like a mythological hero setting out on a long journey, if the hero has no map, no supplies, and no experience, the hero will likely make poor decisions, fall into disaster, and ultimately, the journey may fail. Accrued knowledge is a guide for patients which is critical for their decision-making in the journey of cancer and treatment: "…but in the interim, you may have gained information, or knowledge that you didn't have that changes your position" [in regards to treatment] 6.328A. Nine theme clusters comprise the description of knowledge and the role it has in patients' abilities to be vigilant [see Table 12].

Table 12. Patient Theme Category 5

Theme Category	Theme Clusters	Themes
Knowledgeable Vigilance: Supplies for the journey	Knowledge must be sought	• Reading • Television • Internet • Family • Knowledge from other patients • Physicians /Nurses • Asking questions and getting responses to gain knowledge
	Being familiar with the route	• Familiar with body symptoms • Familiar with what to anticipate
	Captain of the ship-Effective vigilance requires discernment and knowledge	• Cancer patients have a special kind of knowing
	Knowledgeable vigilance must be understood and experienced	• Use with care-About medications
	Lack of knowledge impedes ability to be effective in vigilance	• Reoccurrence has elusive symptoms
	Knowledge is needed to be successful	• Knowledge makes for comforting outcomes-knowledge leads to comfort and energy conservation • Informs decision making • knowledge allows patients to anticipate • Knowledge allows one to share vigilance • Knowledge allows family to be vigilant • Knowledge of others about AML

Knowledge Needs to be at the appropriate level / amount for the person	
Knowledge is about sensemaking	
Ways to learn how to be vigilant	• Vigilance is learned through experience • Previous experience with cancer gave a way to monitor for symptoms • Learn vigilance from others being vigilant • Is learned through demonstration-Knowing what to be vigilant for is learned from healthcare providers or family being vigilant • Vigilance is learned from instruction • Some knowledge is gained by osmosis • Becoming Vigilant is a stealthy process that has an 'AHA' at the end

Theme Cluster 5.1. Knowledge Must Be Sought & Theme Cluster 5.2. Being Familiar with the Route

Patients seem very aware that knowledge is crucial in order to be able to be vigilant for self. Patients seek knowledge from many places, such as through reading, television, and internet and from people such as family, other patients, physicians, and nurses. Patients seek knowledge from people by asking questions and expecting responses: "If I had a question, I certainly questioned anything, whether it would be doctors or nurses" 6.46A. Patients who become knowledgeable about what is normal related to treatments and what is personally normal, are more likely to notice things that deviate from normal. When what is normal is known, patients then can be more likely to be alert to and respond when things deviate from normal: "…nobody else is going to be in tune with your body but you" 8.215A.

Theme Cluster 5.3. Captain of the Ship-Effective Vigilance Requires Discernment and Knowledge, Theme Cluster 5.4. Knowledgeable Vigilance Must Be Understood and Experienced & Theme Cluster 5.5. Lack of Knowledge Impedes Ability to Be Effective In Vigilance

Patients understand that the ability to be effectively vigilant is attached in some way to the knowledge or experience one has. If patients do not know or have not experienced symptoms of cancer before, then it is unlikely patients will make the necessary connections between symptom and disease: “I always had to be checking myself out [since relapse], because that first time [I had cancer], I kept blowing off that, I [thought I] was getting it [bruises] at work or something like that” 1.02A. Despite having knowledge or experience, when the circumstances change, such as with relapse, the patient may be left again with an ineffective way to be watchful for symptoms: “The first time I come in, I was pretty run down. This time here [relapse], I wasn’t thinking I had anything wrong with me. It’s weird” 1.06A. Alternately, when patients are knowledgeable, it allows them to be effectively vigilant. In other words, patients work to learn what to watch out for: “So we kind of know [what I am getting because chemotherapy is] color coded…it’s laid out for us” 5.342A.

Theme Cluster 5.6. Knowledge Is Needed to Be Successful

Knowledge is seen as a means of allowing patients to be effectively vigilant, thus leading to more successful outcomes. When patients have the knowledge they need to be vigilant they conserve energy, make informed decisions, are able to anticipate, and share vigilance with family and healthcare providers, and feel comforted: “…after what I just went through…it was very comforting. Cause instead of them painting a [hopeless] picture they said, ‘hey look, this is what you got, and this is what it does’” 1.116A.

Theme Cluster 5.7. Knowledge Needs to Be at the Appropriate Level / Amount for the Person & Theme Cluster 5.8. Knowledge Is About Sensemaking

While patients do need knowledge and experience in order to be effectively vigilant, patients were clear that there is a balance regarding how much should be known or learned. Too much information is overwhelming and too little information disallows the patient from being effectively vigilant: “…at first, I wanted every single thing laid [out].

And then I was like, no, that's overwhelming. I'd rather have what I'm doing now" 8.286A-8.287A. The right amount of knowledge allows patients to grasp and use the knowledge to make sense of their disease and treatment. When things do not make sense, patients seek more information: "I said, 'there's gotta be more to the story…because what I'm hearing sounds very silly'" 4.257A.

Theme Cluster 5.9. Ways to Learn How to Be Vigilant

Patients differentiate knowing things in order to be vigilant versus learning to be vigilant. Knowing and learning are qualitatively different functions for patients. They describe learning vigilance through: previous experiences, watching others demonstrating vigilance, being instructed in being watchful. Some vigilance seems to be learned with little effort, almost as if by osmosis: "You do stuff that you never did or thought of before, you know? That's being vigilant" 1.191A. In the end, patients become aware of the presence of vigilance as an "aha" experience, realizing that what they know and have learned allows them to be vigilant almost unconsciously.

Theme Category 6. Companions for the Journey: A House of Vigilance

In mythological stories, the heroes of the stories often encounter seemingly impossible tasks to perform. In the majority of stories when heroes need to enlist aid of some sort, the heroes seek out relatives to help them. Although at times other close friends or associates may provide some kind of support, it is the family members of heroes who most often give what is needed to make the task achievable. Much like these mythological heroes and families, patients with cancer recognize the ways in which family members affect the journey-most often for the better. As in ancient times, families still believe that sticking together, especially for vigilance is a way to protect one another: "…that's one thing that I think it's very important to instill in your children. Especially during the time of tragedy, or an emergency. That you stay vigilant with your family" 4.229A-4.230A. This theme category had 12 theme clusters [see Table 13].

Table 13. Patient Theme Category 6

Theme Category	Theme Clusters	Themes
Companions for the journey: A house of vigilance	Family shield-Patients see Family Members Use Vigilance	• Families have meaningful and privileged connections (Orchestrate vigilance) • Families learn how to perform advocacy roles • Family vigilance Is aroused by confusion or unknowing • Family vigilance is considering more than one perspective • Family vigilance is keeping an eye on sustenance (family and food) • Vigilant communication among family members • Families talking about things never before talked about-deeply intimate conversations • A call to arms-vigilance alarms-Arousing awareness in patient for danger
	Legacies (being close to family)	• Staying connected • Family closeness is related to vigilance
	Lean on me –the kinds of things patients expect from or rely on family for	• Patient leans on family's strength (game face) Not emotions-otherwise family cannot be counted on to be vigilant • Patient leans on family to relieve patient from duties • Patient leans on family for excellent thinking • Patient leans on family being available / present • Patient leans on family for maintaining a routine of normalcy • Patient leans on family as sounding boards-disconfirming or confirming patient concerns • Patient leans on family for a connection to the WORLD OUTSIDE • Patient leans on family as a means of information / knowledge • Patients lean on family to spot what's wrong / different
	Lean all you want-family's gifts to the patient	• Families Give patient's strength to fight • Families Conserve patient energy • Families are blessings to patients • Families help patients feel supported • Families Make patients' hospitalization tolerable • Families guard patient dignity • Families help protect patient • Vigilance is about protecting family as a whole • Families are about protecting and recognizing weaknesses in family system
	Family sacrifices on behalf of patient are overwhelming to patients	• Families and patients take on other roles • Families prepare for patient homecoming
	Patient roles in families	• Patient's role as a parent-what is important to patients as parents • Oldest sibling role

Extended family-Siblings and their role in patient vigilance	• Sibling birth order and its role in vigilance • Sometimes it is too scary for siblings to be involved • No sibling is safe-no matter age • Facing one's own mortality through sibling experience
When things interfere with families being watchful	• When families are fearful it interferes with vigilance • When patient does not allow families to be vigilance-it interferes with vigilance • When family is not present it interferes with vigilance • When dangers are not recognized by family it interferes with vigilance • When danger is not communicated by family it interferes with vigilance • Patients having to point out dangers to family in the first place interferes with vigilance • When patient does not kno family well it interferes with vigilance • Patient responses to lack of family vigilance
Too much of a good thing-Family presence can lack optimal benefits	• Families can be over the top protective-isolating patient • Can be demeaning to patient-too much dependency • Can be draining to have too much family presence
Kindness of others and being remembered is a way to be watched over	• Employers who watch over patients • Friends and others who watch over patients
Patient's watching over the journey's companions	• Patient balances needs with those of family • Multiple hard realities considered-the hard conversations patients and spouses need to have • Patients give the appearance of normal to protect family • V is for vigilance-the issue of parents and children and cancer

Theme Cluster 6.1. Family Shield-Patients See Family Members Use Vigilance

Patients feel that family members use vigilance as a shield, both to protect the patient and themselves. Patients perceive that family members often have resources, such as connections with others, to ensure that the patient will receive the best treatment for cancer. Acting on such connections are just one way that patients see family members advocating for the patient. Family members also use special knowledge to understand and inform the patient of the intricacies involved in cancer and its treatment: “My other cousin is a doctor, and she’s like, well tell me what kind of leukemia

it is, and we asked the doctor. And she's like, no, no, no they have little numbers. I want to know the little numbers" 8.144A.

Patients are aware that family members' vigilance is used to watch over many aspects of patients' cancer and treatment. Patients describe family members being vigilant about patients' physical limitations, nutrition, and exercise. Family members pay attention to these particular things and try to arouse, in the patient, awareness of their importance: "[Husband] sees that I have breakfast before he leaves for work in the morning, which is usually like six o'clock in the morning" 2.10A. Patients also commented on the communication patterns of family members. Hospitalization is a time when patients and family members talk about things they may never have talked about before: "The first stay when we [patient and wife] were there for three weeks…we talked about everything" 5.263A. At times, the conversations are difficult: "It's not a conversation that you ever really want to have [about the possibility of dying]…I mean it is kind of a morbid, sad conversation to have. But at the same token, I think that it's a conversation that is a necessity, especially if you have children" 4.74A-4.75A.

Theme Cluster 6.2. Legacies (Being Close to Family)

Remaining close to family and finding ways to stay connected are important to patients. Even if family members are not physically with the patient, it is important for the patient that families stay in touch in some way, whether it is the phone or by computer. Family members' presence is a signal to patients and everyone else that family members are devoted and watchful over the patient: "…and they [healthcare providers] know how much [my wife] loves me" 9.141A. Vigilance in many ways is seen by patients as dependent on family closeness: "I think each and every one of us— [vigilance] it's an individual basis, [and depends on things like] how close knit of a family we have" 4.385A, 4.387A.

Theme Cluster 6.3. Lean On Me –The Kinds of Things Patients Expect From or Rely on Family For

Throughout the treatment for cancer, patients describe relying on, or leaning on family members for multiple things. When patients can lean on family members, patients are relieved from duty for a while. The family member becomes the proxy for duties the patient otherwise would normally assume: “It’s funny…my Mom being in here. I mean she’s my freakin computer internet connection to everybody and everybody sends her tons of emails” 8.142A. Patients rely on family members to remain emotionally strong, think excellently, spot things that may be wrong or different about the patient, and to be present and available with the patient: “But just having her there to wake up in the middle night and just see her [wife] laying over there, it’s comforting for her to be there” 5.239A. Patients rely on family members to create a “normal” routine in the hospital, to be sounding boards-who confirm or disconfirm patient concerns, and to provide the patient with information “That [loss of appetite] even worries my Mom. My Mom knows how much of a eater I am” 8.184A. Patients also rely on family members to provide the patient with information or knowledge and are a means for the patient to remain connected to the larger world outside the hospital unit: “’Cause everytime she [girlfriend] left from here she had to tell me something else that she’d seen…So…yea on a Sunday, when the Colts were playing, she’d go downstairs [and] said you could hear them cheering and everything” 1.129A.

Theme Cluster 6.4. Lean All You Want-Family’s Gifts to the Patient & Theme Cluster 6.5. Families Are Blessings to Patients

When patients are able to lean on families, patients benefit in many ways. Leaning on families allows the patient to conserve energy, gives the patient the strength to fight the cancer, allows the patient to feel supported, makes the hospitalization tolerable, guards the patient’s dignity, and protects the patient: “Family friends [would say]—hey

[patient] is home, can we come over? [Family would respond] ‘Nope, not gonna run the risk of getting her sick’… that shows to me right there how much they [husband and children] worry about me” 4.170A, 4.172A. All in all patients are very aware of the meaningfulness of their family members watching over them: “I’ve just been very blessed to know like they [family] just keep an eye on me” 8.150A.

Theme Cluster 6.6. Family Sacrifices on Behalf of Patients Are Overwhelming

Patients realize in its entire enormity the sacrifices that family members make on their behalf. Patients feel that family members suffer on behalf of the patient, take on extra burdens, and sacrifice time with their own friends: In the context of discussing children telling friends why they could not come to the house: [Children said] “I’m sorry, but my Mom’s health is more important right now than us hanging out and playing.” 4.173A.

Theme Cluster 6.7. Patient Roles in the Family

Patients and family members adjusted or changed roles in relation to the patient’s illness. Patients describe husbands taking on household duties and childrearing, which previously were the patient’s responsibility. They also experience having their children become advocates for their parents, when before the cancer the opposite was true. Patients who are parents take on a more passive role in parenting-because it must be done from a hospital bed, often far from home: “He’ll [husband] call me every once in a while, [and relay that son] did this. Is he supposed to? [patient responds] ‘He’ll be fine’” 8.140A-8.141A. Although patients understand the reason and the need for family members and the patient to adjust or change roles during the illness, the role change is experienced as a loss. Patients desperately want to feel they are still upholding, in some way, their end of the family bargain: [patient stated after spouse took over most of domestic chores] “I told him honey, this marriage is still 50/50. I said, just because I got sick [still], I <u>am</u> home” 4.216A-4.217A.

Theme Cluster 6.8. Extended Family-Siblings and Their Role in Patient Vigilance

Within the family the sibling role seems to produce more tension or anxiety. Patients describe a desire to have siblings involved in the patients' hospitalization, if nothing more than a visit from the sibling. Patients were unprepared for a sibling to be reluctant to visit, however patients do not easily tell siblings just how much the patient needs them to visit: "He [brother] said, 'well, I'll see you next week, or whatever'. [patient responded] I'm like, 'yeah, you will. I'll be fine'. You know he just, I think he kind of underplays the seriousness of it [patient's cancer]" 5.132A-5.134A.

Theme Cluster 6.9. When Things Interfere with Families Being Watchful

While patients depend on family members watching over them, patients are also aware that many things interfere with family members' abilities to be or remain watchful over patients. Patients describe vigilance being interfered with when families are in denial or minimize the patients' illness or risks. Patients also report that when families are fearful or hopeless, family vigilance is not at optimal levels. "But my brother made the comment that 'dad thinks that you're…he's coming down to see you cause he thinks that you don't think you're going to make it out of there, and you're going to die or whatever'. [patient responded] 'Why?…I don't think that'" 5.141A-5.142A. Patients also report that when families lack knowledge or have multiple responsibilities, besides caring for the patient, it interferes with family vigilance. Patients believe that when family members are not present, they cannot be as watchful. Additionally, patients recognize there are things patients do to prevent family members from watching over them: "My wife, I don't think she watches out for me too much because, just because of how my personality is. I wouldn't let her" 5.159A-.5.160A. Patients describe additional things that seem to interfere with family vigilance such as family not recognizing or communicating something that may be threatening to the patient, or when extended family, who patient does not know well, attempts to help watch out. When patients do not know family

outside of their immediate family as well, it seems as though that patient cannot participate in a shared or comfortable kind of vigilance: “I mean they’ve [husband’s family] been good too. Don’t get me wrong, I just don’t know them as well” 8.111A. When family members are not involved in watching out for the patient, it is sometimes distressing. Patients make excuses for why particular family members may not be able to come and see the patient, and patients use humor to deal with the lack of family presence. But on rare occasions patients would voice their true concerns that family members could come and see them but were being dishonest about why they could not come: “…but it’s just, it’s just funny to hear her [sister’s] excuses. [Patient asks] ‘hey when are you coming down?’ Oh, man—she’s a nurse too. And [sister responds] ‘I treated some guy with meningitis last week, I better not, I might get you sick’, and you know she just has a ton [of excuses]” 5.146A-5.148A.

Theme Cluster 6.10. Too Much of a Good Thing-Family Presence Can Lack Optimal Benefits

As much as patients count on family to watch out for them and over them, patients also expressed the negative side of families being involved in their care. Patients describe family member vigilance as something that can become overbearing with family members becoming too protective to the point of isolating the patient, encouraging too much patient dependency on the family, and when family is around the patient all the time, the patient’s energy is drained: “You’re [patient and wife] sitting here in the hospital room all day long, and there’s only a limit, a certain limit of what you can talk about or what you can do” 6.183A. The patient went on further to describe the refusal, on the part of the patient, to have his wife spend 24 hours a day in the hospital with him.

Theme Cluster 6.11. Kindness of Others and Being Remembered is a Way to be Watched Over

As much as family members are important to patients, patients also recognize others who are friends or coworkers who lend some sense to the patient that they too are watching over the patient. Patients describe how kind many people are to them and this leads to patients feeling watched over at levels outside the immediate space and time. Patients also expressed appreciation for employers that recognize the patient's illness and encourage patients to focus all their energy on healing*:* [Patient] "Called them [employer] told them I had cancer and I said' I'll call you back tomorrow'. He [employer] said, 'don't worry about calling me back. You get yourself well, then we'll talk. Okay?' And I woke up the following Friday, and felt like a million bucks" 4.367A-4.368A.

Theme Cluster 6.12. Patients Watching Over the Journey's Companions

Patients talk about concerns they have for their companions on this journey-their family members. Much like the captain if a ship or the hero leading an epic journey, the patient feels some responsibility to watch over those on the journey, as faithful companions. Patients describe family's welfare being a primary concern for the patient: "I mean I think all of those things that I said [about being vigilant] are not only, for me, they're for my family too. Because one of my main concerns is them" 5.109A-5.110A. Patients are concerned about their families and spend thought time about how to best balance their needs with those of the family. Patients weigh what is critical for the patient with what can be done to maintain some normalcy for the family: "Well, I think my children, I don't really worry about too much. We don't put too much on them only washing their hands" 9.094A. Watching over their children, even when they are ill is a primary concern for patients. Patients describe multiple ways in which they watch over their children such as normal kinds of watching for young children, watching over children's diets, making certain children are aware of dangers such as smoking, and helping children understand the nature of the patient's illness: "He [son] goes, 'but can you still die from it?' And I said, 'yeah honey, I still could'" 4.89A-4.90A. However,

patients do not want children to see cancer as a death sentence, but for children to understand that death is a part of all human life: [Patient talking to son] “I said, but I could die going to the edge of the driveway picking the mail up. You know, the way people fly down the street” 4.91A.

Theme Category 7. Half Out of My Mind:

The Complexity of Cancer Detracts from Vigilance

In mythology there are many stories in which heroes act as if they have lost their minds temporarily. A multitude of things contribute to heroes feeling or acting ‘crazy’, but heroes in the majority of mythological stories recover, and go on to complete their task. The ‘craziness’ is just part of the journey, and part of what must be overcome to complete the task. Much like these heroes, patients have moments where they feel they are losing their minds. Cancer, treatment, and life, all experienced together are overwhelmingly complex and patients feel as if they are driven to the brink: “When I was first diagnosed two years ago, I was half out of my mind half the time worrying about things going wrong” 9.049A. The complexities that patients experience are factors that interfere with or take away from their vigilance in some way. This theme category has four theme clusters [see Table 14].

Table 14. Patient Theme Category 7

Theme Category	Theme Clusters	Themes
Half out of my mind: The complexity of cancer detracts from vigilance	Vigilance detractors	• Anxiety • Distracted with thoughts about death interferes with being vigilant for life • Alcohol consumption • Other higher priorities • Difficulty communicating about what is wrong • Standardized practices • Too much to pay attention to • Receiving Blurry pictures –barriers / interference with effective vigilance • Emotional detractors • Physical status
	Navigating with Visibility Zero-It is difficult to be vigilant when signs are hard or impossible to detect	• No body compass to determine status of health-Feeling good-but critically ill • Waiting for the fog to lift-interpreting vague symptoms

	• A small shouting voice-Do something • Confounding readings on the dials-When there is more than one thing that could be / is wrong • Harbor pilot –HCPs help in responsding to vague symptoms • In the wrong shipping lane-Relapse-not the same as before • Seeking the crews opinion-Affirmation is sought when information is incongruous
Like a third world country-When what is perceived as the best healthcare and providers in the world do not meet patient minimum expectations	• Generally poor resources in care • Untrustworthy in unknowing provider • Waiting • Failing at the fundamentals-missing critical signals • Insensitive, nonwatchful communication by healthcare provider
Doing what's right and doing what's wrong and still getting cancer: A sense of blame for failing to be vigilant at some level for one's health	• Do as I say-not as I do-when one supports healthy practices-but gets cancer • Regrets for asking for cancer-what things people think they fail at that leads to the disease / poor prognosis • Exposures / Expectations at work-that may have caused cancer • Cushioning feelings of blame-Justifying not seeking help right away

Theme Cluster 7.1. Vigilance Detractors

Patients comment on several things that take away from theirs' and others' abilities to be highly or effectively vigilant. Patients perceive that things like anxiety, thoughts of dying, and consuming alcohol take something away from the ability to be vigilant. Patients comment on several different emotional states that detract from vigilance. Patients experience loneliness, hopelessness, and being relegated to a 'patient status' as things that made it difficult to be vigilant: "You know that's why I wear clothes here in the hospital cause I don't like that kind of helpless patient persona…most patients they get in their gown, they lay in that bed, the doctor comes in and thinks he's in charge. I don't think that's healthy for anybody" 9.105A, 9.117A, 9.119A. Patients also experience the physical effects of the disease and treatment as taking away from vigilance. Things such as feeling tired, feeling really ill, and memory loss add degrees of difficulty to the ability to be vigilant: "…my husband laughs at some of the ways that I deal [with memory

loss] because I'll call myself chemohead…cause I can't remember things…" 4.196A-4.197A. Additionally, patients perceive that difficulty communicating, too much to pay attention to, or other higher priorities also reduce the quality of vigilance. A patient commenting on what delayed getting help for symptoms she was experiencing: "…this one [bruising] I noticed long enough because he [husband] was still in the hospital. And I was like one [of us is] down. I can't have both of us in the hospital" 8.323A.

Theme Cluster 7.2. Navigating with Visibility Zero-It is Difficult to be Vigilant When Signs are Hard or Impossible to Detect

As patients try to be vigilant for themselves, the complexity of the disease and treatment make it difficult to be certain about what to watch for. Patients experience a range from no symptoms to vague symptoms, which make it nearly impossible to feel as if one is being vigilant: "Start running fevers and gees, it's crazy. It's real crazy…there's a time I don't even know I'll have a fever, but I'll have one" 1.24A. At times, patients could interpret vague symptoms and use them to make decisions about whether to get healthcare: "Cause I didn't go [to get regular labs drawn] unless I actually felt I needed to…when my heart started beating in my chest, I knew that my hemoglobin was low, and it was time to go to the lab" 5.014A-5.016A. Other times, the symptoms patients experience are very noticeable, yet vague, but the patient does not connect the symptom to a serious illness: "Then Sunday, the same thing and come Monday, I just said I'm not going to work. I just don't feel like it. So I called off, and she [daughter] says Mom, I'm going to call the doctor and find what the problem is" 2.46A-2.47A. Complexity is further compounded by cancer masquerading as a different illness such as sinus infections or pneumonia: "The symptoms, which I thought were related to the pneumonia, were fatigue, tiredness, and things" 6.22A. Relapse is a special consideration in symptom complexity, because what patients previously experienced in illness is reported by patients to change with relapse: "No it wasn't like the first time

when I drug down, down, down, down. See, it was early enough in the ballgame…on the relapse that you wouldn't feel that way" 6.244A-6.245A.

When patients begin to suspect something more serious may be wrong, they either bring it up to family members or healthcare providers. Often, the response from whomever patients talk with concerns about dictates whether or not the patient continues to pursue help for the symptoms: "And I told my wife 'I don't feel right …You know I think maybe the cancer's back or something'. And she said, no, you just got a touch of the flu's just going around" 5.092A-5.094A.

Theme Cluster 7.3. Like a Third World Country-When What is Perceived as the Best Healthcare and Providers in the World Do Not Meet Patient Minimum Expectations

Once patients decide to act on concerns for vague symptoms, patients expect healthcare providers to help guide them. Particularly, patients expect timely, high level healthcare, competent and knowledgeable healthcare providers, identification of what is wrong, and direct, clear, sensitive communication. When patients' expectations are not met, they are extremely disillusioned and frustrated: "…I didn't have a good experience at my hometown hospital. Let's put it that way. I do consider that a third world deal there…" 1.102. Patients experience a maze of misdirected healthcare where they perceive that healthcare providers are unsure about what they are doing and what is wrong with the patient: [ER healthcare providers] "put me in an ambulance and …took me to a [different] hospital in [a different city] where I was placed on the cardiac ward for some reason. Cause they did not know what they had a hold of" 6.32A-6.33A. When healthcare providers ship people off to unknown territory and the patient feels unprepared and uninformed, it colors the way patients perceive those healthcare providers: "It's like the mechanic that says, 'your car's in bad shape. I can't work on it here, I gotta send it somewhere else'…You kind of lose faith in that mechanic's ability" 5.326A-5.327A. Almost the worst part of these kinds of confusing experiences for

patients is non-watchful communication from healthcare providers. Patients relay that communication from some healthcare providers is disrespectful, unknowing, and hope diminishing: "…just bad karma…just ecch, you know? She [doctor at first hospital] was concerned that night that counts was down so low that I wouldn't make it through chemo and she was gonna say that right in front of me, you know? [patient responded] What are you talking about? What do you mean? I mean gees! You know? That was…that was a good deal right there. Get me outta here" 1.107A-1.109A.

Theme Cluster 7.4. Doing What's Right and Doing What's Wrong and Still Getting Cancer: A Sense of Blame for Failing to be Vigilant at Some Level for One's Health

Patients are like mythological heroes that are presented with riddles that must be solved in order to advance in completion of their task. The process of unraveling or figuring out the riddle pushes patients to their edges. Patients with cancer review life circumstances and try to make sense of how they got cancer. Patients are confused about how one is vigilant about healthy practices and gets cancer despite their vigilance. Additionally, it is confusing how others can do things that are obviously cancer risk factors, and they remain perfectly healthy: "There's guys that are smoking two packs a day and he'll probably live till he's eighty…I don't want to say unfair, but you figure people that would take care of their bodies should live longer that the ones that don't" 5.045A-5.046A.

Theme Category 8. Metamorphosis-

The Life-changing Forever Events of Getting and Having Cancer

Getting cancer elicits a necessary response from patients. Like heroes called on a journey, there is a requisite response needed from cancer patients-a recognition of what will change in life and how those changes will be managed: “Everyone will find their own little ways of dealing with this type of disease [leukemia]” 4.05A. This theme category is represented by six theme clusters [see Table 15].

Table 15. Patient Theme Category 8

Theme Category	Theme Clusters	Themes
Metamorphosis-the life changing forever events of having getting cancer	The beginning of the end of the way things used to be	• Never in a million years-getting the surprise diagnosis of cancer • The confusion and fear of new diagnosis
	Negotiating the change-things are not the way they used to be	• Learning new role as patient
	Strategies to remain positive	
	A noticeable day’s work-Recognizing the changes in the journey of cancer	• Others help in noticing the changes in the journey of cancer • Finding inner strength
	Changes occur in doing / thinking / being related to cancer	• Patient becomes vigilant for little or ordinary things • Change in attention to others • Change in the way death is viewed-Confronting death as a way of being vigilant for life
	The Quest for the Holy Grail of Remission	• The grail is a return to normal-like life before cancer • The Hail Mary pass of bone marrow transplant-volunteers for the quest • Once the Grail is found-Actively seeking to stay in remission • Normal is a less vigilant state

Theme Cluster 8.1. The Beginning of the End of the Way Things Used to Be; Theme Cluster 8.2. Negotiating the Change-Things Are Not the Way They Used to Be; Theme Cluster 8.3. Strategies to Remain Positive; Theme Cluster 8.4. A Noticeable Day’s Work-Recognizing the Changes in the Journey of Cancer; Theme Cluster 8.5. Changes Occur in Doing, Thinking, and Being Related To Cancer

The change in the way life has been known begins with recognition that things will never be the same. The beginning of the change process is described by patients as negotiating the shock of getting a disease they thought they would never have: “Over the course of the very beginning [of diagnosis] it was just such a shock. I had this huge tumor…it was just a big shock. A shock that I couldn’t quite get my head around” 9.054A, 9.058A-9.059A. Patients describe taking on the role of patient and developing strategies to maintain a positive attitude: “It [having cancer] kind of makes you think about things different, little things…from a different perspective…Try to maintain some kind of positive attitude, well you got to” 1.140A. Patients come to understand that they must acknowledge the uniqueness of this experience. Family and friends help recognize it and at other times, patients recognize the distinctiveness of the journey, themselves: “Little different journey right there [getting cancer diagnosis and treatment], isn’t it?” 1.121A. Ultimately, as the journey progresses, patients find inner resources of which they were previously unaware of possessing: “It is amazing…the inner strength that you can find within yourself when push comes to shove” 4.46A.

Theme Cluster 8.6. The Quest for the Holy Grail of Remission

Patients adapt and change in response to cancer so they can journey to complete the task. Like people on a quest for the Holy Grail, or treasure of untold worth, patients describe seeking remission with the same kind of fervor: “I told my husband, ‘I will beat this…we will do whatever we have to, long time scenario, to make sure that we stay in remission” 4.68A, 4.71A.

Going into remission after an initial relapse for cancer allows at the least the possibility of bone marrow transplant, a possible cure. Patients describe hopes that either one of their siblings will be a bone marrow match, particularly if patients have ethnically diverse backgrounds, or the Bone Marrow Registry will have a match: “And I just have two sisters, and…they matched one another, so they did not match me…They

say it's common for one in four to match. Since my mom had a couple of miscarriages, I guess my match was one of those miscarriages…they had to go to the registry to find a donor. [It was surprising that the registry had a match]…especially with my background…there's not too many Mexicans walking around saying 'I wanna give blood or wanna volunteer to be a donor'" 2.76A-2.80A.

Patients equate remission with being able to be normal again: "…just hope and pray…that I get through this, get a handle, remission whatever and just…go back to some kind of normalcy, per se, you know? That's the goal" 1.120A. There is a danger when patients do reach the goal of "going back to normal" because patients express they return to a pre-cancer level of dealing with life and risks. In other words, patients become less vigilant because less vigilant is normal: *"In fact, once I found myself in remission, and I felt good, my vigilance sort of disappeared into thin air you know?"* 6.208A.

Theme Category 9. Rising Spirits and the Yoke of Hope and Vigilance

Patients are vigilant for signs of hope or reasons to have hope. Hope exists in a spiritual realm for patients, in that hope is not an explicit condition, but much like other spiritual experiences they are sought and personal. Patients describe the difference between healthcare providers who convey messages of doom versus healthcare providers who give patients some reason to hope. Patients are aware that there are no guarantees, but definitely want something to be hopeful about. Patients describe seeking care where there is at least a message of hope: [Healthcare providers talking with patient] "You're going to be treated here and [doctor] went through the whole thing, and basically when he was done, we [patient and wife] felt a lot better. I think that really switched it [from negative to hopeful] for us at that point to say, okay this is good" 5.297A,5.308A. Patients are clear they do not want false guarantees but want to be able to maintain a realistic kind of hope: "That's not to say that I'm gonna be cured. No one

knows, but when you're being treated with something that's cure with intent is a lot better than having a terminal illness" 9.065A-9.066A. Patients experience hope in many different ways. Patients perceive completing treatment as hopeful, use hope as a way to endure treatment, and adjust hope based on potential outcomes. In other words, hope is moderated based on what patients perceive as likely outcomes: "I was hoping for a few years" 9.075A. This theme category had one theme cluster [see Table 16].

Table 16. Patient Theme Category 9

Theme Category	Theme Clusters	Themes
Rising Spirits and the yoke of Hope and Vigilance		• Realistically hopeful • Hope allows endurance to stick it out • Seek care where there is hope • Completing treatment is hope • A different kind of hope
	Knock Wood, appeasing the gods: the spiritual aspect of vigilance	• Protecting oneself from menacing spirits • Out of this world watched over • God weighing in on the course of cancer

Theme Cluster 9.1 Knock Wood, Appeasing the Gods: The Spiritual Aspect of Vigilance

Spiritual beliefs of patients are described as influencing what patients hope for. Like hope, patients experience a duality in beliefs. At times patients feel they are being watched over by spiritual beings and at other times, spiritual beings are menacing and punishing. Like mythological heroes, patients experience that the gods are either with them or against them, based on the patients performance, especially as related to vigilance. In other words, the gods watch over everything and respond accordingly. Vigilance over one's health is considered paramount and when patients are not vigilant, they perceive God may punish them: "I'm a firm believer in the man upstairs, and I figure if you're not listening to him with his subtle cues, bruising of your toes, then he's gonna give you something that's like a smash in the face [like leukemia]" 8.384A. In order to appease spiritual beings, patients perform rituals to invoke protection. Patient describing

constant use of the expression ‘knock wood’: “It has to do with spirits in the wood…and to keep everything at bay and [patients] knock on wood...so that spiritual thing doesn’t cause…havoc or whatever. I [am a] firm believer in it. Because it seems like every time…if I don’t say it, then something happens” 1.70A-1.74A.

Patients also describe feeling comforted by a belief that God is in control- and patients do not have to struggle with the ultimate outcomes of their illness: “Because to me and my personal opinion…we’re all in the good Lord’s hands, and His will will be done whether we think it or not” 4.278A. Patients feel comforted with beliefs that God is all vigilant, watching over patients: “…knowing that God is near and with you through it all” 2.08A.

Theme Category 10. What the Treasure Looks Like:

The Patient Need and Awareness for Vigilance

Patients expressed awareness that vigilance is a valuable commodity, particularly in healthcare. Vigilance is highly regarded and essential enough that patients said it was something everyone needed and deserved: “They [nurses are] all good and…watch…or are vigilant in most parts for everything. There’s a couple here they incorporate the nurturing a little bit…I need that nurturing, I think everybody does” 1.177A-1.180A. This theme category had four theme clusters [see Table 17].

Table 17. Patient Theme Category 10

Theme Category	Theme Clusters	Themes
What the treasure looks like: the Patient need / awareness for vigilance	The need for vigilance is highlighted by the absence of it	
	The downside of HCP vigilance- responses from healthcare providers can be paradoxically appreciated and frightening / frustrating	

A bevy of vigilance-a shared group phenomenon	• The language of group vigilance and the ways it is conveyed to the bevy • Allowing and compelling the bevy to respond to and with vigilance • Things that interfere with the vigilance of the bevy • The appearance that the bevy is extinct-Unaccompanied quest-patients alone in vigilance
360 degree view of the system	• It takes Staff who are competent and trained • It takes Keeping it clean-watchful housekeeping • It takes a watchful Dietary department • It takes specialty units-where people know what they are doing • It takes access to nonmedical facilities • It takes being family friendly • Things that interfere with system vigilance

Theme Clusters 10.1. The Need for Vigilance is Highlighted by the Absence of It; Theme Cluster 10.2.; The Downside of HCP Vigilance-Responses from Healthcare Providers can be Paradoxically Appreciated and Frightening or Frustrating

Patients perceive that vigilance is desired and needed because of the media and public knowledge that errors in healthcare can place patients in danger. Vigilance is not always available or present, so patients feel a need to watch out: “I thought it was terribly important to know what meds I was getting. Because some of the horror stories you know…” 6.43A-6.44A. Patients report that while they appreciate providers’ immediate vigilance regarding the cancer diagnosis, this kind of swift vigilance has a downside as well. If patients do not understand or misread the providers’ response as panic, then vigilance on the part of the provider evokes paradoxical feelings in patients. Patients feel both watched over, yet panic-stricken: “So he’s [doctor] like, ‘Oh that’s Hodgkin’s’. Let’s go, right away. And I was like, wow…” 8.039A-8.040A.

Theme Cluster 10.3. A Bevy of Vigilance-A Shared Group Phenomenon

Patients express awareness that they, themselves cannot be watchful for everything and that sharing vigilance is a way to pay attention to multiple things; in other words, healthcare providers and patients have to work together to maintain an effective

vigilance: “But I think that it’s also very important that you take control in that aspect because the doctors and nurses can only do so much for you. And you’ve gotta meet them halfway” 4.56A-4.57A. Patients describe the subtle ways in which patients and healthcare providers communicate the partnership in vigilance. It may be as simple as the patient feeling believed: “…all the doctors that I’ve talked [to] have been amazing, and never doubted anything I’ve said. [Doctor’s said] ‘if you think this is important, we’re going to look into it’” 8.356A-8.357A. It also may be more complex, such as patients making sure that the team of healthcare providers are all in the loop of communication, in effect, making sure the healthcare team is working together in patients’ best interests: “[Nurse] said, ‘as long as we monitor it, I’m gonna give you a pack or two [of sugar] a day’. [Patient responded] ‘now you’ve discussed this with the doctor?’” 4.345A-4.346A. Without partnerships with healthcare providers or others, patients feel left alone and as if no one is watching over them or is with them: “I felt like I was in prison is what I felt like …just trapped here…behind the curtain” 5.235A-5.236A.

Theme Cluster 10.4. 360-Degree View of the Systems Need to Be Vigilant

Patients perceive that the healthcare environment-the system-also has a responsibility to be vigilant: “[Vigilance] goes back to…confidence in your doctor, and your hospital facility, and your nursing core” 6.317A. Patients believe that the system is responsible to have competent, trained staff and specialty units available to treat cancer: “And they [healthcare providers] put me in ambulance and brought me down here to [hospital and cancer unit]…’cause they really couldn’t treat it up north they didn’t have the experience” 5.292A-5.294A. Patients do not focus solely on professional staff in relation to system vigilance. Patients also believe that support services such as dietary and housekeeping are important aspects of system vigilance: “…I check to make sure they keep the room clean” 9.009A. Finally, patients believe that systems should also be family friendly and have nonmedical facilities available in order for families to remain with

patients as much as possible: “They [hospital] have laundry here on the floor. So she’s [wife is] washing clothes, and this is our home. I think that’s real, real big. That would be something somebody needs to make sure they have...” 5.245A-5.249A.

Patients perceive there are things that interfere with their views of the system as vigilant. Patients describe experiences that lead patients to a view of the system as non-vigilant. Patients believe that quantitative assessments, such as the pain scale detract from healthcare providers being able to accurately assess patient pain and restrict patients from fully being able to express their pain. Patient describing an experience where nurses did not believe patient’s perception of pain: “…a couple of them ask the pain scale, which I absolutely hate the pain scale. I understand its purpose, but I hate the pain scale. [nurses said] ‘oh my lord…you can’t judge between [a] papercut [and real pain]? Last time the papercut was a ten’…so I’m thinking no [pain feels like a ten]” 8.231A-8.232A, 8.237A. Lack of critical thinking or making deeper connections is a concern about healthcare providers expressed by patients as well. Patient wonders about system responses to errors in judgment: “I don’t know if that would go on any record books [putting someone with antibiotic resistant bacteria in with immunocopromised patient] I don’t know if statistics are kept on that, but it’s a systems error…that a person should not have been put there” 9.022A. Patients are especially vigilant when there is shortstaffing or responses that do not make sense. Staff are viewed as representations of the system. Patient is describing a situation where chemo was not completely infused because IV tubing came apart: “And we’d been trying to find out…we don’t how much chemo was in there. Quarter bag, half bag or what. So I was going to ask them [nurses] about it…are we going to make that up or what? Nobody seems too concerned…But, if I need that dose…I’m already here. Let’s go ahead and tap that lost dose. That’s my theory. They didn’t seem to think I needed it. I wanted to go that extra step whatever it takes to keep this stuff [leukemia] under control” 1.53A-1.56A.

Theme Category 11. The Meaningfulness of Vigilance:

Like a Treasure Hidden Within the Seemingly Insignificant Little Extras

Often in mythological stories, heroes are watched over by gods or watched over by others unbeknownst to the hero. There are seemingly minor things that the persons watching over the heroes do that allow the hero to complete the task; slipping them a length of string to find a way out of the maze, handing them some parcels to take on the journey that end up containing crucial items later in the journey. Such help is not requested and is unexpected, yet critical to the heroes successful journey. Patients clearly and consistently describe vigilance as an action healthcare providers take that is above and beyond the basics of the job. Vigilance is always beyond the expected: "… very watchful…just concerned, just very concerned nurses and staff and…Going the extra mile" 2.127A-2.128A. This theme category has six theme clusters [see Table 18].

Table 18. Patient Theme Category 11

Theme Category	Theme Clusters	Themes
The Meaningfulness of Vigilance: Like a Treasure Hidden Within the Seemingly Insignificant Little Extras	The vigilance test-Determining which healthcare providers give that little extra	• Patients evaluate vigilance in healthcare providers • Patients look for that little extra (nursing vigilance) because it may be a lifesaving / self preserving skill • Publicly identifying that if there is a little extra (vigilance) in nurses or not is uncomfortable for patients • Group as a whole nursing vigilance-that little extra evaluated as a group process
	Insignificant significance-actions of healthcare providers that demonstrate that little extra of vigilance	• HCP are present / available / engaged Motherly seasoned nurses • allow patients to have feelings / thoughts • have a flexible and adaptable vigilance • responsive barrier free communication • HCP pick up on cues • connect with patients • Connect with family • A little extra time on the clock-Healthcare provider taking time is everything • patient needs are responded to in timely way • Exhibit very professional behavior • are extremely dedicated • watch patients when they don't even know they are being watched over • are out of the box thinkers • Are the measuring sticks for nurses who aren't

Trust is requisite for sharing vigilance-patient healthcare provider trust	• Trust violations undermine sharing vigilance
The patient benefits when nurses have/do that little extra	• Patient feels nurtured • Patients feel protected • patients feel rested • Patient energy is conserved • patient feels connected • patient can count on nurse / plan-Feels prepared-no surprises • patient feels respected • patients feel human / individual • patient maintains hope • patient limitations are recognized • Patients feel encouraged to be independent • Patients are strengthened • Makes passage through the treatment of the cancer-bearable / tolerable- • A sense of comfort with environment and people • Patient feels listened to / respected / special
Nurses minus the little extra-no treasure to be found	• patient does not feel validated / listened to • patients do not feel safe • patient's moods are not monitored / Cues are not recognized / Leads to disconnection • patient feels helpless • patient cannot bear to stay at hospital • triggers patient to be more vigilant / Uses patients energy • Minus the little extra-characteristics that nurses are not vigilant
The minimum isn't enough	• Nurses are obligated to be vigilant as a minimum threshold • Ordinary vigilance-what patients expect from nurses as the minimum threshold of vigilance • Rules are in place for nurses to follow-nurses reinforcing existing rules is a minimum threshold • Patients check for minimum standards

Theme Cluster 11. 1. The Vigilance Test-Determining Which Healthcare Providers Give that Little Extra

Much like mythological heroes who pose questions to determine who can trusted and who is wise enough to be watchful, patients perceive that nurses, or other healthcare providers, who are knowledgeable are more vigilant than those who know less. Patients describe questioning nurses in order to determine who is more knowledgeable, thus more watchful from the patients' perspectives: "…it is hard to put into words because it's almost intangible…you cannot say that nurse A knows less than

nurse B, but you know she does…the answer to your questions. And you just keep throwing questions at them, until you find the level of their competence" 6.124A-6.125A, 6.129A. Although patients spend time and energy trying to identify vigilance in nurses and other healthcare providers, patients are reluctant to single out nurses who may not be as vigilant as another: "…there's really nobody that gets on my nerves or that I wouldn't like to have for a nurse" 5.207A. While patients do not like to verbalize their judgments of individual nurses, they do express feelings about the overall quality of nursing: "…all the nurses have just been great. I couldn't have asked for a better, better group of nurses" 2.109A.

Theme Cluster 11.2. Insignificant Significance-Actions of Healthcare Providers that Demonstrate that Little Extra of Vigilance

Despite expressing overall satisfaction with nurses and not wanting to single out nurses who may not be as vigilant, patients indicate there are multiple things that healthcare providers do that patients interpret as signs of vigilance. From stories patients tell it could be interpreted that vigilant healthcare providers are present with patients, allow patients to have thoughts and feelings, decrease barriers to communication, and are experienced: "I think all the nurses are kind of watchful…really. There is two nurses here…I call them seasoned nurses, they're the older nurses…Whether it be bandage, bedding…It seems like they always do that little extra, you know? Mothering thing" 1.170A, 1.174A. Patients also indicate that vigilant healthcare providers are flexible or adaptable and pick up on cues from patients. Nurses use their knowledge to make connections between small, insignificant things that patients may otherwise miss, thus protecting patients from potential side effects: "…even with the pills that are supposed to make me sick because of the dairy in them, they [nurses] asked me, did you have breakfast? Or when are you planning on having breakfast [a time when dairy would be prominent]? We'll come back in two hours, [nurses indicate] I can eat my breakfast when

I want to" 8.250A-8.251A. Healthcare providers who connect with patients and their families are viewed as vigilant as well. Connecting with patients and families is seen by patients as healthcare providers going out of their way and going beyond the minimum. Patient is describing all the bedding and other supplies nurses have gotten for husband: "So, it's just not only me, I mean they're kind of watching out for my family also…which, they don't really have to" 2.136A-2.137A. Patients further perceive that healthcare providers are vigilant when they take their time in doing their jobs or provide care in a timely manner: "Instead coming in taking vitals, taking blood, or shutting the machine off and booking… they'll come in and take vitals, take blood, turn off the machine, and talk or talk about the advantages of the treatment and why this does that and they just… they're not in a rushed state of mind…" 1.182-1.183. Vigilant healthcare providers are people who appear professional and are dedicated to their jobs: "There's some [nurses] here that really are dedicated to this, their discipline as well as this disease" 6.153A.

Theme Cluster 11.3. Trust is Requisite for Sharing Vigilance-Patient-Healthcare Provider Trust

Trust is often mentioned by patients in relation to vigilance. Patients express a need to trust someone will be vigilant and then the vigilance reinforces the level of trust. For example, a patient describes the relationship of trust and vigilance developed with a particular nurse: "[Nurse] goes, 'all right, I'll be back at four', and [nurse is] outta here…doesn't jerk me around…doesn't yank on me…does what [nurse is] supposed to do, and tells me what [nurse is] gonna do later…and comes back and does it at that time" 5.198A-5.202A. Trust seems a crucial link between nurses exhibiting vigilance and patients being able to benefit and share in the vigilance in some way.

Theme Cluster 11.4. The Patient Benefits When Nurses Have and Do that Little Extra

When patients perceive nurses or other healthcare providers as vigilant, patients experience requisite benefits. Patients told of many experiences which demonstrate

what patients gain from healthcare providers' vigilance. Patients indicate that when healthcare providers are vigilant, patients feel nurtured and protected. Patients see what nurses do and make connections that the nurses are going out their way to protect patients: [Nurses say] "'let me make sure with the head nurse that this is what's going on. I don't want to give you a wrong answer'… [nurses are] very knowledgeable… [or know how] to get the knowledge" 8.261A8.262A. Vigilant healthcare providers also make it possible for patients to feel rested and strengthened. Patients describe the kinds of things nurses do that help the patient conserve energy: [Nurses ask patients] "Can I get you some water, can I read this for you…" 2.129A-2.130A. When patients know what to expect and there are no surprises because nurses have prepared patients for what is coming, patients are able to relax and rest. Patient describes nurse coming in patient's room at night at the time nurse told patient that nurse would come: "And I just lay back and go to sleep…So there's really no surprises or anything with that" 5.350A-5.351A. Such vigilance on the part of healthcare providers allows patients to relax in ways similar to relaxing at home: "The nurses…where I would get my red blood cells and platelets…have always been so helpful and they're just so friendly and just made you feel at home when you are here, and that means a lot to me" 2.04A.

Patient hope and tolerance of hospitalization and treatment are byproducts of vigilant healthcare providers. Vigilant healthcare providers encourage hope and the ability of patients to bear treatment and hospitalization through patients feel connected, respected, listened to, and made to feel human. The mythological contrast to this is when heroes are recognized for greatness and their role in completing impossible tasks- a sort of hallowed dignity and honor is bestowed on them. It is at this point, the hero seems to be able to recognize the enormity of the task. "They [nurses] are very nice about just standing here and talking to you, and making you feel human…'cause you're

going through a process right now that makes you feel totally inhuman. Totally lost. Sorry [patient began to cry]" 8.127A-8.128A.

Theme Cluster 11.5. Nurses Minus the Little Extra-Like a Treasure that is Not Where it Is Supposed to Be

Just as the presence of vigilance in healthcare providers benefits patients, when vigilance is not present patients pay a penalty of sorts. When healthcare providers are not perceived as vigilant by patients, the consequences for the patient are negative. Patients do not feel listened to, validated or safe when healthcare providers are not vigilant. At times, patients desperately depend on healthcare providers being vigilant because patients cannot defend themselves. Patient is describing laying awake all night, hoping nurse would recognize that roommate had an antibiotic resistant bacteria and was placed in the room with patient who was immunocompromised. "I would have said something last night, but I just felt too sick" 9.012A. The importance of nurses being vigilant and the safety that is imbued to patients by them is summed up by statements such as this: "I like all the nurses, but there's always your favorites, you know? And I don't like it when they get their days off" 1.184. When vigilance is lacking in healthcare providers patients feel as if they are not being monitored, feel helpless, cannot bear to stay in the hospital, and use their own energy to be vigilant: "Those [healthcare providers who are barely or not vigilant] are the ones that worry me more than anything. That's when my vigilant level really goes up" 6.123A. Patients notice things about nurses that cue them that nurses are not being vigilant. Patients perceive things such as letting other things interfere with vigilance, being disrespectful, being inconsistent, and lacking connection with patients are all characteristics of healthcare providers who do not have the above and beyond kind of behavior that indicates vigilance to patients: "They [some nurses] just do their job and they do their vitals and check their stuff, and say call me if

you need me" 5.189A. This minimal to less than minimal kind of effort on the part of healthcare providers is not what patients perceive as vigilance.

Theme Cluster 11.6. The Minimum Isn't Enough to Be Identified as a Vigilant Healthcare Provider

Patients indicate an awareness that vigilance can exist at a sort of minimum threshold. Such vigilance is perceived to lack passionate commitment. "Some [nurses] go through. There's a paycheck here, they like the job, but they like the paycheck too" 6.152A. From such statements patients indicate vigilance can be reduced to a minimum obligation on the part of healthcare providers. "I think it's all professional…that's a tough one really cause… they just do their job" 5.170A-5.172A. While this kind of vigilance is not what patients identify as true vigilance, it is the minimum expected level of vigilance, a sort of ordinary rather than extraordinary vigilance: "They draw my blood everyday to see what my white counts, blood counts are and my platelets and my hemoglobin…they come in every morning and check my breathing and my toes" 8.362A, 8.364A. Ordinary or minimum vigilance is perceived to be guided by rules. "I mean they [nurses] do everything that they're supposed to do…most of the rules are in place" 5.176A-5.177A. The minimum standards for vigilance appear to be fairly obvious to patients. Minimum, or nurses doing their jobs, is what patients minimally expect. Patients are unlikely to say things unless the minimum is not met. "The only thing that I would ever question is if I feel something is honestly, and I don't mean this in a negative way, like below the standard care at the time" 9.041A.

Essential Structure of Patient Vigilance

In the patient findings eleven theme categories were identified. From the narrative description of patients' experiences an essential structure of vigilance experiences of cancer patients was derived. Husserl proposed that essential structures of phenomenon could be derived through the rigorous process of empirical phenomenology. Adherence

to bracketing, or setting aside one's scientific presuppositions allowed researchers to identify "those features that must be present in any and all possible instances of the phenomenon" [134] (p. 168). The essential structure is believed to represent an ultimate truth related to the way the phenomenon appears [135].

For patients, the experience of vigilance in the context of cancer is analogous to a mythological hero's journey. Patients struggled greatly to understand how to be vigilant for themselves and their symptoms, as well as identify vigilant and non-vigilant behaviors on the part of family members and healthcare providers. Their efforts to be vigilant were complex and at times, very confusing and elusive. Patients use trial and error methods to initially learn what vigilance is NOT. They actively seek knowledge in order to be effectively vigilant. Specific experiences trigger vigilance, such as when things that do not make sense or when there is awareness that being vigilant is the best chance to survive. Vigilance is a paradoxical concept for patients; it takes energy to be vigilant, yet being effectively vigilant saves energy because one is focused only that which could or does pose a threat. Vigilance is a focused kind of watchfulness. When vigilance is effective, patients do not use energy to watch over things over which they have no control. Being vigilant for oneself is made more difficult because cancer is a complex disease. Patients described things that took away from their ability to be vigilant, such as the strong emotions that were evoked when patients found out they had cancer. Cancer changes patients lives forever. In order to deal with the cancer and treatment, patients become vigilant for the positives in life and the possibility of remission. Patients are directed in such hopes by their family members who invoke or will hope into the patients. Patients without hope are not able to be vigilant; thus, inducing hope increases the likelihood patients will be vigilant. Ultimately, vigilance is described as a meaningful phenomenon seen by patients as necessary. Patients consistently describe healthcare providers who are vigilant as those who go beyond the call of duty. While vigilance is

found by patients in what others may see as only insignificant acts, the patients see these acts as highly indicative of vigilance. Although vigilance seems to have a minimum level that is acceptable to patients, practicing at a minimum level of vigilance is not enough to be identified as a vigilant healthcare provider by patients. In other words, just doing one's job as a healthcare provider is not enough to be considered a vigilant healthcare provider.

Summary of Patient Results

Patient findings indicated that vigilance for patients with cancer is a complex, multiperspective, and multidimensional process. Although only two broad, data-generating questions were asked of patients, multiple perspectives on vigilance experiences were found. Patients presented experiences of being vigilant for themselves, family being vigilant for them, and nurses being vigilant with patients.

These multiple perspectives provide a level of complexity in the findings that was unexpected. This level of complexity prohibits a full discussion of findings in this dissertation. Therefore, a decision was made to identify key findings from the patient narrative, which will be used to guide the patient discussion section. Sixteen key patient findings were chosen because they were perceived to be findings which either added to current scientific knowledge related to vigilance, or were new scientific ideas about vigilance which emerged in this dissertation study. For key findings identified from patient narrative please see Table 19.

Table 19. Key Patient Findings for Discussion

Patient Perspective	Key Finding	Corresponding Theme Category
Patients' perspectives of vigilance for self	Cancer patients struggled to understand vigilance in order to use it effectively.	1
	The disease and treatment of cancer produced stimuli that were difficult or nearly impossible to detect. Cancer patients needed help in identifying and interpreting ambiguous symptoms.	7

	Patients were frustrated and felt to blame when vigilance for preventive lifestyles failed and patients were diagnosed with cancer. Patients were often vigilant for things that might not be preventable.	7
	Strong, negative emotions were identified by patients as something that interferes with theirs' and other's abilities to be vigilant.	7
	Vigilance was a paradoxical concept in regards to fatigue; while being vigilant used energy and tired patients, vigilance also saved patients' energy.	7
	Knowledge was necessary in order for patients to be effectively vigilant. Patients were educated through many sources and gained knowledge through experience. Knowledge which allowed patients to be effectively vigilant may have the additional benefits of decreasing hypervigilance and increasing patient satisfaction.	5
Patients' perspective of healthcare provider vigilance	When healthcare providers merely fulfill their job requirements, patients view them as minimally vigilant, but being minimally vigilant was not enough to be explicitly recognized as a vigilant provider by the patient. When a patient explicitly identified a provider as vigilant, that provider was doing above and beyond what was merely expected.	11
	Patients perceive vigilance detractors for healthcare providers as different than vigilance detractors for patients.	7
	In order for patients to readily identify healthcare providers as vigilant, the healthcare providers must consistently perform beyond the call of duty and beyond patient expectations.	11
	Patients were aware that the structure and philosophy of the healthcare system influenced vigilance of healthcare providers and family members.	10
	There was an unclear relationship between vigilance behaviors and errors. Patients had insights into the presence or absence of vigilance indicators that were potential antecedents to medical error that were ignored in medical error research.	10
Patient perspectives of family member vigilance	Patients did not discuss feeling like a burden for family members being vigilant.	6
	Evidence supported the patients' perspectives that family member vigilance was beneficial to patients.	6
Patient perspectives of vigilance as a shared phenomenon	There were indications that patients' experienced vigilance as a reciprocally shared phenomenon.	10
	Patients will share vigilance, but not just hand it all over to others. Trust is a potential moderator of sharing vigilance with others.	11
	Hope is a potential moderator for patients remaining vigilant.	9

Family Member Results

Description of Family Member Sample

In many qualitative research reports, participants are usually described in detail. Because patients and family members in the sample for this dissertation study had long term hospitalizations, nurses and other healthcare professionals became very familiar

with them. Families and patients were likewise familiar with the nurses. In order to protect participants' confidentiality, the sample is described minimally.

Six family members participated in interviews. Five were female and one was male. Four of the six family members identified their ethnicity as Caucasian, one as Chinese, and one as Hispanic. Three of the six family members were born outside of the United States, so English was not their first language. Because of this, there are times when the quotations used are reflective of the way someone who has learned English-as-a-Second-Language would speak. Six of the seven, family members were married to the patient and one was the mother of the patient. Three of the patients associated with these family members had newly diagnosed AML, one had B cell lymphoma, and two had relapsed AML. Ages of family member participants ranged from 33 to 63 (m=47.5; SD 10.03). This was an educated group of family members with a range of education from 12-18 years (m=15.3; SD 2.42).

Narrative of Family Member Findings

The overall experience of vigilance for family members of cancer patients is like being in the midst of a big storm, like a hurricane. Family members talk about stories, thoughts, feelings, and experiences that illustrate living through patients' cancer storms. Ten theme categories were identified related to family member participants' journeys. The theme categories and clusters derived from family member participant data are identified in Table 20.

Table 20. Overview Family Member Theme Categories and Theme Clusters

Theme Categories	Theme Clusters
Sucked into the Cancer Hurricane of Family Vigilance	• Family Member Vigilance is Like Trying to Prepare for Multiple Storms • The Complexity and Confusion for Family Members about Patient Disease, Treatment and Hospitalization- n the Midst of a Hurricane • Gathering Knowledge in the Midst of the Storm • Family Members Watch Everyone: Hurricane Survival Depends on Who Can and Cannot be Trusted
Healthcare Providers Who Do Not Seem to Understand How Difficult Cancer is for Family	• Healthcare Providers Who are Less than Vigilant: Like Meteorologists Who Do Not Make Sense

Members and Patients: Like the Meteorologists Who Miscalculate the Magnitude of the Storm	• When HCPs are less than vigilant FMs are damaged by the storm • The system does not make vigilance sense-Like weather equipment that is not working the right way
Characteristics of Vigilant Healthcare Providers as Seen by Family Members: Hurricane Heroes-Beyond the Call of Duty	• Nurses, Doctors, and Others Who Go Beyond the Call of Duty • Indicators of Healthcare Provider Vigilance
The Calming Influence of Family Member Vigilance: Creating the Eye of the Storm	• Things that help create Family Member Vigilance • Things that Make Creating Family Vigilance Difficult • The Unseen Work of Family Member Vigilance: In the Eye of the Storm • Weather Watchers-Things that Trigger Family Member Vigilance: Lightening Before the Thunder
The Balance of Hope, Hopelessness and Family Member Vigilance The Contrast of Cataclysmic Hurricanes and the Blue Skies of Hope	• Family Members Watching for and Protecting Patient Level of Hope: Hope Barometers • Getting others to monitor the hope barometer-enlisting family and friends / cancer survivors / HCP • Spirituality
Patient Benefits of Family Member Vigilance: Shielded from the Worst of the Storm	• How Family Members Fill in Healthcare Providers Gaps in Care to Assure Patient Well-being • Family Member Vigilance Changes the Way Things Turn Out for the Patient
Weathering the Storm-Vigilance as Experienced by Family Members	• What Vigilance Does for Family Members • The Cost and I\Limitations of Family Member Vigilance: Storm Damages • Family Members Need Help to Put Boundaries and Context to Their Vigilance: Orientation to the Hurricane
Who Might Help: Disaster Relief Partners for the Hurricane	• Partnering for Vigilance • Disaster Relief Equipment-What Helps People Partner • Things that Interfere with Partnerships-Blocking Disaster Relief Teams from Responding
The System and Vigilance: Building a Hurricane Proof System	• Wondering if the Environment is Strong Enough to Withstand the Storm • The System's Responsibility in Supporting Family Member Vigilance The Minimum Supplies Needed to Survive the Hurricane
Future Perspectives: Thinking About the Aftermath of the Storm	• Thinking ahead about going home ramps up FM need for vigilance • A return to normal (remission)-the ultimate FM role • Wishing to make it better for others to follow • What I wish I knew- the things FMs wish were so

Six participants provided detailed narratives about their experiences with vigilance, both how others and how family members watched over the patients. In order to avoid confusion over which sample is being discussed, and because this research accrued data from three different samples, patients, family members, and nurses, a specific coding method was used instead of participant names. Participants who were family members of a hospitalized cancer patient were assigned a code beginning with a

number and ending with B. Therefore, when it is noted after a quotation 6.234B, one can interpret that the statement was made by participant 6, significant statement number 234, and this was a family member participant, as designated by the letter B.

Theme Category 1. Sucked Into the Cancer Hurricane of Family Vigilance

Family members describe the initial diagnosis and ensuing treatment for a loved one's cancer as confusing and overwhelming. It is as if the family members are at the mercy of a huge storm with high winds and crashing waves-and there is little, if anything they can do to stop the storm. Family members recall entering the storm at the time of patients' diagnoses. "…the whole process from being diagnosed to…the admittance for this treatment had been really short. So it had been a whirlwind, and I was totally exhausted and overwhelmed anyway" 9.10B-9.11B. Family members' effort to describe experiences surrounding the patients' cancer is an arduous task. At times, words to express responses to such experiences are unobtainable. "…sometimes I don't even know what to say" 5.40B. This theme category has four theme clusters [see Table 21].

Table 21. Family Member Theme Category 1

Theme Category	Theme Cluster	Themes
Sucked into the Cancer Hurricane of Family Vigilance		• The storm of patient illness triggers FM vigilance • Being overwhelmed by the storm of cancer • Cancer is a life altering storm for the FM
	Family Member Vigilance is Like Trying to Prepare for Multiple Storms	• Putting vigilance together takes extraordinary effort
	The Complexity and Confusion for Family Members about Patient Disease, Treatment and Hospitalization-In the Midst of a Hurricane	• Like trying to surf in a hurricane-the Complexity of FMs vigilance when patient is in hospital • Storm trackers-healthcare providers seem crazy • Abandoned and boarded up-everyone disappears during the storm • Every man for himself

Gathering Knowledge in the Midst of the Storm	• Knowledge gives Family Members a base from which to survive the storm • The one advantage in the midst of the storm-Family Members have special knowledge of the patient • Sources of Family Member knowledge: Consulting weather experts- Where Family Member knowledge is sought / earned • The things that are unknown or difficult to find out about inclement weather
Family Members Watch Everyone: Hurricane Survival Depends on Who Can and Cannot be Trusted	• The issue of HCP / FM trust Trusting the weather forecast • What FMs expect from HCP Weather watchers should always be vigilant- What FMs expect from HCP

Theme Cluster 1.1. Family Member Vigilance is Like Trying to Prepare for Multiple Storms

Vigilance is a confusing and overwhelming topic for family members. Like someone trying to put together and explicate a plan to prepare for multiple, major storms, family members think about vigilance on multiple levels and struggle with words to adequately express their experiences with it. Family members believe that everyone may experience vigilance differently. “I guess it [vigilance is] a…part of the process…I mean for me, it’s a big part of the process, and I think that it also probably varies on…what type of person you are” 9.78B. Vigilance is described as something that is not static, but a continual process; family members experience it as adaptive and occurring over time. “…family members…may not be thinking about…those…things…from a vigilance perspective, it’s not just a point in time type of event, it’s a continuing process” 3.193B. Vigilance is similar to being in the midst of planning for the storm-one cannot just abandon plans that may help others survive the storm. Family members put extraordinary effort into remaining vigilant. Under severe storm-like conditions, such as patients acutely ill with cancer, family members do not consider it an option to be off duty. “There was just no way that I would leave his [patient’s] side” 5.57B.

Theme Cluster 1.2. The Complexity and Confusion for Family Members about Patient Disease Treatment, and Hospitalization: In the Midst of a Hurricane

For family members, the storm seems to finally hit when patients are hospitalized. "…the first day was hard because he [patient] was going for tests. Going for this. Going for that. And he was wore out. I was wore out" 6.251B-6.252B. Family members are overwhelmed with the initial onslaught of assessment and readying the patient for treatment. "…he [patient] was admitted on this unit over night, and…they hooked him up to everything…" 9.09B. Family members do not see admission to the hospital as a time to relax their vigilance, rather it is a time in which what and who they are watching expands: "And then when one gets admitted to a hospital, the vigilance then kind of takes it to a next level where one would have to pay attention to how the nursing care is being administered along with the doctors who come in and out of the patient room and that takes quite a lot of effort" 3.13B-3.15B. Admission to the hospital is experienced as overpowering to family members and they perceive that at times, they are left alone to deal in unfamiliar territory uncertain of what to be or not to be alarmed about. "…in the first 48 hours [in the hospital] one of the machines was beeping for a long time and the nurse [who] was not assigned to my wife came into the room and shut off the machine without any explanation…for someone who has not ever been hospitalized before, that is very frightening" 3.80B-3.82B.

Theme Cluster 1.3 Gathering Knowledge in the Midst of the Storm

Family members perceive that having knowledge or gaining knowledge allows them to be vigilant. But, like trying to grab bits of information being blown around by the storm, knowledge gathering is a challenge for family members. Family members are very focused on learning quickly as much as they can. Often family will enlist the aid of others in order to accrue as much information as possible: "I've had to get educated [about

leukemia] really fast, and people really worked hard at doing that for me" 8.107B. Family members describe gaining knowledge as a way to be effectively vigilant and reduce fear. In describing getting information from physicians that helps family members to understand what is going on and decrease their fears, one said: "…or at least help develop a better understanding of the treatment that one is getting. So I think from a vigilance perspective…that helps cut away a lot of the fear" 3.92B-3.93B. Family members need to know many things such as how the hospital system runs, how they can help the patients, and how they can take care of themselves. Further, family needs to understand the details involved in treatment, often at the most elementary of levels: [Wife speaking] "I actually remember the night before he [patient] started, well the night that he did start his actual chemo treatment…he had a lot of anxiety about that, and actually to be honest, he thought chemo and radiation were basically the same thing" 5.139B. Knowledge is perceived by family members as allowing independence, decreasing anxiety, and increasing hope. Knowledge also gives family members information which is needed in order to tolerate patients' labile moods: "These drugs are in there going through his [patient's] body…causing him… [to] go from a high to a low" 6.22B.

One important and crucial aspect of knowing for family members was to know what patients want should the treatment for cancer not work, or something went wrong during the treatment. Family members saw knowledge as a way of being vigilant for decisions that may have to be made. "And I told him [patient]...I have no clue [what patient would want if he died]…we've always just teased about it. And I said I really need to know if something does happen, what do you want?" 7.211B. For all the things family members perceive they do not know, there is a special knowledge that gives family members a vigilance advantage in watching over patients. Family members are very aware that they

possess knowledge about the patient that no one else has: "…because I know him. I know his frame of mind" 6.278B.

Because knowledge is such an important aspect of family member vigilance, family members seek knowledge from many places. When a big storm is coming, people consult weather experts, and with cancer, family members want the latest and most expert knowledge on cancer. Family members perceive that healthcare providers with experience have knowledge that when shared, is meaningful: "…she [nurse has] told us so much about procedures and stuff that no one else had, because she's been here for a long time" 8.63B.

Theme Cluster 1.4. Family Members Watch Everyone: Hurricane Survival Depends on Who Can and Cannot Be Trusted

Family members find themselves and patients in untenable circumstances where survival is questionable. Much like people who are in the midst of catastrophic storms, survival may depend on who can and cannot be trusted. In order to determine who can be trusted, family members watch for cues that nurses and other healthcare providers are being vigilant. Family members make decisions about whether or not nurses are trustworthy based on many things. Family members note even the most subtle interactions that indicate nurses are not responsive, which is an indication to family that the nurse is not vigilant. A family member describes an experience where even the tone the nurse used when called upon indicated to the patient and family member that the patient was not a priority and was perceived by the nurse as a bother: "…one time when my husband put on the light [to call the nurse because the IV was beeping]…whoever answered on the other end [answered rudely and the patient] could tell…'Oh, I must have caught them at a bad time'…then he [patient] feels bad every time he puts on the light because it might bother them [the nurses]" 7.278B-7.279B.

In the beginning of the hospitalization it seems families make an overall assessment of nurses and healthcare providers and judge whether or not the group of nurses or healthcare providers appear to have qualities important in vigilance, such as knowledge and experience, and therefore can be deemed trustworthy. "…what I've seen so far… they [nurses have] all had a lot of experience in the cancer center, or on the cancer field" 6.242B. Family members pay close attention to patients' assessments of nurses and other healthcare providers. "[Patient is] happy with them [nurses], and he talks about them, 'she's got twenty-five years of experience…'" 6.260B.

Family members have certain expectations of healthcare providers. Just as people expect weather forecasters to be watchful for storm conditions, family members expect healthcare providers to maintain vigilance. They expect that healthcare providers will pay attention to many things—the patients, the environment, and even the kind of information they give to families. Family members also expect nurses to reassure patients by sorting out patients' symptoms: "…as far as nurses reassuring the patient as far as the discomfort, the aches and the pains…if it's normal or it's abnormal" 3.155B-3.156B

When family members feel that nurses can be trusted, close relationships develop over time between family members, patients, and nurses. "…you get really close to the nurses, especially as long as we [patient and family member] have been here" 5.151B. When healthcare providers or nurses are vigilant, family members feel they can be trusted and are thus confident in the course of treatment: "[The doctor checking on patient after hours] also makes the patient and the patient's family feel a lot more confident, or at least make them feel that they…are receiving the best medical care" 3.303B.

Family members also note things that interfere with family members being able to feel that nurses or healthcare providers are trustworthy. For example, when proactively

calling attention to a lack of vigilance, family members may experience a response from the nurse or health care provider that actually fosters mistrust. One family member described an incident where the she felt the nurse was not paying attention and did not remove the blood pressure machine from the room after she had used it. When the family member reminded the nurse to take the machine out of the room, the family member commented: “I almost got the feeling that she [nurse] took it [blood pressure] again to just to pretend that she wasn’t finished yet” 8.54B. At other times, family members have difficulty trusting that anyone else watches closely enough or as well as the family member: “I’m a total type A control freak…so… it’s a hard thing to let go of somebody else being in charge of him [patient]” 9.79B.

Theme Category 2. Healthcare Providers Who Do Not Seem to Understand How Difficult Cancer Is for Family Members and Patients Like Meteorologists Who Miscalculate the Magnitude of the Storm

Family members rely on healthcare providers for support and direction when loved ones have cancer. When healthcare providers behave in ways that indicate to family members the healthcare providers do not understand how difficult the cancer experience is for family members, the results are frustrating. Similar to meteorologists that underestimate how bad a storm is going to be, miscalculating how difficult these experiences are for family members prevents them from being prepared; the result is the perception of healthcare providers as less than vigilant. This theme category had three theme clusters [see Table 22].

Table 22. Family Member Theme Category 2

Theme Category	Theme Cluster	Themes
Healthcare Providers Who Do Not Seem to Understand How Difficult Cancer is for Family Members and Patients: Like the Meteorologists Who Miscalculate the Magnitude of the Storm	Healthcare Providers Who are Less than Vigilant: Like Meteorologists Who Do Not Make Sense	• Short staffing • Negative interactions with hospital staff • Negative attitude about coworkers • Lack of responsiveness

	• Nurses / HCP who perform at the minimum • Not getting to the bottom of patient illness • Nurses / HCP / hospital staff who perform less than the minimum • Inconsistent nursing practices • Careless practices
	• Poor communication / chaos / confusion • HCP who do not allow higher levels of patient independence • No excuse for missing things is good enough • Unfamiliar nurses / routines • HCP being in a rush
When HCPs are less than vigilant FMs are damaged by the storm	• Feeling left alone by • HCPs • Not being included in decisions / routines • Not recognized / valued as individuals
The system does not make vigilance sense-Like weather equipment that is not working the right way	• Poor medication systems • Legal systems • Being transferred to different floor / HCP

Theme Cluster 2.1. Healthcare Providers Who Are Less than Vigilant: Like Meteorologists Who Do Not Make Sense

While vigilance makes sense, things that interfere with vigilance do not make sense. Family members believe there are several things that seem to not make sense in their experiences with healthcare providers. Shortstaffing and negative interactions with healthcare providers trouble family members and they perceive these as interfering with vigilance. Negative interactions included nurses who talked down or disparaged coworkers in front of family members: “[Nurse] may have a point that…the first nurse hadn’t put… [IV tubing] as neatly as perhaps it should be. I didn’t like the way she voiced it out loud because I really hate it when you put your co-workers…down in front of other people” 8.85B. Family members also feel as if not getting to the bottom of patients’ illnesses or failing to be responsive in some way indicates a problem with vigilance: “Buzzed for the nurses, they hadn’t come in yet, and he [patient] was waiting for those

nurses to come. And [asked] ‘are they coming? Are they coming?’ Cause he just knew this chemo was leaking…on his skin” 6.18B. When healthcare providers perform at a level of family members’ minimum vigilance expectations, the family perceives the care as just that-minimal: “Not that he [patient] wasn’t taken care of; it was just the whole situation [that had been chaotic and frustrating]” 5.237B. At times, family members perceive that vigilance slips below the minimum expectations. “I feel like that is somebody not being watchful…if [patient is] gonna be immunocompromised… [patient] should not be in with somebody like that [who has an antibiotic resistant infection]” 9.54B-9.55B.

As family members watch nurses intently, they come to expect nurses to perform skills or procedures in a somewhat standard way. Inconsistencies in the way in which nurses carry out duties confuse and worry family members: “I don’t know if it was just a personality, or… [nurses] just somehow seemed to be doing things just a little bit…maybe because they [carried out the]… routine differently” 8.47B, 8.49B. Questions about vigilance are raised for family members when they see inconsistencies in patterns of care: “Like when they [nurses] were putting the chemo on, and…one nurse…went to gown up, gloves, mask and everything when she was giving the chemo meds which maybe another one will only put the gloves…” 7.300B-7.301B.

Communication and the way in which it is carried out is also an important indicator of healthcare provider vigilance. Poor communication leads to chaos and confusion for family members. “… the longer we [patient and family member] wait, the more anxious he [patient] gets, the more anxiety he’s feeling, the grumpier he’s getting…the night shift nurse comes in…and she’s like ‘are you guys ready to go?’ And we’re like ‘no cause last we heard they weren’t for sure if they were sending us’ [to a different unit]” 5.225B-5.227B.

Theme Cluster 2.2. When Healthcare Providers Are Less than Vigilant Family Members Are Damaged by the Storm

When people in a major storm are not watchful or prepared for the storm, it is more likely storm damages will in some way ensue. Family members perceive that when healthcare providers are not watchful, they and the patient experience consequences. For example, when healthcare providers are not vigilant, family members feel left alone and left out, and not recognized as a valued individuals: “You just feel like, okay they [healthcare providers] have a job to do, but…it’s just like you’re faceless, just sitting there” 5.279B.

Theme Cluster 2.3. The System Does Not Make Vigilance Sense-Like Weather Equipment that Is Not Working the Right Way

Family members also indicated being confused about aspects of the hospital system. For examples, the way in which the medication system works and decision-making about what floors patients are assigned to perplex family members. They perceive that the medication system leaves open the possibilities of error: “Nurses continued bringing medication even though [patient is] not taking it, and we just returned [the medication] back to [the nurse]” 3.152B. They come to rely on familiarity with the unit to which the patient is admitted. When patients are transferred to different units, particularly without good explanation or orientation, family members feel vulnerable. “[Patient and family member have] been here enough…we know the layout, when we were up on the sixth floor, we knew no one. We just felt like we were just another number on the door, or they just didn’t know us” 5.273B-5.276B.

Theme Category 3. Characteristics of Vigilant Healthcare Providers as Seen by Family Members: Hurricane Heroes-Beyond the Call of Duty

Contrary to experiences with less than vigilant healthcare providers, family members discussed thoughts, feelings, and experiences with healthcare providers that family

members presented as highly vigilant. Like heroes, who risk their lives during catastrophic storms, vigilant healthcare providers are beyond the ordinary and certainly beyond minimum vigilance expectations. This theme category had two theme clusters [see Table 23].

Table 23. Family Member Theme Category 3

Theme Category	Theme Cluster	Themes
Characteristics of Vigilant Healthcare Providers as Seen by Family Members: Hurricane Heroes-Beyond the Call of Duty	Nurses, Doctors, and Others Who Go Beyond the Call of Duty	• Nurses • Doctors and other HCP
	Indicators of Healthcare Provider Vigilance	• Taking excellent actions • HCPs who are present / listen • HCPs who specialize in oncology / are experienced • HCPs who get to know patient and family personally / value unique identity / connect • Subtle conversations-HCPs who protect FMs behind the scenes work / feeling protected by HCP involvement • Nurses who are responsive • Nurses who pay attention to details • Nurses who are positive and focused on health of patient • Take measures to protect patient • Include patient and FM in decisions and respect those • Vigilant HCPs are creative / flexible / adaptive • Vigilant nurses prepare FM for what is coming / routines • Vigilant HCPs notice patient food intake • Notice patient / FM moods and mood changes / physical needs of patient • Vigilant HCPs are knowledgeable / good judgment • Vigilant HCPs are confident • Vigilant nurses do not have to be prompted / critical thinkers • Give information beyond what is expected • Take their time • Notice things FM may miss

Theme Cluster 3.1. Nurses, Doctors, and Others Who Go Beyond the Call of Duty

Vigilant healthcare providers are not perceived as giving 'routine' care, but rather are persons who listen and are present: "So they're not on such a routine that they walk in, jab him [patient] three or four times, and get his blood, and say see you later…They usually visit a little bit, and make him feel good and relaxed" 6.275B-6.276B. When healthcare providers go beyond the minimum expectations of family members, it is noticed and appreciated. "…they were being vigilant in that they were being, very, very careful, and they were making sure everything was really sterile, and they were very professional and so I guess I feel like they were being vigilant just by being so good at their job" 9.33B, 9.35B. Vigilance is perceived as excellent performance, beyond just the basics of the job.

Theme Cluster 3.2. Indicators of Healthcare Provider Vigilance

Indeed, family members see vigilant healthcare providers as people who not only listen, but take action and are responsive as well: "…that makes me feel good-they're [healthcare providers] not just listening to our concerns and then not really addressing them" 5.198B. Family members indicate that vigilant healthcare providers are valuable and may pick up on things family members do not notice: "I did tell her [nurse] to make sure to still just keep stopping in and checking on us 'cause that really helps" 7.316B. Healthcare providers who are experienced in oncology know that knowledge informs interactions with patients and, family members appreciate this level of expert vigilance. Family member is commenting on the cognitive effects of treatment and the nursing response to such side effects: "…because they [nurses] have seen this time and time again, and they know that this isn't the first time that somebody [patient is] sitting there and can't remember what they're talking about" 6.272B.

Family members believe that healthcare providers who get to know patients and family members as individuals are more likely to be vigilant for patients. "She was

coming in and checking on him more than necessary, or trying to take care of me too because I felt like we were more the same…she could relate to my experience…she was extra watchful of him [patient]" 9.49B-9.52B. Such knowing leads family members to feel they can rely on healthcare providers. Family members report sometimes going behind the patient's back to the healthcare provider with concerns about the patient. They rely on healthcare providers addressing the concerns with patients, without 'outing' the family member as the person with the concern. "I was concerned about his [patient's] state of mind…I talked to the nurse…she talked to the doctor, and [the doctor] was purposely asking him [patient] questions…because I didn't want him [patient] to know that I was concerned…cause I have to stay with him" 5.175B, 5.178B-5.180B.

Family members perceive there are many things that indicate nurses are being vigilant. Nurses, who pay attention to details, such as patient food intake, patient or family members' moods, the health of the patient, and take measures to protect patients are viewed as vigilant. For example, family members believe that healthcare providers are able to intervene and give patients permission to stop regular life and attend to the cancer: "Then [doctor] took him [patient] off of work cause…he would've still probably been working…he just had to have that doctor say 'okay you can quit'…that's how he [patient] is" 7.51B-7.52B. Vigilant healthcare providers are also seen as flexible, creative, and adaptive. They are knowledgeable and have good judgment and are critical thinkers, who do not have to be prompted to come up with solutions to problems. "…one of the nurses was very vigilant and understanding…of the issues with…the set up in the bathroom…she was able to make some changes that make the experience more pleasant…it was one of the those creative aspects of a nurse being vigilant to help make the patient…overcome some of the discomfort with having to go to the bathroom" 3.126B-3.128B.

Family members experience vigilant healthcare providers as professionals who help prepare families for patients' treatments, are confident, and give families information beyond what families expect to receive. [Patient comments to family member] "'oh I want her to be my nurse because she's always got so much information for me, she…doesn't just say this is for this'. End of story. She goes back a little bit, or goes into detail a little bit more than just the basic" 8.64B-8.66B. Vigilant healthcare providers are also perceived as taking their time interacting with family and patients. "Our doctor's been really good…he comes in and he sits down and he takes the time to listen…not all people are like that" 5.161B-5.162B. Family members also notice that vigilant healthcare providers spend time ensuring that patients and families' energies are conserved. This is one way in which family member energy is conserved is by vigilant nurses being on duty. When family members believe vigilant nurses are assigned to their loved one, family members feel they can relax, take a break, and let the vigilant nurse take over for a little while. "…it's…kind of a scale thing. The more confident I feel in the caretaker [nurse], the more I can relax" 8.81B. Family members feel safe enough to be off duty, so to speak, when vigilant nurses are working. One family member expressed it this way: "…I know there was nights when I went to sleep that I could feel like I could go to sleep with that [particular] nurse being there" 7.263B.

Theme Category 4. The Calming Influence of Family Member Vigilance: Creating the Eye of the Storm

In the midst of many catastrophic storms, an eye exists. The eye is the center of the storm, within which calm is found-a place that is in the middle of the storm, but not like the storm itself. Much like this, family members in the midst of the cancer storm use their vigilance to create a calm place in the catastrophe of theirs and their loved ones' lives. This theme category has four theme clusters [see Table 24].

Table 24. Family Member Theme Category 4

Theme Category	Theme Cluster	Themes
The Calming Influence of Family Member Vigilance: Creating the Eye of the Storm	Things that help create Family Member Vigilance	• Attention to detail • taking action • Conversations / listening to / observations with patient • Being in the moment • Being physically present • Being prepared for what is coming • Staying connected to FM sources of power-the necessity of family and friends • Being assertive / getting answers • Limiting what is paid attention to • Being able to take a break
	Things that Make Creating Family Vigilance Difficult	• Lack of experience • Lack of knowledge • Unfamiliar routines / environments • A litany of FM or patient negative emotions • Patient being negative / hopeless / isolating self • Too much to pay attention to / not enough time to pay attention to it • Being tired • Hypervigilance • Chaos and disorganization • This is not normal • Problems with getting to the hospital
	The Unseen Work of Family Member Vigilance: In the Eye of the Storm	• Sacred Responsibilities – FMs choice to be vigilant • The weight of responsibility (ravaged by the storm) • To the best of FM ability • Intimately vigilant • Standing in the gap • FMs are a buffer zone-managing the world outside the hurricane • Building an invisible home-FM making home for patient where patient is A home in the eye of the hurricane • Double the complexity-managing both FM and patient feelings • Family Members Watch Patients-Like Watching the Skies for Clues to the Weather • Working on both sides of the hurricane • Extra sets of ears-FM listens for important information

	• 0ver the levy-the tipping point-when FMs jump in to keep patient from being overwhelmed with or is missing info • Guardians of patients dignity and efficacy / privacy letting the patient lead
Weather Watchers-Things that Trigger Family Member Vigilance: Lightening Before the Thunder	• Medical Interventions • Healthcare providers • Patient as a central concern

Theme Cluster 4.1. Things that Help Create Family Member Vigilance

Family members create environments in which vigilance can be maintained and used optimally. As ways to create such environments, they pay attention to details, journal, converse with patients, and develop a routine while patients are in the hospital. "… yeah we're [family member and patient are] in the hospital, but we try to carry on as normal as possible…have a routine…" 5.133B. Family members also feel their presence is important. By this, family members mean both a physical presence and a mental presence, or being in the moment. One family member describes it this way: "You can only think about today. Because the 'what if' may or may not occur…so you just have to try to put those out of your mind, and go over hurdle A…if another [hurdle] comes along, you step over that" 6.26B, 6.34B. Family members may use legal protection such as family leave in order to be able to stay with patients in the hospital. Being present improves the chances for family members to be prepared for what is coming, be assertive, get answers, and take action, if needed. "I'm so glad I'm able to be here with my daughter [patient] because you just can't long distance…Whereas here [in the hospital] I can ask the questions, I'm right there, I can see what's happening, and I can kind of push a bit for things…" 8.27B, 8.29B.

Family members limit what they pay attention to, so that the focus of their vigilance remains on what is most important. They work to compartmentalize the experience to

remain in the present: “I tend to look at things from a process perspective-from the start, from the beginning of detection of an illness, to the hospitalization, to the recovery, to the post recovery, and then back to normalcy state” 3.190B. In order to stay focused on what is important, family members consciously make efforts to not let the cancer experience overtake their lives: “Can’t just dwell on the disease. I can’t allow the disease to overtake my whole being ‘cause he’s dealing with the disease. I can’t allow that disease to overtake me indirectly” 6.161B.

When watching over patients, family members report needing to discern patient signals and sort incoming information, in order to know what is actually of concern. For example, knowing patients well and having some idea of the emotional aspects of having cancer help families know what to watch for and what to be concerned about. Such discernment skill is made difficult because family members understand there are discrepancies between what patients feel and say, and therefore they have to be really watchful to sort things out: “I can tell when he [patient is] feeling that he doesn’t really need a watchdog…somebody watching…to be with him because then it’s like [patient is saying] ‘You need to leave. You need to leave. You need to leave’. I know him well enough that if he says you need to leave once, you say okay pretty soon. And you wait. And then he doesn’t say anything for another hour or two cause he really didn’t want you to go” 6.234B-6.236B.

Family members perceive many things that encourage or contribute to their abilities to remain vigilant. For example, when patients feel well and are appreciative of family members’ watchfulness, instead of being negative, it gives family members the encouragement or energy to continue in their watching: “…he [patient has]…got a lot better attitude about it [the disease and hospitalization]. It makes it easier to be here ‘cause there were days where I was just like, I don’t think I can do this another day” 5.53B-5.54B. As another example, family members perceive that support and

connection with others gives them the energy they need to remain vigilant for patients. Having a designated person at the hospital to vent to, such as a chaplain or social worker, and communicating with or collaborating with healthcare providers are important connections for family members. Of highest importance is the ability to stay connected with family and friends. Connecting to extended family or friends is a way for family members to renew themselves, take a break, and gain the energy needed to maintain vigilance. "… like just last night, his [patient's] daughter, two of my daughters…We went out to dinner and we just laughed, and laughed, and laughed…Just that takes a little break away from that, and then you come back and it gives you [energy to go on]" 6.165B6.166B. Humor is an important way to renew the energy needed for vigilance.

Family members rely heavily on technology, such as e-mail to stay in touch with family and friends at a distance. E-mail has multiple advantages for family members. One family member describes e-mail connections like this: "…if I'm feeling down…it helps me to re-read those [e-mails]. I guess in the olden days, you get the letters and stuff, but it always takes so much longer, and there's much less immediacy available…" 8.117B-8.118B.

Theme Cluster 4.2. Things that Make Creating Family Member Vigilance Difficult

When family members lack experience, knowledge, and supplies, the ability to be vigilant is impaired. For example, family members are vigilant for patients' food intake. A family member describes the frustration with lack of food supplies and the interference it creates for family members: "…he [patient will] only eat oatmeal, and the little cups of ice cream, tomato soup, and cereal…it must have been when we had the bad weather because the kitchen, they were out of oatmeal…I was feeling like oh, this is the only thing he'll eat…I called down, and I asked them the one day, and I felt like, my goodness, what's taking so long to get my oatmeal" 7.173B, 7.177B-7.178B.

The lack of essential elements to vigilantly care for patients is compounded by family members being in unfamiliar environments with unfamiliar routines, and being spoken to in an unfamiliar language: "…a lot of times one tends to misunderstand terminologies…Especially medical terminologies can be quite confusing" 3.167B. Understanding medical terms is important because family members cannot be effectively vigilant, if terms are misunderstood. Family members or patients may expect one thing- and the reality of the medical term used presents a different picture. For example, a family member comments on the issue with misunderstandings about the term "remission": "So in that regard, understanding and being vigilant is very important because that's going to affect how one perceives…the treatment to be" 3.171B.

Family members also believe that their ability to be vigilant is weakened when patients or family members dwell in negative emotions. Family members perceive that any kind of strong, negative emotions impede vigilance. Feelings such as fear, anger, unstable emotions, and worry, distract patients or family members and impede vigilance: "…that's sort of my philosophy of how to get through all this because you can't…look out into the what if's. 'What if this doesn't? What if this happens?'" 6.33B. In addition to emotions family members experience other issues that are prohibitive of vigilance. When patients symptoms are difficult to detect and there is too much to pay attention to family members have difficulty being vigilant. Additionally, they recognize that as humans, there are limitations to how much they can do. A family member comments on the limitations imposed by the system: "That's the hard part 'cause everything's just-you [family member has] gotta work around the nurses, and the schedule, and the medicines and stuff…" 8.159B.

Trying to adapt to so much that is unfamiliar contributes to a generalized chaos and disorganization that family members experience. Often, this kind of chaos encourages family members to become hypervigilant, a non productive kind of watching. A family

member comments on an IV pump that kept beeping: "…I was like out the door panicked because I just was…so uncomfortable with the whole process…I just felt like I had to watch" 9.19B-9.20B. Even while family members experience the confusion of the hospitalization, there is a pervasive sense or reminder that part of the reason this is so confusing is because the whole experience is not normal. "…I've never had to be in charge of his health" 9.80B. Ultimately, all the struggles experienced by family members contribute to a cumulative tiredness, which also interferes with their abilities to be vigilant. The unfamiliar hospital routines interfere with family members getting decent rest: "…the doctors come in awfully early in the morning and sometimes it's like you're asking me [family member] at 7:30 if I have questions. I don't have them until ten o'clock in the morning cause I'm not awake yet" 8.146B-8.147B.

Family members believe that being present is necessary for them to maintain watchfulness over patients. Contrary to this, is family members' concern that not being present interferes with the ability to be vigilant. Family members worry about becoming ill, which would prevent them from seeing their loved ones. Also, difficulties in getting to and from the hospital related to distance, weather, or trying to balance life outside the hospital is an ever present concern. "…I came every weekend and then cause we was…over two hours away…it was hard. It was hard being away from him, and then trying to work, and keep things going…" 7.77B-7.78B.

Lastly, when vigilant healthcare providers are not working, family members do not take breaks. When family members do not take breaks or rest, they become more fatigued and less able to be vigilant. "…if I don't feel comfortable with that [nurses who are on duty], then what ends up happening is I would rush back to the room only to not get as much rest or break, which kind of would impair, affect my ability to be as vigilant as I should be" 3.299B-3.3000B.

Theme Cluster 4.3. The Unseen Work of Family Member Vigilance: In the Eye of the Storm

In catastrophic storms, the eye of the storm is not visible under normal circumstances. Like the eye, family member vigilance is an often subtle and hidden part of patients' cancer experiences. Family members see vigilance as a sacred responsibility that cannot be abrogated by any circumstances. There is an overwhelming sense of needing and wanting to watch over patients: "I don't think I'll relax completely. That's my baby [the patient-who happens to be a daughter] in there…I kind of have to be more vigilant…" 8.82B-8.83B. Regardless of what the relationship is between patient and family member, husband and wife or parent and adult child, the sense of sacred responsibility is similar. "…one of my biggest feelings that I [family member] have throughout this whole process is that I have to make sure everything is going okay…needing to [be] vigilant is something that's at the top of my list when I come to see him [patient who is husband] in the hospital" 9.01B-9.02B.

Family members experience a need to vigilant over matters of intimacy for patients. Vigilance over intimate matters seems to be a responsibility that patients and family members prefer to handle themselves. "I know he [patient] looks for me [family member] to do like bathing. [patient tells nurses] 'When wife gets here, [she] will do it'… so he waits for all those things for me to do for him…he's more comfortable with it" 6.05B-6.06B, 6.08B. Family members struggle and go to great lengths to watch over theirs and patients' intimate lives. Holidays, especially romantic ones, require family members to be open-minded and creative in the ways in which they celebrate with patients in the hospital: "…I'd went down to the gift shop a couple days before… [and] I'd bought him [patient]…a little bit of candy, even though he can only eat one piece…just something for him…then I bought me something from him to give to me. Stupid, but even though you're sick, you still have those same feelings" 7.102B-7.105B.

Family members also perform the invisible function of standing in gaps for patients. Family members 'fill in the cracks' for patients or healthcare providers. Family members are aware that patients' treatment regimens interfere with patients' being able to be as responsive as they may need to be. "…he [patient will] start to…complain… 'they [nurses] didn't bring something in, or they haven't done my blood yet'…And you [family member] says 'yes they were…in at a certain time" 6.332B-6.333B. Family members also stand in gaps between patients and the world outside. They serve as a buffer zone between the world of the hospital and all that lay beyond the patients' rooms. Because patients are so ill, family members take on proxy responsibilities as a way of watching out for patients: "…a second voice of the patient both to the doctors, nursing staff, to friends and families…by being part of [the] vigilance process…as we discussed here is that I serve more as a bridge, a conduit, a voice of the patient…" 3.262B-3.261B. Family members work to make the hospital a semblance of home for patients. Creating a home-like feeling is one way family members watch over patients and fill in the losses patients have experienced. "… it's nice that you [family members] can do your laundry and feel like you can be right here with him [patient] to still make things good… 'Cause…he's had everything taken away from him" 7.233B-7.234B.

Among other things that are invisible or unseen efforts of family members is the amount of watching over patients that family members do. Like people who watch the skies for clues to weather, family members watch patients for clues to their condition. Family members' special knowledge of patients' gives them an edge in noticing and interpreting clues that others may overlook. "…for the past two days, when she [patient] was sleeping…I was worried because she wasn't asking about her baby. She wasn't asking about anybody. She wasn't on her cell phone…" 8.136B-8.138B. Sometimes family members can discuss concerns with patients, but at other times, family members converse with healthcare providers, without the knowledge of patients. A family member

was concerned about patient's reluctance to take anti-anxiety meds and family member felt patient's anxiety was severe: "I even went to [the] doctor because…I was hoping maybe if he [patient] heard it from someone else that maybe he would feel like it's okay [to take the anti-anxiety meds]" 7.127B.

Family members take on a big role as silent observers. They describe these roles as being a second set of eyes or ears. Family members silently watch and listen to everything that goes on with patients and healthcare providers. Like tape recorders, the information family members retain is ready for playback at the patients' beck and call. "… it's good to have a second set of eyes and ears to listen to what the doctors are suggesting, or indicating so that you [family member] can do a good playback [for patient]…" 3.10B-3.11B. Family members give patients a different perspective related to their medical care and information when patients are ready to hear it. "…when it [patient's brain is]…on its way to overload, he [patient] said 'I just stop listening. I just don't even hear what they're saying'. [Patient counts on family member] to be there so then we can have a discussion after the doctors, or when…he's not [on] overload anymore" 6.104B-6.105B.

Besides patients indicating to family members that they are being overwhelmed with information, family members specifically watch for signs patients are unknowingly being overwhelmed. Here, a family member takes action when the patient has forgotten to ask the doctor certain questions the patient has wanted to ask: "I was able to help jog her [patient's] memory, as far as other questions that she had not…presented to the doctor…those are things I think from a vigilance perspective that are important…Because there's a lot of information overload" 3.183B-3.184B. Yet, family members are very careful in the ways in which they intervene or jump in. Family members are guardians of patients' privacy and dignity and take this role seriously. As one family member put it, "…I don't want him [patient] to get the feeling that I think he's

not capable, or he's too sick to be able to answer these questions, or come up with answers on his own" 6.57B-6.59B.

Yet there are times when family members will be outspoken, particularly if they feel the need to push patients to fight the cancer. Often, it is out of character for family members to border on aggressive, but if they feel patients are giving up or giving in to the cancer, they will give patients marching orders. A family member describes talking to a patient who had been completely depressed and hopeless: "You're not the first person that's had to deal with a set back, a disappointment…it happens, but you have to…pick yourself up and just kind of get above it and just try to stay strong…" 5.73B-5.74B.

Theme Cluster 4.4. Weather Watchers-Things that Trigger Family Member Vigilance: Lightening Before the Thunder

There seem to be things that trigger family member's vigilance. Like people who constantly scan the skies for changes in weather, family members watch for any signs that may indicate danger. Family members particularly focus on anything which is perceived as potentially threatening to patients. Medical interventions are one area which heightens family member vigilance. Family members describe examples of things that trigger their vigilance-issues regarding blood products, abnormal lab values, medications, and chemotherapy. "…the steroids that he [patient] was on was making his sugar just go really high…we had that issue before too, but they [healthcare providers] were able to control it with insulin, but this time…it was the combination of the steroid he was on and one of his chemos…at one point…it was as high as 609" 5.216B-5.218B.

Family members also have heightened vigilance about healthcare providers. When healthcare providers enter and leave patients' rooms, appear worried, are inexperienced, or in a student role, family members pay extra close attention. "… [family member] can remember a couple examples when there were people [healthcare providers] who I felt were either younger, in training and they were sticking him [patient],

and they were doing it wrong and he [patient] had to give them advice which…made me really nervous" 9.41B-9.43B. This family member went on to say that this was not a lack of vigilance as much as it was not enough experience on the part of the healthcare providers.

Primarily, however, family members spend their energy and time watching over patients and specific signs from patients which indicate a need for heightened vigilance on the part of family members. Family members are concerned with things such as sudden changes in patients' usual character, if patients are really ill, and for certain symptoms that family members feel must be responded to by healthcare providers: "… going to this doctor, and that one, and I just called the doctor, and…said 'I don't even know whether it's worth me bringing him to the appointment today I feel like I'm gonna end up wasting more time…I don't think anyone realizes how sick he is…he's getting short of breath…his lips look dead'… [doctor responded] 'you probably just need to take him straight to the emergency room'" 7.40B-7.44B.

Family members are also especially watchful for anything they perceive as potential errors. Family members seem to recognize the complexity of the healthcare system and have the idea that risks are likely. "…I know that mistakes happen. I know that people are really sick in a hospital. I know that physicians and nurses are just regular people, and I don't just trust them implicitly because I know they're just regular people" 9.22B-9.24B. Patients' food intake seems to be one area of risk that family members particularly focus on. Attention to food includes watching that food is prepared in such a way to reduce risk of infection. Family members and patients feel as if the guidelines for food preparation are pretty straightforward and infractions, on the part of dietary, produce distrust. Therefore, family members make sure the food patients are getting is safe: "I had to go up and buy food and bring it in because he [patient] said 'if they [dietary department] can mess up on whether if my thing says no fresh fruits or

vegetables, and then they brought lettuce on my sandwich, what else are they going to mess up?'" 6.307B.

One last area that seems to trigger family vigilance has to do with the emotional states of patients. Family members have experiences in which patients' emotions range from withdrawal, to anger, to fear, and anxiety. Family members are very attuned to patients' emotional states and believe it is imperative to help patients' moderate their emotions. "…before he [patient] was so down…he'd get up in the morning and you can just tell by looking at him. Okay, he's not having a good today. So what can I say to kind of help him get through the day? It was just really I guess mentally exhausting at times" 5.45B-5.46B.

Theme Category 5. The Balance of Hope, Hopelessness and Family Member Vigilance: The Contrast of Cataclysmic Hurricanes and the Blue Skies of Hope

Family members experience a myriad of emotions related to patients' cancer and treatment. It is difficult for family members to find a balance of emotions. Much like being in the midst of a hurricane and experiencing the overwhelming power and destruction of it and suddenly, the storm ends and blue skies and sunshine are present, family members feel the juxtaposition of these kinds of emotions, hope and hopelessness, almost simultaneously. "It's all actually all a mixture. You [family member] go from all different feelings…one day you're depressed. The next day you feel a little bit of happiness 'cause you hear a little bit of good news. Then maybe the next day, down deep inside, you're scared to death, and you feel like you're going through hell" 7.00B-7.03B. Family members spend a lot of time monitoring and nurturing hope for themselves and patients, and looking for a critical balance between hopelessness and hope. This theme category has three theme clusters [see Table 25].

Table 25. Family Member Theme Category 5

Theme Category	Theme Cluster	Themes
The Balance of Hope, Hopelessness and Family Member Vigilance The Contrast of Cataclysmic Hurricanes and the Blue Skies of Hope	Family Members Watching for and Protecting Patient Level of Hope: Hope Barometers	• Hope is confusing and elusive for FM to induce in patients • Physics and Hope- or every negative reaction there is an equal and opposite positive reaction • Creating balanced hope • The costs of monitoring hope: An Expensive barometer to monitor • Partly sunny-never partly cloudy-focusing on the positive and avoiding the negative
	Getting others to monitor the hope barometer-enlisting family and friends / cancer survivors / HCP	• Seeking the expertise of those who have survived the hurricane- others with cancer have an understanding that FMs sometimes do not
	Spirituality	• Spiritual Challenges • Spiritual Support

Theme Cluster 5.1. Family Members Watching For and Protecting Patient Level of Hope: Hope Barometers

Like barometers used to monitor upcoming weather conditions, family members monitor patients for symptoms of hope or hopelessness. Hopelessness is considered by family members as negative and life threatening. "…then this morning he [patient]…said 'just to think of all this money that is being spent on treating this [leukemia] this time…when it's probably gonna to end up being useless down the road…the leukemia is gonna end up being the end of [me] anyway'" 6.206B-6.207B. When patients make statements such as these, there is a swift and positive response from family members. In this instance, the patient's daughter changed the focus or what could be hoped for: "… his daughter said, 'but look at this way, by you spending all these thousands of dollars on you, it may help someone else down the road…think of polio, you don't spend thousands and thousands of dollars on polio anymore…it could be the same thing with leukemia. With all these patients that are being treated for leukemia, maybe someday

they'll be able to make it a lot easier...And then someone doesn't have to go through all of this…' [Patient responded] '…well, that's a good way of looking at it. I never thought of that…'" 6.209B-6.211.

While family members focus on hope, they are not unrealistically hopeful. Part of their work in hope / hopelessness is finding a balance between what is hoped for and what is realistic. "…on one hand you [family members are] everyday trying to think the positive, and it's gonna be okay, and on the other hand, you think well, things may not" 7.204B-7.205B. So, family members hold the notion of what is hoped for with a realistic eye of what possibly may happen, but that does not mean that the situation is always tempered by realism. Family members evoke tremendous effort into positive thoughts and positive foci. They go to great lengths to avoid the negatives, and allow patients, through family members, to see partly sunny, as opposed to partly cloudy skies. "…when he [patient] was feeling bad, or feeling down, just try to look at the positives to kind of help keep him up, which kept me up…I just tried really hard not to let him see me down because I think it made it harder on him" 5.10B-5.11B. Presenting this kind of sunny skies attitude and preventing negative interactions often means additional vigilance for family members: "…one of my rules is to screen all the mails, and emails, cards, etc…to make sure that the tone of the communication that's going out and also coming in are consistent and present something in the positive light…But also at the same time, as well wishes comes in, we hope they are well wishes but if there are things that makes one feel like there is not much hope left…You want to be able to screen those out, and just put those aside and not kind of show those to the patient because that doesn't help in one's recovery process" 3.256B-3.259B.

Theme Cluster 5.2. Getting Others to Monitor the Hope Barometer-Enlisting Family, Friends, Cancer Survivors and Healthcare Providers

Family members are aware that bolstering patient hope is a full time endeavor. Family members enlist the aid of others; friends, family, cancer survivors, or healthcare providers in shoring up the patients hope levies. Here, a family member describes the change from hopeless to hope after the patient talked with a cancer survivor: "…as soon as he [patient] got off that phone with him [survivor], his whole attitude, his whole demeanor, just everything even the way he looked just changed…talking to someone who had gone through it and could relate to what he was going through just made it easier for him" 5.97B-5.98B.

Theme Cluster 5.3 Spirituality: Role in Hope and Hopelessness

Family members barely mentioned topics related to spirituality. The few experiences relayed, in relation to spirituality, mirrored family members' issues with hope and hopelessness. On one hand, things in the spiritual realm could be used to reduce hope. In one instance, a family member felt the need to protect the patient (who had no religious affiliation) from messages that implied bad outcomes if the patient did not ascribe to certain religious beliefs. "…if one [family or friends] thinks that [patient is] dying, one tends to make overtures that depending on one's religious beliefs may be hurtful to the patient" 3.254B. On the other hand, family members felt that their best hope and support was from a spiritual connection: "I depended on a lot of my faith to kind of help me through that [patient's illness], and it was very, very helpful" 5.06B.

Theme Category 6. Patient Benefits of Family Member Vigilance: Shielded from the Worst of the Storm

Family members' use of vigilance in watching over patients is beneficial to patients in many ways. Like providing shelter from a raging storm, patients are shielded from the worst the storm has to offer. This theme category has two theme clusters [see Table 26].

Table 26. Family Member Theme Category 6

Theme Category	Theme Cluster	Themes
Patient Benefits of Family Member Vigilance: Shielded from the Worst of the Storm	How Family Members Fill in Healthcare Providers Gaps in Care to Assure Patient Well-being	
	Family Member Vigilance Changes the Way Things Turn Out for the Patient	• FM Makes hospital tolerable for patient • Sustain / validate patient emotions / decisions • Decrease patient anxiety • Instills a sense of confidence in patient • Allows patient to maintain higher level of independence • Vigilance is a way for FM to protect family • Conserve patient energy / helps patient rest • FM vigilance strengthens the patient

Theme Cluster 6.1. How Family Members Fill in Healthcare Providers Gaps in Care to Assure Patient Well-Being

Family members understand that healthcare providers are not instantly with patients every time they need something. Family members being with patients and watching out for them insures that patients' needs can be responded to immediately, and patients do not have to wait for busy healthcare providers to respond. "…'cause if [patient] needs something, there's somebody right there… [patient] could…buzz the nurse. The nurse may take a little bit longer, but if there's somebody [family member] sitting over there, [patient] can say go get the nurse…It's that feeling of if there's an

urgent [need], if you need something, there's somebody right there to help you with it" *6.178B-6.180.*

Theme Cluster 6.2. Family Member Vigilance Changes the Way Things Turn Out

Family members believe that the time they spend watching over patients changes the way things turn out. Family members believe patients feel better when family members are present and that healthcare providers pay more attention to patients, leading to better outcomes. An analogy is used by a family member to drive home the importance of family members' presence on patients' well-being. "…I thought the same thing in school. The kids where the parents are actively involved tend to do better, and…because the kids know that somebody's keeping an eye on them…the teachers keep a better eye on these kids because they know…parents are gonna come and ask questions. [family member then links this to healthcare providers in hospital in relation to family member presence] "…because they [healthcare providers] know that there's somebody there and there's somebody watching, and that somebody's gonna hold them accountable at some level" 8.20B-8.24B.

Family members influence patient outcomes in several ways. Family members who are vigilant make the hospital stay tolerable for patients, decrease patients' anxiety, instill a sense of confidence and strengthen patients, sustain and validate patient emotions, and allow patients to maintain higher levels of independence. Family members consciously give patients as much autonomy as possible and are flexible with helping patients. This allows patients to feel as if they have some control over their disease and environment. "…he does his own, the rest [most of his bath] and I just do his legs and his back, but…I let him pick what time [family member tells patient] 'whenever you feel like it [getting washed up]. Or if you don't feel good, that's okay...we can change it [bed] tomorrow" 7.190B- 7.191B.

Family members' vigilance is used to conserve patient energy and encourage patients to rest. Family members are concerned about patients being able to get enough rest, particularly when they cannot be present. "…my middle son woke up with a bad dream at four in the morning, and I never went back to sleep because I kept imagining him [patient] in the hospital room, and I was worried if he'd be depressed, or if he was sleeping…" 9.57B-9.59B. When family members take on some responsibilities for patients, it relieves patients so they can focus on resting and healing. "I think that [family members taking on extra responsibilities] helps take a lot of pressure from the patient, and allows the patient to totally focus on their own well being and the recovery" 3.264B-3.265B.

Finally, patients benefit from family member vigilance because family members use vigilance to protect patients and prevent negative outcomes. "…vigilance would be in my opinion…watching him [patient], and watching for signs…there are sometimes signs that occur that he's not even aware of…so I have to…be there so that I could pick up on things that he doesn't pick up on to make sure…that nothing slips by that he's not getting the best care that we could possibly get for him at this particular point" 6.00B-6.03B. Family members make certain that vigilance changes how things turn out for the better, whenever possible.

Theme Category 7. Weathering the Storm-
Vigilance as Experienced by Family Members

Vigilance sometimes allows people to survive catastrophic storms, but in a paradoxical way, vigilance used also costs people. Sometimes, people need help understanding what to watch for in major storms. Family members describe experiences similar to these in that vigilance benefits family members, vigilance has a cost and limitations, and family members are not always sure how or what to be vigilant for. This theme category has 3 theme clusters [see Table 27].

Table 27. Family Member Theme Category 7

Theme Category	Theme Cluster	Themes
Weathering the Storm-Vigilance as Experienced by Family Members	What Vigilance Does for Family Members	• Vigilance is a way FMs feel in control • Gives a focus on meeting goals • Gives confidence in preparation to take over if needed • Gives a sense of pride / accomplishment efficacious • Gives a way to make sense of things
	The Cost and Limitations of Family Member Vigilance: Storm Damages	• Viglance is an energy drain on FMs-it is taking the brunt of the storm • Waiting for the storm to hit-Emotional eggshells • Getting pounded-The Whipping Boy • Living in and out of the storm-Divided responsibilities-balancing home, job, patient • Blown into unfamiliar territory-the role and relationship change
	Family Members Need Help to Put Boundaries and Context to Their Vigilance: Orientation to the Hurricane	• No orientation to the storm • Focusing on something / anything if not oriented on: Watching raindrops instead of the hurricane

Theme Cluster 7.1. What Vigilance Does for Family Members

While vigilance is used by family members to watch over patients as described in the majority of these findings, vigilance is also experienced as something used by family members that is beneficial to them. Family members perceive that using vigilance allows them to feel in control. "…it's very helpful because when you [family member are] vigilant…it makes it easier to get through some very difficult times. Just to be aware, and not get frustrated, but to look on the positive side and just say, I am going to be in charge" 3.213B, 3.215B-3.216B. Vigilance is also perceived by family members as a way to meet goals and to prepare in case family members need to take over. Family members want to be prepared, not only to fulfill patients' wishes, but to protect

themselves. “I said, ‘honey, you have such a big family…[and] I really don’t need all your family coming down on me thinking that they know what you want…I much rather that be you that would make those decisions’…he actually told me where he wanted to be buried, and that he didn’t want to be cremated. Well, I never knew that before” 7.213B-7.215B.

Family members also experience vigilance as a way to make sense of things. When family members notice something out of the ordinary their vigilance is only relieved when things make sense to them. Once things make sense, family members can relax a little bit of their vigilance. “[Patient would] go from one topic to another, and back and forth…you could tell he wasn’t tired. Wasn’t sleepy…for two and half hours straight, he was just a babbling on, and on, and on…and they [healthcare providers] did say…if he’s on steroids…he’ll probably have more energy, and be more hyper…at least we found out why he was behaving that way” 6.45B-6.48B.

Theme Cluster 7.2. The Cost and Limitations of Family Member Vigilance: Storm Damages

After every catastrophic storm, there are inevitably storm damages. Although vigilance offers many benefits to patients and family members, there is a paradoxical cost to vigilance. Family members experience vigilance as an energy drain. To remain ever alert and watch over patients, family, and home life is tiring. “…I’ve noticed here [in the hospital when family member is sleeping] somebody comes in the room, and I notice it” 8.97B. Family members are also tired from trying to watch over life inside and outside the hospital. “…not only am I worried if everyone’s watching out for him [patient]…I’m an hour away from home…and I’m terrified that whoever’s picking up [children] won’t pick up [children]…And if the kid who always forgets his homework, forgot his homework… does that mean that he’s not gonna do well in math…” 9.66B-9.68B.

Family members also describe emotional costs of being watchful. Though monitoring patients emotions are part of family member vigilance, there is a cost for having to do so. It is extremely difficult for family members to see patients, who are normally strong people, giving up on life. “I know he [patient] doesn’t realize how bad it was...he’s always been so, so strong, and to see him to the point where he was just like, ‘this is it…I’m never going to see the girls again. You know start making funeral arrangements’. I mean it was that bad. It was just, he pretty much had just thrown his hands up and was like, ‘okay I’m gonna die’” 5.63B-5.68B. When family members are present in order to be watchful, it makes them available to be on the receiving end of patients’ bad moods. “He [patient will] get grouchy sometimes and he’ll say [to family member] ‘don’t talk’…he’s not normally kind of nasty to me in front of others, but he’s been more so in front of the family [since the hospitalization]” 7.86B-7.87B.

Another difficult aspect of family member vigilance is the role change that often occurs between patients and family members. Difficulty in role reversal is compounded because family members usually have never experienced taking on any of the patients’ usual roles. Previous to illness, patients and family members’ roles often were clearly delineated. Cancer changes this drastically: “…for me to be the one kind of looking out for him [patient] was kind of different because…that’s his job” 5.02B. The dynamics of relationships must also change. Because of the risk of infection, family members cannot express intimacy in any kind of usual way. “I’m not up around trying to give him [patient] a hug around his neck, or anything like that because you have to be very careful when his counts are low” 6.119B.

Theme Cluster 7.3 Family Members Need Help to Put Boundaries and Context to Their Vigilance Orientation to the Hurricane

When people are unprepared for cataclysmic storms, their risks for negative outcomes are higher. Without basic knowledge of what to watch for and how to protect themselves, people would be at the mercy of the storm. Life within a storm is not like life outside the storm. Family members are like people who need to be prepared for how to deal with storms. Family members need to have a context within which to use their vigilance. "…what could have helped alleviate some of our fears, and also put us at ease would've been some kind of a guidance check list where one [family members] can inform the patient of the events that would take place during the first 24 to 48 hours of admission…When you're not familiar with those things, you begin to wonder are you really being [vigilant], are the nurses being vigilant?" 3.65B-3.67B. Family members want to be prepared in their vigilance role. "…we just like to know. Kind of feel the more we know, the better prepared we can be" 8.67B. When family member vigilance is not situated they become overly focused on concrete issues such as nutrition or medications. When family members are focused on these kinds of issues because it is what they can focus on, they will be very persistent in getting responses from healthcare providers. "…by being vigilant in the last 24 hours…trying to get my wife's nausea under control [which] happened at a time when…nurse was attending to another patient…by being aggressive, and by being there to be vigilant of how her physical appearance started to look, and the discomfort I was able to get up quickly, approach the nurse's station, and ask for medication immediately. Even though we had pushed the button asking for a nurse, the responsiveness was not as timely" 3.106B-3.108B.

Theme Category 8. Who Might Help: Disaster Relief Partners for the Hurricane

Family members seek help from healthcare providers and have some awareness that family members, patients, and healthcare providers working together is a way patients can receive the best care. "…it again reinforces the concept of having a full team perspective of family, nurses, and doctors…that work together to provide the vigilance that the patient needs…" 3.307B. This theme category has 3 theme clusters [see Table 28].

Table 28. Family Member Theme Category 8

Theme Category	Theme Cluster	Themes
Who Might Help: Disaster Relief Partners for the Hurricane	Partnering for Vigilance	• Takes both of us to watch out • Share the emotional aspects of cancer
	Disaster Relief Equipment-What Helps People Partner	• Knowledge allows for partnerships • Respect allows for partnerships • Access to manager alleviates issues • Disaster relief is needed / wanted
	Things that Interfere with Partnerships-Blocking Disaster Relief Teams from Responding	• Knowing we are two different people with two different experiences

Theme Cluster 8.1. Partnering for Vigilance

Family members notice that certain combinations of family, nurse, and patient seem to work together better than others. Being able to form and depend on such combinations is beneficial to patients. "…I was kind of…happy to find out that we [family member and patient] could request certain nurses because there were…some [nurses] where I've thought [patient] responded better to these nurses" 8.56B.

Family members also develop deeper relationships with their loved ones-developing almost orchestrated relationships where each partner takes on some of the responsibility. Patients take on the role of fighting the cancer and family members watch

over patients so they can focus energy and effort on fighting the cancer. A family member describes the relationship like this: “It’s almost like it’s a partnership. We have to really, he [patient] feels more comfortable [when family member takes care of things]” 6.124B-6.125B.

Theme Cluster 8.2 Disaster Relief Equipment-What Helps People Partner

Family members perceive there are things that contribute to partnerships between themselves, patients, and healthcare providers. Knowledge, respect, and access to someone in charge of the hospital unit are things that family members see as helping people to be able to work together and watch together for the good of patients. Access to nursing managers held special importance to family members because it removed family members and patients from directly having to deal with conflict with specific nurses themselves, which is seen as ensuring protection for patients in the long run. “… [having access to the nurse manager] allows me [family member] to provide feedback back to her and to her nursing staff…we [avoided] having any confrontational contact with any of the nursing staff…because you do not want to jeopardize the care that is being provided [to the patient]” 3.373B-3.375B.

Theme Cluster 8.3 Things that Interfere with Partnerships-Blocking Disaster Relief Teams from Responding

Family members perceive many things as interfering with family members, healthcare providers, and patients being able to work together. When patients will not share feelings or thoughts with family members or nurses, the ability to develop meaningful vigilance relationships is impaired. Family members sometimes feel stuck between what patients tell them and what patients tell nurses. Discrepancies make it difficult for family members to be or feel effectively vigilant. “He [patient] can be sitting there [saying to family member] ‘oh my legs, they ache’…and then they [nurses] come in, [and patient tells nurses] ‘oh I’m fine’” 7.122B. When family members do not know

how patients feel, it leaves them feeling helpless to know what to even watch for. “I’m not able to really help him [patient] because I couldn’t even begin to know how he feels and what he’s going through” 5.103B.

Theme Category 9. The System and Vigilance: Building a Hurricane Proof System

Family members perceive that certain things need to be in place in healthcare systems in order for them and patients to survive the hurricane. Much like special buildings constructed to withstand gale force winds family members desire a healthcare system that is safe, responsive, and competent. This theme category has 2 theme clusters [see Table 29].

Table 29. Family Member Theme Category 9

Theme Category	Theme Cluster	Themes
The System and Vigilance: Building a Hurricane Proof System	Wondering if the Environment is Strong Enough to Withstand the Storm	• Construction that seems able to withstand the ravages of the storm
	The System’s Responsibility in Supporting Family Member Vigilance The Minimum Supplies Needed to Survive the Hurricane	• HCPs who offer excellent care • Being able to request nurse • Facilities for family use-so family can stay near • Appropriate staffing • Maintaining supplies • Technology access • Education and information for FM • Available support for FM • Parking • Ability to maintain placement on specialty unit • The Government’s responsibility in Storm Protection-Health Policy / legal protection

Theme Cluster 9.1. Wondering if the Environment Is Strong Enough to Withstand the Storm

Family members assess healthcare systems and the likelihood that the healthcare system can contribute to positive patient outcomes. Family members watch for signals that healthcare systems engage in structures and behaviors that indicate the presence of system vigilance. "…we have experience at two different hospitals. He [patient] was really pleased with our other hospital, but I think he is super pleased with this hospital. They seem to have more of a team approach than what we had at the other hospital, which I really like…there is a lot more communication…" 6.192B-6.195B. Likewise, family members notice behaviors of healthcare employees that may indicate a lack of system vigilance. When employees are careless around family members, the carelessness is interpreted as a reflection of the healthcare environment: "I [family member] was down eating the one day, I…heard two employees talking and they don't think…'Cause…the one girl said a cuss word, and one man [another visitor] was sitting over here, and we both looked at each other…'Cause she was saying 'I'm on my lunch right now' and she said a cuss word, and we're like…boy you really like your job" 7.309B-7.311B.

Theme Cluster 9.2 The System's Responsibility in Supporting Family Member Vigilance-The Minimum Supplies Needed to Survive the Hurricane

Family members indicate there are some things that systems do or need to do in order to support family member vigilance. In some sense family members seem to believe that it takes a system: "So by being proactive from the medical or from the healthcare facility perspective…that would certainly help family members understand…how the whole infrastructure is behind them to make for a pleasant stay, and a pleasant experience" 3.367B, 3.369B. Although some of these issues have been mentioned as part of other findings, it bears repeating of a few in the context of system

responsibilities. Family members perceive that vigilant systems include excellent healthcare providers, appropriate levels of staffing, facilities, such as laundry, for family members to use which allows them to stay near patients, and maintenance of basic supplies, such as common foods. Additionally, family members perceive that systems that support family member vigilance will provide technology access, particularly internet access (preferably wireless), education, and support for family members, the ability to keep patients on specialty units, and a safe and free place for family members to park. Such requests are not selfishness on the part of family members, but part of their watchfulness for what is best for patients. For example, in regards to parking, one family member relayed the issue this way about husband's decision to come to a National Cancer Institute designated facility: "…when he [patient] made the choice to switch hospitals, the doctors…that was a big decision. He almost chose not to come here. Did he tell you why? Because of where I [family member would] have to park. And he almost chose not to come here because he was concerned over where I would park the car or where I would have to walk…" 6.339B-6.340B, 6.343B.

Theme Category 10. Future Perspectives: Thinking about the Aftermath of the Storm

In all that family members have to deal with while the storm is raging, they are aware and have hopes for after the storm lets up. Family members do spend time thinking about life after hospitalization, and life after cancer. This theme category has 4 theme clusters [see Table 30].

Table 30. Family Member Theme Category 10

Theme Category	Theme Cluster	Themes
Future Perspectives: Thinking About the Aftermath of the Storm	Thinking ahead about going home-ramps up FM need for vigilance	
	A return to normal (remission)-the ultimate FM role	
	Wishing to make it better for others to follow	
	What I wish I knew-the things FMs wish were so	• Vigilance decreases when things go back to normal / or is variable according to need

Theme Cluster 10.1 Thinking Ahead about Going Home-Ramps up Family Members' Need for Vigilance

Even while patients are still in the hospital, family members do spend some thought time, preparing mentally for the day patients will be discharged to come back home. At that point, a big vigilance burden is shifted back onto family members, necessitating some advance thinking about homecoming. "…when he gets home, with being vigilant about keeping the house as clean and sterile as possible, and that's a whole other wrinkle that we'll have to live through once we get home" 9.83B.

Theme Cluster 10.2 Wishing to Make it Better for Others to Follow

Family members exhibit a certain admiration for patients who participate in research and like patients are ardent supporters of any research that may allow others to have better experiences with cancer in the future. "…because he [patient has] had it [rash] twice now, and this came on again with the onset of leukemia. Was it related to leukemia or not? So they [doctors] asked if he would participate [in research] with some of his biopsies that they did on him, and also his skin…he said, 'well, it may not help me, but it may help someone else down the line'" 6.202B-6.203B. In some ways, it is like

patients and family members are being vigilant for future others who will also experience cancer.

Theme Cluster 10.3 What I Wish I Knew-The Things Family Members Wish Were So

Family members reflectively thought about things that seemed to be missing in their vigilance experiences. There are some things that family members wish were part of their vigilance experiences. Family members wish they could learn explicitly about vigilance and be given information about what to watch for with patients. Family members would like to have information about ways to maintain intimacy with patients who are ill and at risk for infection. Without specific kinds of information, family members will err on the side of caution and perhaps miss out on extraordinary moments with patients. “I asked the one day, can I at least still hold his hand cause I know we’re not allowed to kiss right now…” 7.249B.

Essential Structure of Family Member Vigilance

The second group of participants, the family members’ data had 10 themes identified. From the narrative description of family members’ experiences an essential structure of vigilance experiences of family members of cancer patients was derived. Husserl proposed that essential structures of phenomenon could be derived through the rigorous process of empirical phenomenology. Adherence to bracketing, or setting aside one’s scientific presuppositions allowed researchers to identify “those features that must be present in any and all possible instances of the phenomenon” [134] (p. 168). The essential structure is believed to represent an ultimate truth related to the way the phenomenon appears [135].

The family members’ journey is different from the patients and is described as “Sucked into the Cancer Hurricane of Family Vigilance”. Family members are like people who unwittingly find themselves in the midst of a huge, overwhelming, destructive storm.

Family members are vigilant in many ways for patients and healthcare providers in the midst of the storm. Family members see gathering knowledge about cancer and treatment as integral to being vigilant, as in quickly identifying which healthcare providers can be trusted. Family members contrast experiences of vigilant healthcare providers with those who are not vigilant. Those who are not vigilant do not seem to understand how difficult the patient's cancer and treatment are for family members. Yet, vigilant healthcare providers are like heroes in catastrophic storms. Such healthcare providers go beyond the call of duty. Family members see vigilant healthcare providers as present, interested in the patient and families on a personal level, and prepare patients and families for what is coming, which allows family members themselves to be vigilant.

Family members spend much of their vigilance energy on creating a safe place for patients-a home-like atmosphere where routine is created to "normalize" life in such a way that patients can focus on cancer treatment. Family members spend a lot of time monitoring patients' level of hope and creating a focus on the positive.

There is a cost for families being vigilant, such as being emotionally exhausted. Family members look to healthcare providers to support and help with vigilance. They become knowledgeable in ways the healthcare system as a whole contributes to or detracts from family member vigilance.

Summary of Family Member Results

Family member findings indicated that vigilance for family members of patients with cancer is a complex, multiperspective, and multidimensional process. Although only two broad, data-generating questions were asked of family members, multiple perspectives on vigilance experiences were found. Family members presented experiences of being vigilant for themselves, being vigilant for patients, nurses being vigilant with patients and family members, and perspectives on shared vigilance.

These multiple perspectives provide a level of complexity in the findings that was unexpected. This level of complexity prohibits a full discussion of findings in this dissertation. Therefore, a decision was made to identify key findings from the family member narrative, which will be used to guide the family member discussion section. Eleven key findings were chosen because they were perceived to be findings which either added to current scientific knowledge related to vigilance, or were new scientific ideas about vigilance which emerged in this dissertation study. For key findings identified from family member narrative please see Table 31.

Table 31. Family Member Key Findings for Discussion

Family Member Perspective	Key Finding	Corresponding Theme Category
Family members being vigilant for patients	Family members modify the hospital environment to create an environment more conducive to family member vigilance.	4
	Family members are watchful about intimate aspects of theirs' and patients' relationships.	4
	Family members place a high value on knowledge accrual and connect knowledge with their ability to be effectively vigilant for patients.	1
	Special knowledge about the patient gives family members a vigilance advantage in being able to identify "different than normal" in the patient rather quickly.	1
	Family members are specific in their watchfulness and there are certain issues which trigger family member watchfulness.	4
	Family members spend a majority of their time monitoring patients' levels of hope.	5
	Spiritual issues were not associated with vigilance experiences of family members as they were with patients.	5
Family members watching healthcare providers	Healthcare providers must exhibit vigilance is order for family members to develop a trust relationship with them.	3
	Family members recognize the healthcare systems responsibility in supporting their vigilance.	9
The effects of vigilance on family members	There are indications that vigilance may be highly relevant to caregiver burden.	7
Family members perspectives of shared vigilance	Family members implied that there was a need to share vigilance with patients and healthcare providers.	8

Nurse Results

Description of Nurse Participant Sample

In many qualitative research reports, participants are usually described in detail. Because patients and family members in the sample for this dissertation study had long term hospitalizations, nurses and other healthcare professionals became very familiar with them. Families and patients were likewise familiar with the nurses. In order to protect participants' confidentiality, the sample is described minimally.

Seven nurses participated in this dissertation research. Each nurse was identified as a vigilant nurse by a patient or family member. All nurses but one were female and all nurses reported Caucasian as their ethnic background. Three nurses were married, three were single, and one was divorced. Nurses ranged in age from 28-52 (m=38.2; SD 8.38). The majority of nurses had an associate's degree in nursing (n=4), one had a diploma, and two had bachelor's degrees. Years practicing as a nurse ranged from 2.5 to 32 (m=12.7; SD 9.9). Years practicing in oncology ranged from 1.5 to 19 years (m=6.35; SD 6.47).

Narrative of Nurse Findings

Findings from nurse narratives allowed a picture of vigilance to emerge which is similar to viewing a perfectly balanced mobile. Like physicists who have mastered the science of measurement, balance, and proportion, nurses put together a mobile of nursing vigilance. Like artists, nurses also considered elements that are often overlooked by others that when put together by an experienced nurse, creates a mobile of nursing vigilance that is a work of art. Ten theme categories emerged related to nurses' experience with vigilance [see Table 32].

Table 32. Overview of Nurse Theme Clusters and Theme Categories

Theme Category	Theme Cluster
Vigilance as a Routine Nursing Phenomenon-Like Experts at Constructing Mobiles	• Vigilance Is Not Always A Conscious Process • Vigilance Is Difficult To Describe • Recent Or Unusual Cases Highlight Vigilance – Like Remembering An Extraordinary Mobile
The Elements Of Nursing Vigilance- Like Assembling All The Parts For Making A Mobile	• NOT VIGILANCE • Vigilance Is About Voracious Advocacy And Protection Of Patients • Vigilance Is About All Kinds Of Communication • Thinking Like A Vigilant Nurse • Vigilance Is Noticing Small Things In The Moment • Routines Allow Nurses To Be Purposely Vigilant • Vigilance Is Looking For Patients Results / Response
Things That Encourage And Promote The Use Of Vigilance-The Reasons Behind And Contributors To Making The Mobiles	• Cancer/Oncology Nursing Encourages Vigilance • Hospitalized Patients • Ways The System Contributes To Vigilance • Healthcare Provider Behaviors • Positive Attitudes
Things That Help Hold Vigilance Together-Like Materials That Hold The Mobile Together	• Connectedness-Vigilance Glue • Trust-Another Kind Of Glue For Vigilance • Nurses And Hope
Threats-Things that Draw Nurses' Attention to the Mobile	• Nursing Vigilance Is Directly Proportional To Threats • Identifying Threats • Dealing With Threats • Decreasing Threat Status
What Interferes With Vigilance-Things that Upset The Balance Of The Vigilance Mobile: End Of Life (EOL), Healthcare Specific Interference, and Energy	• Nurses Are Vigilant For End of Life Issues • Healthcare Specific Interferences • Putting a Balanced Mobile Together Uses Energy
Knowledge and Experience Are Critical Pieces of Vigilance-Knowing How to Construct a Mobile that Works	• Knowledge / Experience Is Developed Over Time • Nurses Are Committed To Giving Patients / FM Knowledge • Early Hospitalization Is Characterized By Lack Of Knowledge For Family Member And Patient • Knowledge Must Be Current Or Updated • System Role In Education • Lack Of Knowledge Interferes With Vigilance
The Three Most Difficult And Important Pieces to Balance In the Vigilance Mobile-Patients, Family Members, and Healthcare Providers	• Nurses Family Members and Vigilance • Nurses, Patients, and Vigilance • Nurses, Healthcare Providers, and Vigilance
Vigilance Outcome s-What Happens When One Creates and Watches The Mobile	• Vigilance Leads to Patient and Family Member Safety / Decreasing Risks / Decreases Negative Outcomes • Nurses Feel Are Appreciated and Benefit From Using Vigilance
Hints of Shared Vigilance-The Dream of the Perfectly Balanced Mobile	• Nurses See Sharing Vigilance as Necessary • Things that Interfere With Shared Vigilance

Seven nurse participants described their experiences of vigilance; how they watched over patients, families, and other healthcare providers. Participants were oncology nurses who were identified by patients or family members as vigilant nurses. Nurse participants were assigned a code beginning with a number and ending with C. Therefore, when it is noted after a quotation 6.234C, one can interpret that the statement was made by participant 6, significant statement number 234, and this was a nurse participant, as designated by the letter C. Because this research accrued data from three different samples, patients, families, and nurses, these terms will be used instead of participant, in order to avoid confusion over which sample is being discussed.

Theme Category 1. Vigilance as a Routine Nursing Phenomenon-Like Experts at Constructing Mobiles

Nurses struggle to describe vigilance because vigilance is such a routine part of being a nurse. Nurses describe vigilance as an essential element of their daily job and could not imagine functioning as a nurse without being vigilant. “To me vigilance is a really big word for something that [nurses] just do all the time” 1.00C. This theme category had three theme clusters [see Table 32].

Table 33. Nurse Theme Category 1

Theme Category	Theme Clusters	Themes
Vigilance as a Routine Nursing Phenomenon-Like Experts at Constructing Mobiles	Vigilance Is Not Always A Conscious Process	
	Vigilance Is Difficult To Describe	• Struggle to know how or if vigilance works
	Recent Or Unusual Cases Highlight Vigilance –Like Remembering An Extraordinary Mobile	• Patients are the symbols of vigilance for nurses

Theme Cluster 1.1. Vigilance Is Not Always a Conscious Process

Highlighting the struggle that nurses have to separate vigilance as a phenomenon from their everyday nursing experiences is the revelation that vigilance is so ingrained that nurses are vigilant without being consciously aware of being vigilant and the results

of it. “I had one patient…I didn’t realize how much I made him…feel more secure…until his family came up and hugged me, and thanked me. And I was like for what?” 6.255C-6.257C.

Theme Cluster 1.2. Vigilance Is Difficult To Describe

Struggling to describe vigilance is not just difficult in reference to nurses themselves. Nurses also struggle to identify what constitutes vigilance in others, or how others perceive vigilance. One nurse ponders aloud about vigilance: “… is it really vigilant? Is being strict considered being vigilant, or is it just being watchful? Do patients perceive that as just being watchful, or are they being cautious” 2.140C-2.141C. Nurses also struggle to know if, or how, vigilance works. As nurses work with life and death situations, they try to delineate what levels of vigilance make a difference and what kinds of situations are so serious that all the vigilance in the world may not help. For example, one nurse questions the significance of vigilance in a situation where a critically ill patient subsequently died: “Most of the time the doctors are pretty receptive when we tell them that [patients] need to be in a higher level of care, but… that day, [the doctors] weren’t [receptive]. So I don’t know if would’ve made a difference or not” 7.35C-7.36C.

Theme Cluster 1.3. Recent or Unusual Cases Highlight Vigilance-Like Remembering an Extraordinary Mobile

One way in which nurses seem to remember using vigilance is when they think of patients or families whom they have recently been assigned, or if there is an unusual or serious incident with a patient or family member. Like remembering mobiles that recently caught one’s eye, thinking of specific patients or families seems to place vigilance within a context for nurses. “…there’s all kinds of cases [where nurses use vigilance], but those are the most severe ones that pop out to mind” 5.172C. Many of the cases that nurses’ recall are related to patients. Being vigilant for patients is a primary and central focus for

nurses: "…any time you're [nurses] doing anything, like…there's certain kinds of chemo we [nurses] do that were one on one" 7.52C.

Theme Category 2. The Elements of Nursing Vigilance-

Like Assembling All the Parts for Making a Mobile

Nurses perceive there are many essential elements needed in order to be vigilant. Like making sure one has all the parts and equipment needed for constructing a complex mobile, nurses describe many considerations and elements that would be required to be vigilant. This theme category has seven theme clusters [see Table 33].

Table 34. Nurse Theme Category 2

Theme Category	Theme Clusters	Themes
The Elements Of Nursing Vigilance-Like Assembling All The Parts For Making A Mobile	NOT VIGILANCE	• Vigilance is not optional • Vigilance is never less than
	Vigilance Is About Voracious Advocacy And Protection Of Patients	• Vigilance is about speaking up • Vigilance is about being assertive and setting boundaries • Vigilance is about taking action
	Vigilance Is About All Kinds Of Communication	• Vigilance is about listening and watching • Vigilance is about asking questions • Casual Conversations are not so Casual
	Thinking Like A Vigilant Nurse	• Vigilance is about considering all the possibilities • Vigilance is about sensemaking / seeking answers • Vigilance is about making critical connections between thoughts and ideas • Pointing out connections to others • When connections are not made • Vigilance is held in the Mind • Being prepared and organized • Vigilance is about being focused and prioritizing • Vigilance is about sifting through and knowing what to be vigilant about • Can be adapted according to need • According to medical specialty
	Vigilance Is Noticing Small Things In The Moment	• Vigilance is timely and present oriented • Vigilance is attention to detail-Picking up the small things • Catching symptoms early • Vigilance is paying attention to the environment • Vigilance is about seeing for oneself-being present and in patient room • Physical and mental presence • Even a little is better than none

	• Nurses have advantage over doctor because nurses are present
Routines Allow Nurses To Be Purposely Vigilant	• When nurses skip routines
Vigilance Is Looking For Patients Results / Response	• When there is not a response

Theme Category 2.1. NOT VIGILANCE: I Know What a Real Mobile Looks Like

Nurses are not fooled by imitations of vigilance. Like trying to pass of a paper plate and yarn as an exquisite mobile, nurses are not fooled by things that are not vigilance. Even if it is sometimes difficult for nurses to understand or describe vigilance, it seems that nurses are certain of what vigilance in nursing did not look like. In the scope of doing their job and being vigilant, nurses are certain that falling behind in observations did not constitute vigilance. “If you let things go, then you forget. You’re not doing well being an observing nurse. If you don’t add it all up to the end of the day, what if there was something drastic at noon? [nurse] didn’t catch it till six o’clock” 3.88C-3.89C.

Nurses could not imagine not being vigilant. In other words for this group of vigilant nurses, vigilance is not optional, even if there are negative consequences for nurses: “To me, there’s no choice. I have no choice. This [vigilance] is what I have to do, and if that’s the price I have to pay, whether it be my health, or my whatever, that’s what I’ll do…” 4.213C. Nurses recognize that being vigilant is beyond the call of duty and vigilance is never about doing the minimum. “If you just…sit there and look at it as a paycheck, you’re not gonna do your job [be vigilant] because you’re not putting your heart into it” 6.311C.

Theme Cluster 2.2. Vigilance Is About Voracious Advocacy and Protection of Patients

Nurses perceive being vigilant as being highly committed to advocating for and protecting patients. Advocating for patients includes speaking up when patients have a need. For example, a nurse describes a situation where the nurse had to advocate for the doctor to order tests for a patient who was not doing well: [Nurse asked residents]

"'…would you maybe want a head CT because it [headache] just isn't going away and it just worries me.' And she [patient] had a head bleed and they took her right off to ICU" 1.42C, 1.45C-1.46C.

Nurses also have to be assertive and set boundaries in order to protect patients and prevent the nurse from getting distracted by negative behaviors. At times, the stress of the patient's hospitalization contributes to negative and out of control interactions between patients and family members. Vigilant nurses set boundaries on such behaviors. "They [patient and wife] were arguing…there was words flying that you don't hear very often, and threatening…I [nurse] finally had to get in between the two of them, and say listen you guys, you've gotta stop this" 4.261C-4.262C.

Another element of nursing vigilance is taking action. Nurses feel that in order to be vigilant, one has to be responsive. Taking action is another way that nurses provide advocacy for patients and protect them. "[Nurses] have to be vigilant with every patient cause things can turn around so quickly with [oncology] patients…one day they could be doing fine. The next hour, they could be having a fever, and you have to get their blood cultures and everything has to go really quickly. Get blood cultures. Send urine. Get their chest x-rays, or antibiotics all in an hour" 7.39C-7.41C.

Theme Cluster 2.3. Vigilance Is about All Kinds of Communication

Vigilant nurses describe communicating in many different ways as a means of being vigilant. Nurses feel it is necessary to both listen and watch in order to be vigilant. Listening, in particular, is a way to catch things that might otherwise go unnoticed. The nurse is describing the relief there is when listening alerts the nurse to a potential threat: "… am I glad that somebody said this, or did this, or brought it, so that it brought it [potential threat] to mind, [and] I was paying attention to it" 1.213C. Often communication is not passive, such as just hearing something by chance that is helpful, but nurses assertively seek information from patients or families by asking questions. Asking

questions helps the nurse be attentive in a way that is meaningful to patients and families. "…if you [nurses] ask questions about their [patient] treatment and family, then you get to know them and understand how they like to be taken care of" 3.07C.

There is an art to communicating with patients and families. Nurses are so subtle in gathering or recognizing important information that many times an untrained observer would suspect that the conversation is casual and has little purpose other than mindless chatter. One nurse describes the significance of such casual conversations: "[Patients sometimes make] a really innocent kind of statement, and [nurse] picks up on it…and starts questioning them about it and then you come to find out more, and that yes that could be a potential for a complication" 1.13C-1.15C.

Theme Category 2.4. Thinking Like a Vigilant Nurse-There Is a Thought Process When Putting a Mobile Together

An important aspect of being able to be vigilant is the specific way in which nurses learn, over time, to think. Just like a scientist or artist does not just throw any old pieces together to create a balanced mobile, this type of thinking evolves over time. Vigilant nurses do not have narrow foci, but think broadly so they do not miss something important that may be less obvious. Nurses who are vigilant assertively seek answers for concerns and put a lot of effort into making sense of situations or symptoms. Nurses will remain highly vigilant until an explanation is hopefully found. One nurse describes a situation where patient symptoms did not make sense and the nurse's action to try and discover what was wrong: " [Nurse] would check [patient's] heart rate [and it] would be over two hundred, and then it would go back down…I talked to the doctor and the doctor didn't know what to do and [the doctor told the nurse] 'if you care that much, you can just hook him up to a monitor yourself and watch him'. So…I [nurse] spent…all night with him [patient]" 5.02C, 5.04C, 5.06C-5.07C.

An important aspect of thinking like a vigilant nurse is to make critical connections between thoughts. Oftentimes, these connections are not clearly identified right away. “You [nurse] might not be able to pinpoint it right away either…until you go on in the day just a little, and then…sometimes you can put things together and say ‘oh, I think it’s this’” 1.102C-1.103C. Nurses also put an emphasis on helping patients see connections between problems that help patients to be more vigilant for themselves. “If you [nurses] give them [patients] a reason for a symptom, or what they’re going through, then they’ll put the picture together” 3.82C.

Because vigilant nurses recognize that it may take a period of time to make connections, they hold information in their minds, sometimes for a period of days. In this way, nurses can check and recheck situations of potential concern, or make a critical connection when other information becomes available. “…everything looks just fine, and then [nurse notices] that [patient’s blood] pressure’s just a tiny bit lower than what it had been the last days that you’ve [nurse has] been in there” 1.110C.

In order to be vigilant nurses perceive they must be prepared and organized in managing the tremendous amounts of information that is required when caring for several patients. “…probably the best way to put it would be [make sure] all your ducks are in order…vigilance [is] also… preparative…like preparing for that patient” 2.03C-2.04C. When nurses are organized, they are more readily focus and able to prioritize care that allow them to be attentive and vigilant for patients. A nurse describes an organized routine that leads to being able to set priorities for care: “Checking vitals, doing my assessment and…if I think someone is sicker or needs attention soon, I go to see that person first” 5.135C.

Theme Cluster 2.5. Vigilance Is Noticing Small Things in the Moment

When working with patients and families, nurses sometimes need to notice subtle cues. Vigilant nurses perceive that an essential aspect of vigilance is to notice small

things, in the moment. Not getting behind, staying on time, and immediately addressing issues is a way nurses are vigilant. Nurses believe that patients perceive nurses as being vigilant when they are responsive to concerns and needs in a timely way. "…if they [patients] have a concern or something that needs to be addressed by the doctor. I always let them [patients] know what's kind of going on so that way they just don't think 'oh she forgot about me.' They don't feel like I [nurse] forgot, or nobody addressing it…that's just [one of the] things that I do that I think the patients probably think as being vigilant" 7.20C-7.21C.

Vigilance is often not about large, noticeable, or even unusual symptoms. Vigilance is about tending to and monitoring the small, on a daily basis. Vigilance is about watching the mundane, just in case. "So it might not be anything…but sometimes it is… it's just all those little things that you [nurses] look for throughout the day… [like] vital signs" 1.107C-1.109C. Particularly for oncology nurses, noticing the little things and monitoring to prevent complications or catch them early is of special significance. Because patient's immune systems are not functioning properly, not letting complications begin is paramount. A nurse comments on the belief that potential complications need to be caught early: "My motto is 'prevention, and no need to suffer'…once…things go too far, it takes too long to get you [patient] feeling better again…" 3.84C-3.85C.

Nurses describe presence as an advantage in being able to be vigilant, and a particular vigilance advantage that nurses have over doctors. Entering patients' rooms is not a casual undertaking. Vigilant nurses are performing a myriad of assessments every time they enter patients' rooms: "…every time you [nurses] go in, you're not just doing ins and outs [fluid intake and output], monitoring on a twelve-hour timeline…every time you go in the room, you're measuring, you're monitoring" 3.87C. If the nurse has been off shift for a couple of days, but the family members have been present, the nurse

especially values what family members have to report. Additionally, being physically present with patients reduces patient anxiety because patients see that the nurse is available and watching over them*:* "…when I [nurse] go into there I think that helps because of the anxiety and the fear and everything that they [patients] have gone through" 2.186C.

Theme Cluster 2.6. Routines Allow Nurses to Be Purposely Vigilant

An important element in being able to construct the mobile of nursing vigilance is to develop a routine. Nurses perceive that routines allow them to be more effectively vigilant. A nurse describes elaborate routines of assessing patients and dispensing medications that help them define and focus their vigilance: "…then I usually do vitals and assess. And then I go to the next person, do vitals and assess. And I go all the way around basically seeing everyone" 5.136C-5.138C. In routines, nurses could focus on the task at hand in a watchful way. When routines are interrupted, nurses are frustrated and anxious, because there is something interfering with their ability to be vigilant. In other words, interruptions in routine are distracting and therefore, nurses are less able to be vigilant. For example, a nurse describes what happens when family members interrupt nurses' routines: "Sometimes you [nurses] have [family] where they go over the top [become hypervigilant], and you [nurses] literally have to actually make them [family] leave because you [nurses] can't get…job done because they [family] are disrupting the flow of things" 4.250C.

Theme Cluster 2.7. Vigilance Is Looking For Patients Results / Response

Nurses indicate that vigilance is not a one time action, but is in part, about checking back to see how patients respond to interventions. For example, a nurse describes monitoring a central line dressing site over a period of days that suddenly began to look red and irritated. In order to be vigilant for infection, nurses need to check back often to see if interventions are changing how the site looks: "…on Thursday, we [nurse and

nurse orientee] went to change it [central line dressing] again, and I just made sure that I went in with her and we changed it…when we took it off this time, it really was looking kind of raw…when I checked back with him [patient] on Monday, he said this [the site] was much better" 1.62C-1.63C, 1.65C.

Nurses' vigilance is only decreased when patients have positive responses to interventions. Confusing or unstable patient conditions elicit a sustained, heightened watchfulness in nurses. Nurse describes a situation where the patient did not respond to interventions: "…he [patient] was having a lot of problems breathing…I [nurse] was just in there almost the whole time and I kept telling the doctors he can't breathe. We keep having to go up on the oxygen, and finally he's on a mask…and they [doctors] still hadn't sent him [patient] to the ICU or anything…so the next nurse that came on…started trying to get him sent to the ICU because he [patient]…probably to be intubated" 7.26C-7.28C, 7.30C.

Theme Category 3. Things that Encourage and Promote the Use of Vigilance-

The Reasons Behind and Contributors to Making the Mobiles

Just like artists and scientists have things that drive them to create beautiful and balanced mobiles, there are things that encourage nurses to be vigilant. Additionally there are things that contribute to nurses' abilities to be vigilant. Just like having access to the right materials may help build a better mobile, nurses who behave in certain ways or are surrounded by persons or systems that behave in certain ways could be more effectively vigilant. Nurses describe several ways in which they are motivated to be vigilant and what contributes to their vigilance. This theme category has five theme clusters [see Table 34].

Table 35. Nurse Theme Category 3

Theme Category	Theme Cluster	Themes
Things That Encourage And Promote The Use Of Vigilance-The Reasons Behind And Contributors To Making The Mobiles	Cancer / Oncology Nursing Encourages Vigilance	
	Hospitalized Patients	• Certain kinds of patients (personality, confused, really ill, patients who do not watch) • Patients who are unstable • Last chance to be together • Giving meds • Pain meds • No one else to help watch
	Ways The System Contributes To Vigilance	• Errors that raise awareness • Clear guidelines and protocols • Sustained connection with patient • Primary nursing • Accommodating environment • Concrete measures
	Healthcare Provider Behaviors	• Organized • Written plan • Identifying risks • Experience • Collective vigilance • Vigilance exhibited and valued by leaders
	Positive Attitudes	• Grateful families and patients

Theme Cluster 3.1. Cancer / Oncology Nursing Encourages Vigilance

Nurses perceive that being a nurse, specializing in oncology, encourages them to be highly vigilant. Cancer, its treatment, and the real possibility of patients dying push nurses to be really vigilant. Nurses also believe the nature of cancer strongly enforces the need or awareness for patients to be vigilant as well. "…when you [patient] are diagnosed with cancer that's your life, and that kind of almost forces people to be vigilant to some extent. Not that any other medical conditions are less important, but say you have a cold and you have normal [neutrophil] counts versus you get a cold and you have not normal counts, the likelihood of you having something tragic happen is higher" 2.129C-2.130C.

Theme Cluster 3.2. Hospitalized Patients

Nurses notice that they feel more compelled to be vigilant for certain kinds of patients, beginning with patients who are hospitalized. Nurses recognize the vulnerability associated with patients in the hospital: “When I came into the clinical [hospital] setting…I noticed that yeah, you do have to speak up more for your patients [who are in the hospital as opposed to in home care]” 4.66C. Patients have layers of vulnerability and nurses recognize many of these threats and are extra watchful in relation to such patients. Nurses perceive that patients who are confused, really ill, do not watch out for themselves, and do not have anyone else to watch over them require the nurses to be that much more vigilant. “Just any time the patient…is not doing well, you’re always extra [vigilant]…just try to be with them as much as possible so…they don’t fall, or they don’t hurt themselves, just anytime a patient isn’t doing well” 7.22C-7.24C.

Nurses not only perceive there are situations or beliefs that encourage the use of vigilance, but nurses also have experiences where certain behaviors or the environment contributes to or enhances their abilities to be vigilant. Nurses indicate that the healthcare system, certain healthcare provider behaviors, and positive attitudes on behalf of patients and families enhance nurses’ abilities to be vigilant.

Theme Cluster 3.3. Ways the System Contributes to Vigilance

Nurses perceive that the healthcare system has the potential to contribute to the nurses’ use of vigilance. When the system has clear policies and protocols in place for delivery of chemotherapy, as well as ways to deal with errors, nurses feel their ability to be vigilant is heightened. Nurses also perceive that being able to maintain a sustained connection with patients through primary nursing enhances their abilities to be vigilant for individual patients. Finally, nurses express that concrete measures improve their ability to be effectively vigilant. Nurses describe monitoring labs and taking vital signs as a means of confirming and supporting vigilance. A nurse shares an experience of

monitoring concrete measures as a means of being vigilant: "…doing his [patient's oxygen] sats and vital signs frequently to make sure to see how he's doing" 7.49C.

Theme Cluster 3.4. Healthcare Provider Behaviors That Contribute to Vigilance

Nurses perceive that certain healthcare provider behaviors enhance nurses' abilities to be vigilant. If nurses are organized, have a written plan of care, and collectively watch out for one another, nurses feel like this promotes nursing vigilance. Further, nurses believe that more experience contributes to a provider being able to be more effectively vigilant. A nurse relays a belief that being experienced contributes to assertively watching over patients: "…I'm [nurse] not taking no for an answer when I know they [patients] need something… I'm not a new nurse anymore and I'm not afraid to get yelled at…" 4.160C, 4.162C.

Theme Cluster 3.5. Positive Attitudes

Nurses feel like patients and families who exhibit positive, grateful attitudes validate nurses' efforts at being watchful. A nurse describes one such circumstance where the nurse was monitoring a critically ill patient. Another nurse was assisting and indicated to the patient that the patient was in good hands with the primary nurse. The nurse relays that the patient responded by saying: "…I know. He's got my life in his hands, and I totally trust him" 5.33C-5.34C.

Theme Category 4. Things that Help Hold Vigilance Together-Like Materials that Hold the Mobile Together

Nurses describe three major things that they use to tie vigilance together. Like someone putting a mobile together, the material that connects the mobile pieces together must be something that lends strength to the design. Vigilant nurses use three things to tie their vigilance mobiles: connectedness, trust, and hope. This theme category has three theme clusters [see Table 35].

Table 36. Nurse Theme Category 4

Theme Category	Theme Clusters	Themes
Things That Help Hold Vigilance Together-Like Materials That Hold The Mobile Together	Connectedness-Vigilance Glue	• Vigilance and connectedness • What makes connecting difficult • Connectedness is not always encouraged • Knowing patients gives nurses a vigilance advantage
	Trust-Another Kind Of Glue For Vigilance	• Vigilance and trust • Trust depends on relationship • Trust takes time and effort • Trust among HCP • Difficulties with trust • Vigilance and trust • Trust depends on relationship • Trust takes time and effort • Trust among HCP • Difficulties with trust
	Nurses And Hope	• Focus on positives • Realistically hopeful / balanced hope • Struggle to remain hopeful • Changing hope focus • Hope traitor

Theme Cluster 4.1. Connectedness-The Vigilance Glue

Nurses perceive that spending time with patients and families is something that allows the nurses to have a vigilance advantage. Nurses hold together a holistic, consistent picture of both patients and families. One nurse describes the importance of vigilantly holding patient care together this way: “I [nurse] would say for the role that I’m in…I don’t know if you want to call it the glue that holds things together…I think it’s important to have one person that is that point person, and is being vigilant…” 2.229C-2.230C.

One important reason nurses feel it is essential to connect with their patients is because knowing what is normal for the patient allows the nurse to more quickly pick up on what is not normal. “…If you [nurse] happen to be the one to admit a patient, you can sign up as that first primary, meaning that when you’re here, you have first dibs on taking care of patient…it’s good for you [nurse] because you get to know the [patient] better…which I think is very helpful because that’s when you pick up on things quicker”

1.89C, 1.91C-1.92C. Nurses perceive that getting to know patients allows them to be more vigilant than doctors who spend less time with the patients. “ I [nurse] don’t mean to say we know more than the doctors do ‘cause we don’t, but we know more about the patients than they do on a personal level…” 4.168C. In other words, the nurses are aware that their getting to know patients is an important and integral part of the healthcare provider team being able to be vigilant.

Nurses value being able to make close, personal connections with patients, but are aware that some things interfere with making connections such as, time off work and personality mismatches between the nurse and patient. Additionally, connectedness is confused with crossing boundaries. Nurses’ confusion about how to connect versus what are the limitations of connectedness began in nursing school: “In nursing school, they [nurse educators] always told you [student nurse]… to keep your distance from your patient” 2.233C.

Theme Cluster 4.2. Trust-Another Kind of Glue for Vigilance

Nurses indicate that trust is an important aspect of vigilance, particularly between patients and nurses. When patients trust nurses, they share information with them, which in turn allows the nurse to be more effectively vigilant and better equipped to meet patients’ needs. One nurse illustrates the difference between relationships based on trust compared to when there is no trust. “You [nurses would] ask him [patient] a question, and he’d be real short. ‘Yes. No.’ And I [nurse] had to sit in there [patient room] with him [patient] for ten hours, and for some reason, we clicked, and he trusted me. And from that point on, he opened up to nurses…[before] he wouldn’t ever tell us like if he needed something for a stool, or this hurt, or if he didn’t feel good, he would just keep it to himself. But when…he trusted me, he would tell…us things versus keeping it to himself. Trusted the nurses” 3.55C- 3.59C.

Developing trust with patients occurs over time and takes time and effort on the nurse's part. Nurses take developing trust seriously so patients will risk telling them anything, without fear of embarrassment or their feelings being minimized. "I [nurse] want them [patient] to feel like 'hey she's doing everything she can. She wants to know everything about me, and it's okay…she's not gonna make me feel like an idiot'" 6.249C.

Theme Cluster 4.3. Nurses and Hope

Nurses need to pay attention to hope, in all its different forms in order to specifically focus their vigilance. Nurses are mindful of keeping attitudes positive, being realistically hopeful, and being attentive to what one should be hopeful about. Nurses clearly shift hopes based on the realities of patients' life-threatening illnesses. A nurse indicates hope is not just based on remission or cure: "Miracles get worked all the time, and it's not people being saved, their lives necessarily, as it is they're getting their eyes opened, and learning to love" 4.177C.

Nurses are vigilant for positive attitudes because nurses believe it helps patients' have an improved sense of well-being. "It [positive attitude] makes a big difference 'cause when you [nurse] see someone [patient] who can be so depressed, so withdrawn, and flat in the face [compared] to someone who's laughing, they're eating more, they're enjoying people coming in there…" 6.207C.

Nurses are also aware that there is a time for a more serious perspective on what is realistically hopeful. Nurses have a difficult time changing the focus of hope and conveying that change to patients or family members. "I [nurse has] had to deal with family with some of the…disappointments…you're [nurse] trying to be the cheerleader for…I don't know if hope is a good word, but for a remission…and [there is a] feeling… [when treatment fails that] you given up on them [patient and family]" 2.73C-2.75C.

Theme Category 5. Threats-Things that Draw Nurses' Attention to the Mobile

Nurses are extremely watchful for things that could upset their vigilance balance. Much like someone who constructs a mobile is attentive to where they hang the mobile and what kinds of things could produce instability in its design; nurses perceive there are things that could be hazardous to the balance of nursing vigilance. This theme category has three theme clusters [see Table 36].

Table 37. Nurse Theme Category 5

Theme Category	Theme Cluster	Themes
Threats-Things That Draw Nurses' Attention To The Mobile	Nursing Vigilance Is Directly Proportional To Threats Identifying Threats	• Multiple threats increases vigilance • Higher risk in hospital • Early Hospitalization / beginning treatment increase threat • Threat of death increases vigilance • Knowing Common risks • Unfamiliar doctors • Really ill patients • No FM present • Chemotherapy • Immunocompromised • Nurse tries to balance vigilance and threat for FM and patient
	Dealing With Threats	• Abnormal anything requires a response to reduce threat • Different than normal is a reason to be vigilant
	Decreasing Threat Status	• Nurse tries to prepare patients to decrease vigilance • Nurses have trouble letting go of vigilance

Theme Cluster 5.1. Nursing Vigilance Is Directly Proportional to Threat

Nurses are watchful for anything that may constitute a threat. The more threatening something appears to be, the more vigilant nurses become. "…there are certain circumstances, or things that come up…like an error… it makes you [nurses] be a little bit more vigilant…if someone's [patient] more critical, it heightens your vigilance also" 2.13C-2.15C. When patients have multiple threats, nurses are particularly watchful for anything that maybe a potential threat. When a nurse was trying to relay a story about a patient she had been vigilant for, with multiple threatening conditions, quickly came to

mind: “He had lymphoma, and then he wound up with leukemia…some lung problems related to both of those. He’s been in remission, but he’s been back a couple times with complications with lung wise or sometimes infection. Several different, big problems” 1.129C-1.132C.

Theme Cluster 5.2. Identifying Threats

In order to be effectively vigilant, nurses must be knowledgeable about what kinds of things constitute a threat. Nurses indicate there are many things in day-to-day experiences that they view as threatening, or having the potential to be threatening. Especially in oncology, nurses are aware of the threatening nature of patients’ illnesses and treatment. “You have to be watchful, pretty much on all the time…our patients can become septic just like that. They’re neutropenic. They have no immune system” 5.167C-5.169C. Nurses perceive that early in the hospitalization, patients are at higher risk because they are overwhelmed and lack the knowledge to be effectively vigilant. “…it’s really unusual to find a patient that is really vigilant about themselves…especially when they first come in. They might get that way later on, but when they first come in, they’re so overwhelmed…” 7.92C-7.94C.

Oncology nurses need to be aware of the common risks their patient face such as bleeding, abnormal lab values, infection, and medical errors. In oncology, nurses are very watchful in regards to chemotherapy. Not only does chemotherapy have the potential to produce many side effects that nurses and patients need to be aware of, but if the delivery of chemotherapy goes awry, there can be devastating consequences. “They [administration] don’t want anybody…to give vesicant, and it to extravasate is like horrific…I [nurse] cannot even imagine what it would be, what it would be like to do that to somebody…it can just lead to amputations and stuff. So you [nurses] have to be like really careful” 7.70C-7.71C, 7.73C-7.74C.

Theme Cluster 5.3. Dealing with Threats

For nurses, vigilance is an action verb. When nurses recognize threats, they follow through by taking some kind of action. For example, if something abnormal is identified, nurses feel a need to respond or get a response from a doctor. The sooner the nurse can get a response, the less likely the threat will occur. A nurse provides an example of one such situation: “If somebody’s [patient’s] hemoglobin is six or seven, and their platelet count is two or three, maybe they [doctors] will get those orders written eventually throughout the day, but in those cases, the sooner you get something done about it, the better off they’re [patients] gonna be…those of us [nurses] that have been here longer will just look [at the doctor and say] ‘I don’t have time to mess around, I need these orders, so please write them’” 1.228C, 1.232C.

Another way nurses’ watch for threats is through patients. Nurses teach patients to notice things that are abnormal and to alert the nurse. “…like bleeding, whenever platelet counts go low on a patient, they know like to call out when they think something is wrong, or [ask] ‘can you [nurse] look at this?’” 5.200C.

Theme Cluster 5.4. Decreasing Threat Status

Nurses are aware that it is not normal or necessary for patients to be highly watchful all of the time, so nurses try and prepare patients who are going off treatment that the threats are less now and encourage patients to decrease their vigilance. However, decreasing vigilance from a high level to a more normal level is a process that tapers over time. “…we [nurses] shelter them [patients] for this month [they are in the hospital and] they continue those [precautions] at home until they [patients] get to a comfort level themselves of kind of loosening up on how strict they are” 2.135C.

Theme Category 6. What Interferes with Vigilance-Things that Upset the Balance of the Vigilance Mobile: End-of-Life, Healthcare Specific Interference, and Energy

Nurses indicate there are several issues that impede vigilance and interfere with nurses being able to be as vigilant as they would like. Like a strong and damaging wind that threatens to damage a perfectly balanced mobile, certain issues create precariousness in the balance of nursing vigilance. This theme category has three theme clusters [see Table 37].

Table 38. Nurse Theme Category 6

Theme Category	Theme Clusters	Themes
What Interferes With Vigilance-Things That Upset The Balance of The Vigilance Mobile: End of Life (EOL), Healthcare Specific Interference, and Energy	Nurses Are Vigilant For End of Life Issues	• When EOL is not addressed it interferes with vigilance balance • Many things to consider with EOL • Telling FM / dealing with FM and EOL issues • Orchestrating the end / Final wishes • Spiritual Vigilance • Things that make EOL difficult and interfere with EOL
	Healthcare Specific Interferences	• Issues with healthcare providers • Patients issues • Other issues that interfere with vigilance • The healthcare system
	Putting A Balanced Mobile Together Uses Energy	• Cost of Vigilance • Things that use energy • Ways to save the energy being expelled to be vigilant • Recognizing limitations • Normal is less vigilant • Cost of vigilance • Recognizing what one cannot be vigilant about / questioning vigilance

Theme Cluster 6.1 Nurses Are Vigilant for End-of-Life Issues

Nurses describe being particularly watchful for end-of-life issues related to patients. Nurses feel that patients have a right to know about the hoped for recovery as well as the possible reality of death. Nurses perceive that not informing patients about end

(EOL) of life choices is not being vigilant. “The fellow [who was on call for another doctor] had made a remark…that I [nurse] had no right to say anything to that family [about patient’s end of life status]. I felt like I did, and [if I] have it to do again, I would have done the same thing” 4.100C.

While nurses feel that patients and families have the right to be educated about end of life choices, nurses have other reasons that they believe EOL care must be discussed. If EOL is not addressed by the doctor, and the patient shows signs of becoming critically ill, nurses become anxious. For example, one nurse describes how a critically ill patient upsets the whole balance of vigilance for the unit and for the individual nurse. “…there was one instance where this patient…looked like [he was] gonna code on [his] way in the door. And family left, and they [doctors] didn’t discuss code status with this patient…he became unresponsive, he was gurgling…respirations like sixty, he’s an older guy and the doctor’s were like, we’re not taking him to the ICU. We’re not doing that. They [doctors] wanted us [nurses] basically to do one on one nursing, which we don’t have staffing for that” 5.85C-5.92C. Thus, nurses believe that when they have be one-on-one vigilant for critically ill patients, it interferes with their ability to be vigilant for the rest of the patients to whom they are assigned.

As much as there is at stake if code status and EOL issues are not discussed, nurses perceive that there are certain things that must be considered when addressing EOL. The emotions nurses have when dealing with EOL care adds to the complexities of addressing end of life issues. Nurses have to know themselves and their own, personal feelings about life and death in order to more effectively address EOL. “…I think it helps you [nurses to] reevaluate your own life, and how you feel about certain things. Obviously death, and how would I feel, even though maybe you [nurses] don’t have cancer” 2.235C-2.236C.

Regardless of anything else, nurses feel compelled to uphold and honor patient's final wishes. Nurses are vigilant for patients as they live and die. A nurse describes in vivid detail a patient whose final wish was to die in the hospital. Despite one doctor's vehement opposition to the patient's dying wish, the nurses felt compelled to fulfill the request. The nurse describes the kind of vigilant effort it took to honor the patient's final wish: "So we [nurses] went round and round [with the doctor], and I stayed vigilant with that [keeping the patient in the oncology unit]. I stayed right on top of it, and when I wasn't here, I made sure at least the nurse coming off of the next day was vigilant as well because this [final wish to die on the oncology unit, in the hospital] is what they [patient and family] deserved" 4.38C-4.39C.

Nurses indicate that several things interfere with addressing EOL issues with patients and families. Because nurses view discussing EOL as a primary responsibility of physicians, nurses get upset when physicians do not follow through with this responsibility. Nurses believe that there are two things that impede doctors' abilities to discuss EOL: [69] 1) Not having enough experience; and 2) Denying the reality that treatment has failed. Because there are no clear protocols, nurses feel conflicted in how to respond to EOL issues when they have not been discussed by the doctor. "…I [nurse] have no problem with that [discussing end of life] if I have to do that. I don't like to do that…sometimes I think we [nurses] all get a little resentful that we get put in that position, but we also understand as oncology nurses, it's our job" 4.102C.

Theme Cluster 6.2. Healthcare Specific Interferences

Unaddressed EOL discussions are not the only interferences with vigilance. Nurses indicate there are additional things that could interfere with their vigilance. Nurses perceive that healthcare providers, patients, and health care specific issues could interfere with vigilance.

Healthcare providers and vigilance interference. Nurses feel that unfamiliar healthcare providers, inexperienced healthcare providers, healthcare providers who do not do their job, and too many healthcare providers involved in care can interfere with vigilance. One prominent issue that nurses perceive as interfering with vigilance is the monthly physician switch that takes place on their unit. Nurses wonder how much the change in physicians on weekends or every month affects the patient-physician relationship. "…the physicians change every month, and…I perceive is difficult for [patients to] have the physician change. Because also on the weekends, they'll [patients] see different staff physicians also…a good question [for patients] would be 'do you trust the physician that covers [for the primary doctor]…like they trust the physician during the week?'" 2.208C, 2.213C, 2.215C-2.216C.

Nurses' work and vigilance interference. Nurses feel like there are also things that are directly related to the nurses' work that creates the potential for vigilance interference. Nurses perceive there is a greater likelihood of vigilance being disrupted when nurses have days off, not enough staffing, have disagreements with the healthcare team, and are unfamiliar with the patients or protocols. Nurses especially indicate that not being prepared, being disorganized or distracted, having a disrupted routine, and being in a hurry interferes with their ability to be vigilant. "And sometimes we [nurses] get in a hurry and we forget things" 7.10C.

Patients and vigilance interference. Nurses experience issues with patients that have the potential to interfere with vigilance. Nurses feel as if patients, who are heavily medicated, do not want to talk or contribute to their care, are critically ill, and have no support are potential pitfalls for the nurses' vigilance. Nurses also feel that vague or unclear symptoms interfere with their ability to balance vigilance, especially since their focus turns towards making sense of one patient's symptoms, which then distracts them from their other patients. Adding to the confusion is that patients' symptoms are not

always as they appear. One nurse describes a patient who became very ill and the cause of the downward turn was not obvious: “Whenever I [nurse] had done my original rounds, he [patient] was fine” 5.22C. At other times, patients can appear to have something critically wrong and it turns out to be minor. A nurse contrasts one such situation where symptoms indicated one thing and the reality was another. “Cause I [nurse] thought he [patient] pulled his chest tube. All I seen was blood all over his gown” 6.58C-6.59C. As the nurse investigated the situation, it became apparent that things were not as bad as they first appeared and the nurse relays this to the patient: “…there’s chemo on the floor…but I don’t care…your [patient] safety, knowing that you’re okay...you didn’t fall…you’re not on the floor not breathing. That’s what matters to me” 6.70C-6.71C.

Additional considerations and vigilance interference. Nurses feel there are other extraneous things that could interfere with their vigilance. In particular, the presence of strong, negative emotions and increases complexity, such as too much to pay attention to, could interfere with nurses’ vigilance. Strong negative emotions, whether they are the nurses’, patients’, or families’ have the potential to interfere with vigilance. A nurse describes the way in which intense sadness, and a breakdown into tears over a patient’s death affects her at work: “…and then I was okay because I knew I couldn’t go in the other rooms crying. I got myself together, and it was alright, but it caught me off guard. I wasn’t expecting it” 4.219C-4.220C. Strong, negative emotions from family members or patients also interfere with nurses being vigilant. A nurse describes her response to family members who the nurse is glad to see leave the hospital and hopes not to see again: “…the angry people. Mean. They are the ones you’re glad that their time is done. Cussing all the time. Like vulgar, rude. That’s when… [nurse says]… ‘okay they’re gonna have to do [for themselves]. If they need me, call’…” 3.145C-3.146C, 3.148C-3.149C.

Thus, when families exhibit strong, negative emotions, such as anger, nurses tend to go in the patient's room less often, which may lead to a decreased nursing vigilance.

Nurses feel that as complexity in direct patient care increases, it becomes more difficult to be effectively vigilant. Nurses are aware that there is a limit to how much one person can do: "… as soon as the patient isn't going very well the doctor will [tell the nurse], 'I want this lab, this lab, this lab. I want you [nurse] to bolus them [patient]. I want you to do an EKG. I want…" [the nurse responds] '…okay, you're just listed off like ten things you want me to do right now. It's really hard for one person to do that'" 5.117C-5.115C. Additionally, nurses describe being overwhelmed with family members. "We had like a whole waiting room of people [family members] camping. Like living in our waiting room. Kind of overwhelming when you have that much family, and like they take over the room. One [family member] doesn't know what has been done…and sometimes you have to repeat a lot what you said [already to other family members]" 7.195C-7.106, 7.198C-7.199C.

Healthcare systems and vigilance interference. There is a perception on the part of nurses that the healthcare system, at times, interferes with vigilance. When patients are critically ill, nurses feel unprepared to handle it. A nurse comments: "…that's not my area [critical care]…I [nurse] don't like it when they [patients] go bad. I'm just not like a code person" 3.97C-3.96C. When patients make a turn for the worse, nurses' request and expect that patients will be transferred to the intensive care unit. At times, it is difficult for everyone in the healthcare system to work with one another and focus on making the best decision for the patient. A nurse describes a situation where a medically complex patient stopped producing urine. "…when…the [specialty teams] teams came in…they started fighting over what to do" [about the patient's condition]. [Nurse intervened and said] "…Hey the patient can't be in two places at one time. We need to do this one thing

at a time here. We gotta get her off this floor…She [patient] ended up going to the PCU, but I don't know what happened to her" 6.170C-6.171C, 6.174C.

Theme Cluster 6.3 Energy-Putting a Balanced Mobile Together Uses Energy

Nurses indicate that being vigilant is a drain on energy, similar to putting all of one's energy into completing a project such as creating a perfectly balanced mobile. Vigilance is an expensive resource to expend, which leads to nurses to feeling exhausted. "So it [being highly vigilant] does come with a cost. It takes its toll on your health, and your mental status" 4.215C. Because vigilance is a drain on energy, nurses do many things to conserve and renew their energy. Nurses conserve energy by taking breaks, using humor, knowing the patient, and recognizing there are some things for which nurses cannot be vigilant. Nurses also renew themselves by changing the way they think about life. Taking care of cancer patients changes nurses negative thoughts to positive ones and reframes life. Nurses seem to get a renewed sense of energy from such thinking. "…you [nurses] find you gain as much from them [patients] as they gain from us…I gain strength. If they [patients] can make it through it, I [nurse] can surely go home, and clean my house…no big deal, but you think is a big deal. It's nothing in comparison [to what patients go through]" 3.66C-3.67C.

Theme Category 7. Knowledge and Experience Are Critical Pieces of Vigilance-Knowing How to Construct a Mobile that Works

To create a balanced mobile of vigilance, nurses perceive that patients, nurses, and families must be knowledgeable. Much like the amount of mathematical and artistic knowledge needed to create a beautiful and perfectly balanced mobile, nurses need to know many things, and they encourage patients and families to become knowledgeable as well. This theme category has six theme clusters [see Table 38].

Table 39. Nurse Theme Category 7

Theme Category	Theme Clusters	Themes
Knowledge And Experience Are Critical Pieces Of Vigilance-Knowing How To Construct A Mobile That Works	Knowledge / Experience Is Developed Over Time	• Previous experience with cancer informs vigilance • Personal experience with cancer informs knowledge
	Nurses Are Committed To Giving Patients / FM Knowledge	• Level of knowledge must be assessed • Information repeated often
	Early Hospitalization Is Characterized By Lack Of Knowledge For Family Member And Patient	• Chemotherapy
	Knowledge Must Be Current Or Updated	• Must have current knowledge about meds
	System Role In Education	• Knowledge of errors must be shared • Wonder if all system is like oncology
	Lack Of Knowledge Interferes With Vigilance	

Theme Cluster 7.1. Knowledge / Experience Is Developed Over Time

Knowledge does not occur instantly. Knowledge is accrued over time and through experience. A nurse contrasts her experience with that of less experienced residents or interns: "…making sure that the interns and residents who rotate through [and are] ultimately responsible for the orders…[nurse is] checking through that they've ordered the appropriate coag labs…not that I don't trust them, but I think having another set of eyes to check labs when they [labs] are critical, and it's a life and death situation, and knowing that I've [nurse] done it [this job] forever…it's just old hat for me" 2.18C-2.21C.

Theme Cluster. 7.2. Nurses Are Committed To Giving Patients / Family Members Knowledge

Nurses are especially committed to giving knowledge to patients and families because they perceive it allows them to be effectively vigilant. Nurses maintain an awareness of the effects of chemotherapy and complications of forgetfulness that it produces, leading to a commitment on the part of nurses to repetitively educate patients:

"You're [nurses] always reinforming, retelling them [patients] to get so much information…if they're on medicine, they don't remember it. So…going over everything helps. And then maybe if they [patients] think about what you [nurses] told them, then maybe they'll take up here **[**into their minds] and then make them feel better instead of sitting there suffering" 3.79C- 3.80C.

Theme Cluster 7.3. Early Hospitalization Is Characterized by Lack of Knowledge for Family Members and Patient

Nurses are especially watchful of patients early in their hospitalization because nurses believe patients and families do not know enough to be effectively watchful for themselves. "…it's [education] usually all at the beginning when they first come in, cause if they've never been neutropenic before…they've never had low counts, and we [nurses] discuss with them what they're not allowed to use…what certain toothbrushes…they can't shave with a regular razor anymore cause of the chance of nicking themselves…it's all part of the education at the beginning" 5.213C-5.216C.

Theme Cluster 7.4. Knowledge Must Be Current or Updated

An important aspect of nurses' knowledge that contributes to being effectively vigilant is to stay up-to-date on patient information. Particularly if nurses have a couple of days off work, they come back to work with a knowledge deficit about patients' current status. One of the first things nurses do is to update their knowledge of the patient since the time the nurse was off work. Nurses rely on hospital documentation, other nurses, family members, and patients to update them on current patient conditions. A nurse describes a situation where she had been on vacation and patient updated her on his condition and explained his symptoms to the nurse: "…the rest of the day I [nurse] got to know… his situation better…by the end of the day, I kind of knew too…but I was relying on him throughout the first several hours…to tell me [whether symptoms were better than they had been when nurse was off work or not]" 1.148C-1.150C.

Theme Cluster 7.5. System Role in Education

Nurses are aware that the healthcare system has a role in educating nurse, patients, and families. Although, this is a small theme cluster, it is worth mentioning that nurses are aware that policies are constructed to guide safe practice. Specifically, nurses mention policies for safe delivery of chemotherapy and policies for reporting errors in such a way that all healthcare providers on the unit become aware of potential errors. The stringent policies that are used to uniformly educate nurses are in place to protect patients, especially from chemotherapy errors. Nurses perceive that policies, such as ones for chemotherapy delivery, are the kind of policies that should be in place throughout the whole healthcare system: “I’m [nurse] sure that it should be all through the hospital, but I know for a fact on this floor, that’s the way it’s done” 7.80C.

Theme Cluster 7.6. Lack of Knowledge Interferes with Vigilance

Nurses perceive if knowledge is lacking, so is the ability to be vigilant in an effective way. Lack of knowledge effects nurses, as well as patients and families. Nurses rely on patients and family members being knowledgeable about patients’ disease and treatment, in order for nurses to be effectively vigilant. If patients are not knowledgeable about their own health and treatment, then nurses cannot respond in a vigilant way. When nurses lack vital information about patients, it is like looking at all the pieces of a mobile, lying unassembled and not having a clue of how to put it together. One nurses describes a situation where a patient did not know enough, so the nurse could not effectively intervene to help the patient, or prevent future complications: “…there’s been some [patients]…that it was sad that they didn’t know what antibiotics they took, and there was the one [patient] that came in with the rash. We [nurses] didn’t know if it was Vancomycin. She [patient] doesn’t know what she took” 6.275C-6.276C.

Theme Category 8. The Three Most Difficult and Important Pieces to Balance in the Vigilance Mobile-Patients, Family Members, and Healthcare Providers

When artists or scientists are creating mobiles, they must consider all the pieces that will be used to create a balanced mobile. For nurses, the three central pieces that are considered in creating a balanced mobile of nursing vigilance are patients, family members, and healthcare providers. This theme category has three theme clusters [see Table 39].

Table 40. Nurse Theme Category 8

Theme Category	Theme Clusters	Themes
The Three Most Difficult And Important Pieces To Balance In The Vigilance Mobile -Patients, Family Members, And Healthcare Providers	Nurses Family Members and Vigilance	• Nurses watch over Family Members • Nurses know Family Members know things that allow them to see what nurse may not (othersightedness)Nurses believe • Family Members positively effect patient outcomes • Nurses rely on family member vigilance • Nurses engage family members in vigilance • Negotiating the tensions and sometimes negative aspects of family member vigilance • Things that nurses perceive interfere with family member vigilance
	Nurses, Patients, and Vigilance	• Nurses want / rely on patients to pick up some of the vigilance for self • Nurse looks for clues that patient is being vigilant • Things nurses especially watch over for patients • Nurses have some difficulty in relation to patient / nurse vigilance
	Nurses, Healthcare Providers, and Vigilance	• The issue of nurses and doctors and vigilance • Nurse to nurse vigilance

Theme Cluster 8.1. Nurses, Family Members, and Vigilance

Nurses indicate awareness that family members are an integral part of the patient experience of cancer. “You [nurses] just can’t sit and act like they’re [family members] not there because they’re also part of the equation because this is that person’s family [the patient] that’s laying in bed…” 6.180C. Nurses are vigilant for family members

because of an awareness of what family members are going through, but also because in an indirect way, it helps nurses be more watchful for the patient. Vigilant nurses take family members concerns seriously because what they have to say may be a critical piece of information that helps the nurse be effectively watchful: "…I've [nurse] learned through experience, to always listen to what they [family members] say because if you don't, you might miss something" 1.197C. Nurses watch for clues that family members are being vigilant: "Some [family members] write down even the vital signs…when you [nurse] come in and out. Others aren't that bad. Some will just write down major things that happen, or tests they go to, or things like that. But…they'll [family members] watch over them [patients], and they'll want to know what the tests are for and things like that…" 7.101C-7.102C.

Nurses admire family member vigilance. Nurses admire families who demonstrate devotion and are vigilant for patients in the hospital. A nurse describes what she sees as devoted, vigilant family members: "She [daughter] sleeps on a cot next, her and her mother both sleep in a cot next to his [patient's] bed. She doesn't leave him at all except to go home and shower, and things like that" 4.257C-4.258C.

Vigilant family members can safely take care of the patient at home. In part, nurses identify vigilant family members so nurses know who will take care of the patient after discharge. Nurses are relieved when patients are discharged with a vigilant family member to watch over them. "We [nurses] sent him [patient] home with no [immune] defense, and fevers, and he is still alive. And his wife was very on it about asking questions. Why is this happening? Why is this doing this? And I thanked her for being so meticulous. I thanked her for being so on it" 6.213C-6.212C.

Vigilant family members reinforce nurses' own vigilance. Nurses rely on family members to be vigilant. Nurses use what family members observe to reinforce the nurse's own vigilance. When nurses rely on family members input, it can benefit

patients. A nurse tells of an experience with family members whose intense watchfulness and knowledge of the patient helped effectively treat his pain: "…his family and him [patient] both…were like 'okay this is not working. We tried this dose. Can we try a higher dose?'…them being on top of it, made a big difference because I can't sit and tell you the guys in pain. He didn't look like he was in pain. He wasn't cringing. He wasn't doing anything…thankfully his family and him being on top of it you know we finally got his pain under control" 6.296C, 6.298C-6.299C, 6.301C.

Nurses encourage family member vigilance. Nurses see family members' vigilance as important for both patients and nurses. Nurses purposely engage family members in activities that will help family members be vigilant. One way nurses do this is to educate family members: "I think…helping them [family members] be vigilant; a big part of that is education" 2.80C. Another way nurses engage family members in vigilance is to help define and direct family member vigilance: "Family members…want to do stuff, and if you [nurse] give them stuff to do, it kind of helps them cope a little bit better too I think. If you give them little assignments and things to do; Show them where the linen is, and show them where the ice machine is, and show them where the food is" 7.108C-7.109C.

Nurses are vigilant for family member emotions. Nurses also monitor family member emotions. At times, there can be negative interactions with family members, which as mentioned previously, nurses perceive as interfering with vigilance. Nurses focus on encouraging positive emotions in family members. Positive family members are perceived as having an effect on nurses and patients: "[Nurse] had a family [of a patient] who was just fun. They always played games. It just enlightens you [nurse] to see them…I think the patient…was pepped up, and they kept him going" 3.117C, 3.120C-3.121C.

Nurses, family members, and interference with vigilance. Despite all of the positive interactions nurses have with family members, there are some issues that create tension

between nurses and family members. At times, nurses feel that family members overstep their boundaries and interfere with the nurses' vigilance. Yet, it is really difficult for nurses to express negative perceptions of family members: "That was an interesting, interesting family, but I'm not here to judge…" 2.159C. When family members interfere with nurses' vigilance routines, nurses become frustrated. Nurses perceive that family members lack consideration of the nurse's role: "…sometimes the patient's family makes it like we're [nurses] supposed just drop everything, and come running to their family member when we have our hands full as it is" 5.190C. Nurses recognize that families are sometimes driven to hypervigilance, but nurses see this as ineffective and interfering at times: "…families sometimes are hyper vigilant [and they worry about the patient becoming]…neutropenic. [families then begin hypervigilant behaviors] 'We have to wipe off everything. We have to wipe off'…poor housekeepers, they'll come in and clean, and then the families clean behind them" 7.153C-7.157C. Occasionally, nurses feel uncomfortable with the ways in which family members choose to be vigilant. For example, one nurse mentions that some nurses are uncomfortable when family members write in a journal or question the nurse: "…a lot of people [nurses] get kind of intimidated when family members write stuff down…" 6.218C.

Nurses believe that there are several issues that interfere with family members' abilities to be vigilant. When family members lack knowledge and assertiveness, nurses feel family members cannot be as vigilant. Nurses also feel like family members who are negative and have too much to attend to are not as vigilant. Finally, when family members are not present or are sleeping, nurses feel like family cannot be as vigilant. One nurse comments that family members' vigilance seems reduced because there are not as many of them present at night: "Usually at the most, there's only one family member that would stay at nighttime and a lot of times, they're sleeping" 5.236C.

Theme Cluster 8.2. Nurses, Patients, and Vigilance

A primary experience nurses relate to vigilance and patients is that nurses want patients to be appropriately vigilant for themselves. Nurses rely on patients being watchful and conveying to nurses for any symptoms or concerns patients may have. "[Nurse encourages patients to call nurse if patient notices anything]…If they think there's anything wrong. If they see something… [nurse] would rather them [patients] be over careful than me walking in, and they've got their line laying out and blood everywhere" 5.205C-5.206C. Vigilant nurses know that patients are often the first to recognize something has gone awry and nurses rely on patients letting them know: [Nurses tells patient] "…but you might notice something I won't…you're [patient] gonna be the first person who's gonna know before I do, and I hope that you feel open enough to always tell me" 6.243C-6.244C.

When patients fail to take on some of the vigilance responsibility, nurses become somewhat exasperated. When patients show no interest in their own health and no ability to participate in vigilance with nurses, it seems unbelievable to the nurses: "She [patient] just didn't know. She didn't even know what meds she took. She didn't know anything, if that could be possible" 7.170C. The nurse continues commenting about this experience which reveals the underlying fear for nurses when patients do not participate in being vigilant for themselves: "She [patient] absolutely…totally was not [vigilant]. I told her what her meds were that I was giving her, but she just…wouldn't know. She didn't know if I was giving her something wrong, she wouldn't have known it cause she didn't, she completely did not [know]" 7.178C. Nurses also want patients to be watchful for themselves so that when patients are discharged, they can at least protect themselves at home. "I [nurse] like to make sure they [patients] know what to do when they get home" 3.17C.

Nurses watch over a multitude of concerns with patients. Nurses watch over patients' conditions, their nutrition, and treatments. But nurses perceive they particularly watch over patients' emotional states and their energy levels. Nurses feel as if certain emotional states put patients at risk for being less able to be vigilant. "I [nurse] would think that as a patient it would be difficult to be vigilant when you're going through a devastating diagnosis" 2.31C. Nurses indicate that they make sure patients understand that nurses are watching out with them, in order to preserve some of the patient's energy: "…we [nurses] try to take some of that [vigilance] for them [patients] and from them so there's not so much weight on their shoulders, and it seems to help. So that's what we do" 4.125C.

Theme Cluster 8.3. Nurses, Healthcare Providers, and Vigilance

Nurses experience vigilance for other healthcare providers. Nurses indicate they are watchful for both doctors and other nurses. However, there seems to be a tension between nurses and doctors in regards to vigilance. Nurses feel a need to be watchful and protect patients from doctors who do not seem to have patients' best interests in mind. Nurses indicate there are times when doctors ignore nurses' expertise and values and either do not give helpful orders or actively disagree and try to countermand what nurses feel is best for patients. A nurse describes a situation where a patient wanted to die on the unit. The doctor who was now covering the patient disagreed and wanted the patient off the unit to make room for other patients. "…everyday we [nurses] were faced with the confrontation [with the doctor who wanted to move the patient and they responded] 'no, we are not gonna move him. We are going to keep him here.' Then the doctor decided well, he [patient] needed to have Ritalin because he needed to be more aware of the dying process. The patient nor the family wanted him more aware of the dying process. He was quite aware as it was…again I had to bring that up to the doctor, and we had to discuss it, and once again he [doctor] didn't agree" 4.25C-4.28C.

Nurses trying to get vigilant responses from doctors. Nurses occasionally feel uncertain about how to balance critical situations where orders from doctors are needed. Nurses struggle with finding the best approach to get a helpful response from doctors. Being organized in trying to give doctors information so they could get helpful responses is another way nurses try to get helpful responses from doctors. Nurses seem to couch important requests in subtle ways. “[Nurses] try to be respectful in a way because of course, they’re doctors, and you [nurse] try to put into as nicely as possible” 5.80C. Nurses describe being vigilant for things that the doctors themselves should be vigilant for, such as lab work, the ways in which doctors interact with patients and families, and for end of life discussions.

At times, nurses have to become assertive to get patients’ needs met. Nurses feel a great need to be assertive with doctors who are inexperienced or not familiar with the patients. Nurses feel confident that they are more knowledgeable about patients than doctors and believe they are better judges of patients’ needs based on their familiarity with patients. “[The nurse] knows them [patients]…a doctor could come in and say oh they’re not that way. [The nurses want to say to the doctor] ‘How long did you spend with them, thirty seconds? You [doctor] can’t make that judgment if I’ve [nurse] spent twelve hours with them [patients], and I’m telling you something’s wrong, and you saw him, and asked him one question. So sometimes it takes being assertive and just really pushing” 3.49C-3.51C.

Nurses and doctors sharing vigilance. When doctors and nurses work together and have a mutual respect for one another’s expertise, it seems that they can share in being vigilant for patients. Nurses can go to doctors for support and communicate freely in order to be effectively vigilant as a team. “…I feel like the team doesn’t feel like I’m overstepping their bounds [by double checking that orders are written by doctors] because I think they’re aware of the importance of that” 2.22C-2.23C.

Nurses are watchful for each other. Nurses also experience vigilance with and for other nurses. Nurses are watchful for each other and each others' patients, as well as watchful for inexperienced nurses. Nurses know they cannot be watchful for everything, all the time, particularly if they have to be in one patient's room for an extended period of time. A nurse describes such a circumstance and how the other nurses on the unit were vigilant for the nurse's assigned patient. "He [patient] just walked…around the room, and left the blood trail. So if it wasn't for my floor [other nurses] stepping in, it could've been a lot worse than it was. So in that state, I'd say we're [nurses are] all vigilant for each other, for our patients. God bless. I work with the most wonderful nurses on Earth" 6.76C-6.77C.

Nurses indicate awareness that new nurses or nurses new to the unit cannot be as vigilant as nurses who are experienced. Oftentimes nurses are taken by surprise by the lack of knowledge new nurses have, rendering them virtually unable to be vigilant. A nurse tells of an experience where a new nurse asked for help in picking out suction supplies for a patient who needed suctioned. When the suction did not seem to be working the new nurse asked the experienced nurse to look at it. "So I walked in there, and I'm like 'oh my gosh, he needs way more than this.' I mean the patient was in so bad of pulmonary edema. I have never seen a patient this much in pulmonary edema" 5.43C-5.44C. Situations such as these lead experienced, vigilant nurses to carefully question and follow through with new nurses. A nurse describes one such interaction with an orientee who was new to the unit. "And she [orientee] changed the bandage, and I [experienced nurse] asked her…she'd been doing them, so she could do it by herself. But asked her how it looked, and she said 'well it was a little bit red around the outside.' And so I said 'well, let's go look at it'" 1.53C-1.55C.

Theme Category 9. Vigilance Outcomes–

What Happens When One Creates and Watches the Mobile

After an artist creates a beautiful mobile certain outcomes may occur, such as being admired by others, putting the model on public display, or the artist becoming famous. Much like these outcomes, nurses perceive there are certain outcomes that occur when nurses are vigilant. This theme category has two theme clusters [see Table 40].

Table 41. Nurse Theme Category 9

Theme Category	Theme Clusters	Themes
Vigilance Outcomes-What Happens When One Creates And Watches The Mobile	Vigilance Leads To Patient And Family Member Safety / Decreasing Risks / Decreases Negative Outcomes	• Patient feels safe • Helps patients have better QOL • Helps FM heal
	Nurses Feel Are Appreciated And Benefit From Using Vigilance	• Vigilant nurses are recommended to others • Satisfaction from being a sentry • Life perspective

Theme Cluster 9.1. Vigilance Leads to Patient and Family Member Safety / Decreasing Risks / Decreases Negative Outcomes

Nurses are watchful in many ways to try and prevent negative outcomes. Nurses perceive that when they are vigilant, negative patient outcomes can be prevented. “It’s [vigilance] just wanting to try to pick up on any little problems…that could turn into a problem…and trying to avoid that” 1.04C-1.06C.

Nurses perceive that being vigilant has a positive influence on patients’ quality of life because it helps the family heal and allows patients to feel safe, protected, and not alone. A nurse describes an awareness of patients’ situation in the hospital and the nurse’s need to be vigilant: “… I [nurse] think it’s important for those patients to know that there is someone there…I just feel like I want to be there, and need to be there for them…I can’t imagine going through this, being in the hospital thirty days…in isolation” 2.103C-2.106C.

Theme Cluster 9.2. Nurses Feel Appreciated and Benefit from Using Vigilance

Nurses experience positive outcomes from being vigilant. Nurses feel surprised, but proud when their vigilance is recognized by patients, especially when patients recommend the nurse to other people outside the hospital. Nurses indicate that sometimes patients or family members give them gifts in recognition of their contribution. While nurses do not expect or encourage this, it nevertheless helps nurses feel as if all their energy and effort to be vigilant is worth it. A nurse describes one such experience: "…I [nurse] get burned out up here sometimes, and then things like that happen [patient and family giving nurse small gift], and it's like 'okay I caught my breath. I'm okay'" 4.203C.

Nurses also report other benefits from being vigilant. Nurses change their life perspectives and focus on the gratitude they gain from watching patients conquer their struggles. Nurses indicate they get satisfaction out of being vigilant. A nurse describes a situation where a doctor was trying to transfer a patient who wished to die on the unit, out of the unit. "…we [nurses] had problems the whole time [with doctor trying to move patient off unit], but he [doctor] didn't prevail. The man [patient] passed away where he wanted to be, and we [nurses] granted his wishes" 4.44C-4.45C.

Theme Category 10. Hints of Shared Vigilance–

The Dream of the Perfectly Balanced Mobile

Nurses indicate there are instances where vigilance is shared among themselves, other healthcare providers, patients, and family members. Like hoping or dreaming of making a perfectly balanced mobile, nurses indicate that vigilance can be used more effectively when everyone participates. At times, it seems clear that the healthcare team is working together to be vigilant: "…it's [vigilance for patients] intertwined…there's also other people on the team be it pharmacy, and social work, and dietician that round too

that….are vigilant" 2.223C-2.224C. This theme category has two theme clusters [see Table 41].

Table 42. Nurse Theme Category 10

Theme Category	Theme Clusters	Themes
Hints Of Shared Vigilance-The Dream Of The Perfectly Balanced Mobile.	Nurses See Sharing Vigilance As Necessary	• Nurses watching each others patients • Nurses depend on patients / FM participating
	Things That Interfere With Shared Vigilance	

Theme Cluster 10.1. Nurses See Sharing Vigilance as Necessary

Nurses indicate that they encourage patients and families to be actively vigilant. Nurses help guide and direct families in being assertive about items of concern and how to engage the doctor with these concerns. Nurses also let family members know that the nurses are engaged in vigilance along with them. "We [nurses] encourage them [family members] to be vigilant for [patients]… not to be afraid to speak up… Don't be afraid to do that, and I'm [nurse] gonna be right there behind you [family member] to remind them [doctors] as well. I [nurse] remind the 'families…these doctors work for you, you don't work for them'…sometimes they needed to be reminded of that" 4.244C-4.247C.

Nurses indicate regularly sharing vigilance for one another's patients. When one patient becomes really ill, there is little choice except for all nurses to watch out for each other and each other's patients. A nurse relays an experience where a really ill patient had test ordered that required the nurse to leave the unit with the patient. "…I'm…going have to leave the floor with this patient to take them down to the basement, and they could be down there for twenty minutes or so. That's twenty minutes where I'm not even on the floor to be with my patients. I mean you [all nurses on the unit] have to have help [watch out for each others patients]" 5.163C-5.165C.

Vigilant nurses seem to have awareness that the ability to be effectively vigilant improves when everyone upholds their own responsibility to be vigilant for themselves. A

nurse indicates to patients and family members that vigilance is not just about the nurse being watchful: “[Do] not [rely on] us [nurses] to be watchful, be watchful for yourself ‘cause there might be something we [nurses] don’t notice” 6.240C.

Theme Cluster 10.2. Things that Interfere with Shared Vigilance

When vigilance is not shared among nurses, patients, and family members, nurses feel less able to be effectively watchful. They also feel particularly frustrated if patients seem to have no interest in being watchful or if they are working against the nurse being watchful. A nurse tells of an experience with a patient who was purposely increasing IV fluids to extremely high delivery rates, thinking it would deliver pain meds faster: “[Nurse said to the patient]…’I want to make sure you’re safe. I don’t want to see something to happen to you…I care a lot about what happens to you…there’s no way in this world I’m gonna let anything happen to you on my watch.’ I talked to the doctors about it, and I talked to other nurses about it…found out that she [patient] is chronically doing this, and it took a couple times before they finally took her whole fluids and everything away, and put her on when you ask for it, we’ll give it to you” 6.147C-6.150C. The nurse reflects on the effects this kind of non-vigilant patient behavior has on nurses. “…that [patient turning up IV fluids] scared me ‘cause I was like what if she just fluid overloads herself? I’d have that on my conscious that she died, or she coded because of what happened’” 6.151C-6.152C.

Essential Structure of Nursing Vigilance

In the nurses’ findings ten theme categories were identified. From the narrative description of nurses’ experiences an essential structure of vigilance experiences of oncology nurses was derived. Husserl proposed that essential structures of phenomenon could be derived through the rigorous process of empirical phenomenology. Adherence to bracketing, or setting aside one’s scientific presuppositions allowed researchers to identify “those features that must be present in

any and all possible instances of the phenomenon" [134] (p. 168). The essential structure is believed to represent an ultimate truth related to the way the phenomenon appears [135].

Nursing vigilance is like a balanced and esthetically pleasing mobile. The experience of vigilance is elusive for nurses because it was a routine part of their job. Nursing vigilance is experienced through the practice of certain behaviors nurses participated in such as, advocacy and protection of patients, communication with patients, families, and healthcare providers, thinking like a nurse, noticing small things, performing specific routines, and monitoring for patient responses or results.

Identifying threats is an essential aspect of nursing vigilance. Nurses' vigilance is proportional to threats nurses identify; the higher the threat, the higher the vigilance. Identifying threats allows nurses to respond in a vigilant way.

Nurse vigilance is promoted by specializing in oncology, caring for hospitalized patients, positive attitudes, and healthcare provider behaviors such as organization. Nurse vigilance is impeded by unaddressed end of life discussions with patients and families, fatigue and, healthcare specific interferences, such as inexperienced or unfamiliar healthcare providers.

Knowledge, which is developed over time, is a critical element for nurse vigilance. Nurses themselves need knowledge and they are adamant that patients and families cannot be as vigilant without specific knowledge, thus patient and family education is important. Nurses experience interference with their ability to be vigilant when healthcare providers, patients, or families lack knowledge.

Nurses use three strategies to strengthen their abilities to be vigilant; connectedness, trust, and hope. Nurses must know and connect with patients and families in order to be highly vigilant. Nurses must also develop trust relationships with patients and families so they will freely interact with the nurse and give the nurse important information that the nurse uses to be more vigilant. Nurses also maintain hope

and are vigilant for what hope should be focused on, in order to better guide patients and families.

Nurses spend most of their time balancing vigilance among three priority groups: patients, families, and healthcare providers. Difficulties in any one of the groups may interfere with vigilance within that group or for another group. Nurses rely on patients, family, and other nurses to share in some of the vigilance burden, which allows nurses to maintain an overall balance of vigilance for these three priority groups.

Outcomes of nursing vigilance include patient and family member safety, through decreased risks and negative outcomes. When nursing vigilance is recognized by others, nurses feel appreciated, which reinforces the continued use of vigilance.

Summary of Nurses' Results

Nurses' findings indicated that vigilance for oncology nurses is a complex, multiperspective, and multidimensional process. Although only two broad, data-generating questions were asked of nurses, multiple perspectives on vigilance experiences were found. Nurses presented experiences of being vigilant for healthcare providers, being vigilant for patients, being vigilant for family members, and nurses had perspectives of shared vigilance.

These multiple perspectives provide a level of complexity in the findings that was unexpected. This level of complexity prohibits a full discussion of findings in Chapter V. Therefore, a decision was made to identify key findings from the family member narrative, which will be used to guide the family member discussion section. Fifteen key findings were chosen because they expanded on existing vigilance research and seemed to be the most compelling and / or unexpected findings relevant to clinical practice. For key findings identified from the nurses' narrative please see Table 42.

Table 43. Nurses' Key Findings for Discussion

Nurse Perspective	Key Finding	Corresponding Theme Category
Nursing vigilance	Although vigilance is recommended as the solution to many clinical issues and lack of vigilance is a common category on error reporting forms, nurses struggled to understand and describe vigilance, despite their knowledge that it was a daily part of their practice.	1
	Nurses identified specific issues which were viewed as interfering with their abilities to be vigilant.	6
	When patients are not watchful or knowledgeable about their care, nurses' ability to be vigilant for that patient is impaired.	8
	Vague patient symptoms impeded nurses' abilities to be effectively vigilant.	6
	When doctors are inexperienced or unfamiliar with patients, nurses perceive a threat for vigilance interference, and therefore heighten their vigilance for these particular physicians.	8
	When physicians do not discuss end-of-life issues with patients and families, there is a dramatic potential for nurses' balance of vigilance to be disrupted.	6
	When patients become critically ill oncology nurses do not feel they are adequately prepared to safely care for them and a critically ill patient detracts from the nurses' vigilance for all other assigned patients.	6
	Nurses develop routines in order to be more effectively vigilant.	2
	In order for patients to appraise the nurses as vigilant, nurses perceived they need to be present in patients' rooms.	2
	In order to enhance their ability to be vigilant, nurses intentionally develop connectedness with patients.	4
Nursing vigilance and family members	Vigilant nurses rely on and encourage family member vigilance.	8
Nursing vigilance for patients	Nurses are particularly watchful over patients' emotions and energy levels.	8
Nursing vigilance for other healthcare providers	Nurses approach doctors in different ways to try and get vigilant responses from the doctors.	8
	Nurses are especially vigilant for inexperienced or novice nurses.	8
Nurses' perspectives on shared vigilance	Nurses rely on patients and family members to share vigilance in order to enhance nurses' abilities to be effectively vigilant.	10

Results: Specific Aim 2

Specific Aim 2 was to evaluate commonalities in the lived experience of vigilance as described by patients receiving treatment for cancer, one of their family members, and a nurse caring for them. A matrix was designed in order to identify common themes across groups. Matrices are used to compare results in qualitative research. Matrices may be used a variety of ways, and how they are used is based on the goals of the researcher

[126, 136]. The matrix design used for the analysis and comparison of common findings across groups was modeled after one designed by Stiffler, Haase, Hosei, and Barada [137] for comparing experiences of parenting between mothers with breast cancer and their adolescent daughters.

The ten most compelling commonalities experienced across groups were chosen for inclusion in the matrices. Quotes from each group were provided for each identified commonality to offer support and evidence that specific commonalities existed across groups. Commonalities that were identified may provide the basis for a beginning model of shared vigilance. The first five commonalities were chosen to guide discussion of clinical and research implications. These five commonalities, shared vigilance, vigilance as a beyond the call of duty performance, knowledge as critical, connectedness, and hope were most compelling and offer groundbreaking evidence for vigilance as a complex and interactive phenomenon. Commonalities are presented in Table 43.

Table 44. Matrix Analysis of Across Group Vigilance Commonalities

Common Themes Across Groups	Patient	Family Member	Nurse
Shared Vigilance	"… it's also very important that you take control in that aspect because the doctors and nurses can only do so much for you…you've gotta meet them halfway."	So I asked…this nurse I said…he's [patient] really got a lot of anxiety about this first bag of chemo that he's gonna be experiencing... do you think you can kind of sit and talk to him and just put his mind at ease a little bit…"	"…thankfully his family and him being on top of it we finally got his pain under control…And I was appreciative towards them for being so on top of it…it made all the difference."
Vigilance is Beyond the Call of Duty-More than the Minimum.	"It just seems like they [vigilant nurses] do that little extra. They always do something a little extra."	"I felt like she [nurse] was coming in and checking on him [patient] more than necessary, and she was asking me you know you know if I needed anything…"	"Monitor, do your [nursing] assessments not just twice a day, but all the time, every time you go in. You're always observing, they're [patients] always under your care, not just when it's ordered."
Knowledge is Imperative	"…because your knowledge affects your vigilance."	"…we just like to know. Kind of feel the more we know, the better prepared we can be…"	"…one of the things I feel is my responsibility is to teach them things are a lot less scary if you have some education with it…"
Connectedness is a Signal of Vigilance	"[nurses] come in, and they'll talk to me and…share their family…How many children they have, and where they live…they don't hesitate about sharing anything with you."	"…I felt like she [nurse] did extra things to be extra vigilant with him [patient] because I felt that there was just a connection there in terms of the experience that she could put herself in my shoes."	"We have a primary care system with the nurses, where … you sign up for patients…and it's good for you [nurse] because you get to know them [patients] better, which I think is very helpful because that's when you pick up on things quicker."
Hope and Vigilance	"I believe in the treatment I'm doing, and I'm hopeful that it will give me success."	" it [cancer] happens, but you have to, kind of pick yourself up and just kind of get above it and just try to stay strong…"	"…you're trying to be the cheerleader for, I don't know if hope is a good word, but for a remission for this lady."
Becoming Vigilant Happens When You Get Cancer	"But I just think that you become more alert."	"…what sets you off in some way will effect how vigilant you are."	"…when you're, when you're diagnosed with cancer that's your life, and that kind of almost forces people to be vigilant to some extent."
Identifying Threats	"I said something about that patient [with VRE] last night. Nobody else said nothing about that, so I did."	"Because sometimes when he [patient] gets up, he's kind of wobbly or dizzy so I make sure and tell him you know you sit up on the edge of the bed first you know and let yourself catch your, you know get your gears or whatever before you get up."	"[chemotherapy] gives them possible side effects, if I'm gonna be the first person to hang their chemo, I generally will just kind of discuss with them the most common things to kind of look for."
Things that Interfere with vigilance: Hypervigilance	"As an individual, you can over analyze this thing. You can go from vigilance to over analyzing this very easy."	"You can drive yourself crazy with things."	"It's kind of a bad thing maybe, but I want to know everything that goes on around me. I'm always paying attention to every call light."

Things that Interfere with Vigilance: Strong, negative Emotions	"…A shock that I couldn't quite get my head around. So that made it hard for me….it's still stressful for me…"	"...sometimes fear and stress inhibits our ability to assimilate information and also be able to hear what's being said, and comprehend what was said…So I kind of, that's kind of a lapse…"	"…I finally had to get in between the two of them, and say 'listen you guys, you've gotta stop this.' …they were both so scared, they were lashing out at each other."
Trust as a Companion to Vigilance	"And you must make a determination of the competency of that core [of healthcare providers] as a whole. And once you feel comfortable with that, then you give up a little of yourself and place it in their hands."	"… at least to reassure the patient that if they don't have a loved one who could be vigilant for them, at least there is a certain level of vigilance that the hospital and the medical community would provide to help get them through these difficult times."	"I care about everything they want to talk about. No matter if it's something at home, or if it's something there. That way they feel more comfortable. They feel more safe, and they feel a sense of security."

CHAPTER V

Discussion

Patient Discussion

Findings from research on patient perspectives confirmed previous qualitative research in which vigilance emerged as a complex phenomenon, rather than a performance of a task. The participants provided full, rich descriptions of their experiences with vigilance. Patient data was complicated and patients presented multiple perspectives of vigilance. Patients experienced being vigilant for themselves, having family be vigilant with them, and having healthcare providers be vigilant for them as a complex phenomenon. Because of the complex nature of the experiences, a decision was made to forgo a full discussion of all findings, which would have been prohibitive. Instead, key findings, as described in Chapter IV, were chosen to guide each participant discussion section.

Discussion of findings is organized by key findings which are grouped into four sections. First, patients' experiences with being vigilant for themselves are presented. Second, patients' experiences with healthcare providers being vigilant are discussed. Third, patients' experiences with family members being vigilant are examined. Finally, patients' perspectives of vigilance as a reciprocally shared phenomenon are explored, with a particular focus on the relation of trust and hope to shared vigilance.

Patient Experiences of Being Vigilant for Self

The key findings regarding patients' being vigilant for themselves included: 1) the complexity and difficulty of describing experiences of being vigilant for themselves; 2) things that interfered with vigilance; and 3) knowledge as a critical attribute of vigilance.

The Complexity of Vigilance: The Experiences for Patients

Key Finding: Cancer patients struggled to understand vigilance in order to use it effectively (from Theme Category 1).

It was not surprising that patients with cancer experienced many complexities in their disease and treatment that required vigilance. Additionally, it was not surprising that cancer patients were aware of the complexities associated with cancer, particularly in light of ambiguous or undetectable symptoms. Such complexities contributed to patients struggling to articulate the meaningfulness of vigilance. Patients' experiences indicated they struggled to understand and delimit what vigilance was. They arrived by default at an understanding of what vigilance was, by first experiencing what vigilance was not. The degree to which participants explained vigilance by saying what vigilance was *not* was unanticipated. This difficulty, of articulating vigilance, was not found in the literature.

The ways patients described what vigilance was not, and the difficulty that patients had in describing what vigilance was, or how they went about being vigilant, indicated that vigilance was not an innate skill, but one that was developed incrementally, over time. Haase [122] noted similar findings in research about courage in adolescents with chronic illness. Courage was not found to be innate, but rather described by participants as a developed awareness over time and through many, small courage experiences that leant form and shape to the larger picture of courage.

Patients placed a level of importance on understanding vigilance. If patients used strategies that were not actually vigilance, but some masquerading imposter of vigilance, such as hypervigilance, micromanagement, or chaotic activity, they did not achieve desired outcomes. For example, in this study patients believed hypervigilance was unlikely to lead them to clear identification of threats to their health, but was more likely to exhaust them to the point that they could not be vigilant at all. In addition, patients perceived hypervigilance to be an excess watchfulness, a condition that was undiscerning, and led to wasted energy. Literature similarly described hypervigilance as related to anxiety-based disorders, such as post-traumatic stress syndrome [138, 139]. Hypervigilance was also associated with hyperarousal, irritability, and an overattention

focused on internal and external stimuli [138]. Additionally, the literature indicated an outcome of hypervigilance may be withdrawal from others, including family and healthcare providers [140].

Cancer Complexities Necessitate Vigilance to be More than Stimulus-Response

Key Finding: The disease and treatment of cancer produced stimuli that were difficult or nearly impossible to detect. Cancer patients needed help in identifying and interpreting ambiguous symptoms (from Theme Category 7).

From the perspective of cancer patients, vigilance was more complex than the literature descriptions of vigilance as task performance, or even the literature on vigilance with other diagnoses, such as Meyer's [18] study of vigilance in patients with migraine headaches. In the literature, task performance studies on vigilance were carried out in simulated or laboratory environments, and thus have not picked up on the complexities of vigilance as experienced in real healthcare environments [23, 24, 28]. So researchers could easily keep track of how and when stimuli were missed in task performance vigilance studies, the stimuli were deliberately unambiguous. In the only healthcare task performance study, conducted under a controlled, simulated anesthesia / surgery environment, the complex realities of vigilance as experienced by cancer patients were not reflected. What made vigilance for cancer patients so complex and more difficult was the variability and unpredictability about what one needed to watch. Compared to findings from task performance studies, vigilance for symptoms provides a good, illustrative example of the greater difficulty and complexity cancer patients' experience.

To be vigilant for symptoms, patients found clear and measurable results to be most helpful. For example, blood tests were helpful as indicators of the potential for bruising, bleeding, or infection. When symptoms were barely perceptible or ambiguous, findings indicated patients needed to remain vigilant for any and all symptoms. The meanings of

things such as bruises or fevers could not be interpreted by patients alone and help was needed to discern meanings of symptoms within the overall picture of the cancer and treatments. Patients also needed help to distinguish how and when the symptoms experienced at diagnosis and during treatment were different than symptoms that may have indicated relapse. In relapse, symptoms were often so vague that being watchful for them was not helpful; instead, vigilance focused on early detection, such as keeping regular appointments for blood draws and checks with the hematologist, was more effective.

Complexity of Cancer and Preventive Lifestyles

Key Finding: Patients were frustrated and felt to blame when vigilance for preventive lifestyles failed and patients were diagnosed with cancer. Patients were often vigilant for things that might not be preventable (from Theme Category 7).

Preventive vigilance had both positive and negative consequences for patients. A dilemma arose for patients when, what they had been vigilant to try and prevent occurred anyway. Patients were frustrated when preventive efforts failed. Despite preventive vigilance efforts, such as balanced lifestyles, eating nutritiously, and exercising regularly, patients found themselves in not just poor health, but life-threatening cancer. Findings from this dissertation study are supported by findings from another study by Quinn [141] that indicated cancer patients tended to blame themselves when their efforts to be preventively vigilant for their health failed.

Additionally, when patients went into remission, a preventive kind of vigilance such as early detection of relapse was sometimes challenging, because the patient's greatest desire was to return to life as normal, and being normal meant being less vigilant. Once in remission, patients confirmed they were often less vigilant and resumed previously 'normal' behaviors, such as smoking or excessive drinking. Thus, vigilance from a prevention perspective seems especially complex.

The literature included few discussions of the downside to primary or secondary prevention [142]; no articles were found that included patients' perspectives when their efforts for primary or secondary prevention failed to protect them from cancer or other diseases. Prevention theories do not address paths to take should strategies fail and patients end up with a catastrophic illness.

Patients Experience Emotional and Physical Detractors from the Ability to be Vigilant

Patients perceived there were many things that interfered with or detracted from their ability to be vigilant. In particular patient findings indicated that emotional detractors such as strong, negative emotions, and physical detractors, such as fatigue detracted from patients' abilities to be vigilant. Each is further discussed.

Emotional detractors. Once patients defined what vigilance meant to them, they were able to identify detractors from their ability to be vigilant.

Key Finding: Strong, negative emotions were identified by patients as something that interferes with theirs' and other's abilities to be vigilant (from Theme Category7).

Being able to identify detractors was not new and was similar to findings from task performance vigilance studies [23, 24, 28] whereby researchers identified what interfered with vigilance. As a reminder, the list of detractors found in the vigilance as task performance literature included long tasks, boredom, increased number of false alarms, isolated work environment, no evaluation of efficiency, difficult tasks, and long response times.

In contrast to the task performance detractors found in the literature and supported by findings in this dissertation study, the emotional detractors from vigilance identified by patients were not found in any previous research on vigilance. This was a key finding in that patients indicated that feeling any kind of strong, negative emotions, such as anxiety, fear, or anger, interfered greatly with their abilities to be vigilant.

The picture of detractors identified in task performance studies is incomplete. It seems reasonable to suspect that being emotionally distressed while monitoring things,

like radar screens, would interfere with being vigilant, but the consideration of the impact of emotional factors was surprisingly absent from the task performance studies. Such detractors might be missed because studies of vigilance as task performance were done under controlled, laboratory conditions.

Physical detractors. Emotional detractors were only one type of detractor from vigilance that patients experienced.

Key Finding: Vigilance was a paradoxical concept in regards to fatigue; while being vigilant used energy and tired patients, vigilance also saved patients' energy (from Theme Category 7).

Patients also felt there were physical detractors from vigilance. In all the vigilance studies found, even those not specifically focused on task performance [18, 23, 24, 27, 28, 30], it was assumed that one must be physically able to respond to stimuli and that being tired interfered with the ability to be vigilant. The longer one was on task being vigilant, the more tired and the less able to be vigilant one became. In this dissertation study, cancer patients had little choice regarding the time they spent on task in relation to being vigilant for themselves. Essentially, there was little ability for cancer patients to safely take time off from being vigilant for themselves. Thus, they were more likely to become overly tired and less able to identify threats.

In this dissertation study, of the physical detractors patients identified, fatigue emerged as the most interesting physical detractor in relation to vigilance. Cancer patients' fatigue was found to be an important physical detractor from their ability to remain vigilant, and being vigilant used additionally energy. Despite the influence of fatigue on the ability to remain vigilant and the drain being vigilant contributes to fatigue, this key link has received minimal attention in the cancer-related fatigue literature. Instead, the majority of studies on management of fatigue symptoms included taking naps, resting, pacing oneself, eating properly, and of recent interest, use of exercise to

combat fatigue [143-146]. Yet, the literature on these fatigue management strategies did not consider how certain strategies such as taking naps and resting may interfere with patients' desires and abilities to be vigilant.

A link between fatigue and vigilance was found in the literature. Along with fatigue, a common symptom mentioned in the literature, was treatment-related cognitive effects. Although many researchers focused on cognitive effects of cancer treatment, very limited studies examined the cognitive effect of fatigue, as related to attention. Attention is another word often used interchangeably for vigilance [68, 69, 71, 72, 75, 76]. Cimprich was the primary researcher in studies related to attentional fatigue [147-150]. Cimprich described attentional fatigue as interfering with the ability to "focus and concentrate" (p. 285) and contributed to distractibility. Cimprich found that fatigue interfered with breast cancer patients' abilities to learn and be able to understand their disease and treatment, thus interfering with their abilities to make treatment decisions. Cimprich proposed interventions to improve attentional abilities of breast cancer patients [147, 150].

In this dissertation study, the issue of energy used for being vigilant was paradoxical. Similar to Cimprich's study, findings indicated that fatigue interfered with patients' abilities to remain vigilant or attentive; yet, patients also described being vigilant as a way to conserve energy. When patients were vigilant, attention was limited or focused on the essential things one needed to watch for, and patients were then able to expend their energy on priority concerns. Although patient concerns about fatigue would seem to set up a potential conflict with the need to remain vigilant, the patient findings surprisingly did not indicate such a conflict. Patients described many ways in which they renewed themselves in order to maintain the energy needed to remain vigilant. Patients used humor and breaks to maintain energy, which were similar to other research findings about managing fatigue, but perhaps more importantly patients described relying on the vigilance of others, such as family members and healthcare providers,

thus reducing the need for patients to feel wholly vigilant for self. Letting others share some of the vigilance allowed patients to reduce the energy output that being vigilant required.

The Critical Aspect of Patient Knowledge and Its Role in Vigilance

Key Finding: Knowledge was necessary in order for patients to be effectively vigilant. Patients were educated through many sources and gained knowledge through experience. Knowledge which allowed patients to be effectively vigilant may have the additional benefits of decreasing hypervigilance and increasing patient satisfaction (from Theme Category 5).

Patient findings indicated a positive relationship existed between knowledge and vigilance; when patients had more knowledge, they were more effectively vigilant. Patients experienced knowledge as a critical element in making decisions, making sense of symptoms, and being able to discern normal from abnormal. Patients perceived that there was a 'just enough' amount of information that they needed and obtained over time about their disease and treatment. Too much information was overwhelming, while not enough information interfered with patients' abilities to be vigilant.

Findings indicated knowledge needed to be specific to the diagnosis. The cancer diagnosis for this sample was leukemia. Little recent literature was located regarding patient education and leukemia. In one European study which examined information needs of patients with acute myelogenous leukemia (AML) researchers indicated that patients avoided information about their disease and did not try and gather knowledge for themselves [151]. Alternately, in another study that investigated how people with cancer wished to be cared for [152], participants indicated that they wanted knowledge and information from the minute they were diagnosed. Although Kendall et al. [152] did not provide further explanation for why patients wanted information immediately, findings from this dissertation study indicated patients clearly sought knowledge from many

sources and associated knowledge with being able to be vigilant and protect themselves from threats.

Research related to patient education needs revealed a potential mechanism linking knowledge and vigilance. In a comparative study of patients who received and did not receive preparatory patient education about radiation treatment, findings indicated that those who received information ahead of time demonstrated reduced patient anxiety and increased satisfaction with nursing care [153]. Although Poroch [153] made a link between patients receiving education and positive outcomes, there was no discussion about why patients receiving education had decreased anxiety and increased satisfaction. Patient findings from this dissertation research suggested that knowledge and experience allowed patients to be effectively vigilant, as opposed to hypervigilant or overly anxious and watchful. This mirrors the findings from Poroch that knowledge and information decrease patient anxiety.

Knowledge was included in the conceptual definition of vigilance for this dissertation study. The derived definition of vigilance for the concept analysis was: Vigilance is the degree to which an interactive (between persons) process of *knowledgeable* watchfulness exists in healthcare in response to threats [79]. In the concept analysis preliminary study, presented in Chapter II [79], only one vigilance as task performance source [23], identified knowledge as an attribute of vigilance. None of the other research on vigilance explicitly included knowledge as an attribute of vigilance [18, 68]. In addition, no previous definitions of vigilance were found that included knowledge as part of the definition.

Patients' Experiences with Healthcare Provider Vigilance

Findings from this study indicated patients had experiences where they felt healthcare providers were vigilant, as well as experiences where patients felt healthcare providers were less than vigilant. In contrast to the difficulty patients had describing what

vigilance was, they readily and easily identified the nurses they thought were vigilant. Discussion of findings regarding patients' experiences with healthcare provider vigilance is divided into three sections: 1) The minimum level of healthcare provider vigilance; 2) Healthcare providers who perform beyond the minimum; 3) patients' perspectives of detractors from healthcare provider vigilance; and 4) patients' awareness of the healthcare system and its role in vigilance.

The Minimum Level of Healthcare Provider Vigilance

Key Finding: When healthcare providers merely fulfill their job requirements, patients view them as minimally vigilant, but being minimally vigilant was not enough to be explicitly recognized as a vigilant provider by the patient. When a patient explicitly identified a provider as vigilant, that provider was doing above and beyond what was merely expected (from Theme Category 11).

As discussed in Chapter II, in studies conducted from a task performance perspective, persons who were vigilant either responded or did not respond to a stimulus; thus, such persons were dichotomously measured as either vigilant or not vigilant, a state of being. Contrary to this perspective, patients in this dissertation study experienced vigilance, particularly on the part of healthcare providers, on a continuum, meaning persons were seen as having degrees of vigilance. Patients perceived that the low end of the vigilance continuum or the minimum level of healthcare providers' vigilance was indistinguishable from merely doing their jobs. Patients expected healthcare providers to perform at this minimum level of vigilance because patients perceived this to be part of the healthcare providers' job obligations.

As an example of what was considered by patients as a minimum level of a healthcare provider being vigilant, patients expected that healthcare providers would follow sterile procedures. Following sterile procedures was considered part of the general duty and training of healthcare providers and was also considered the least level

of vigilance a healthcare provider should have. When minimum levels of vigilance were not met, patients felt as if they might as well be receiving healthcare “in a third world country” (Patient statement 1.102).

Although unanticipated, two studies were found that indirectly supported this finding regarding minimal levels of vigilance. Research studies indicated that being a “good” nurse was associated with being competent [154]. In light of this, there was an underlying assumption that competence was associated with the absence of negative patient outcomes in medical care such as death, disease, disability, discomfort, and dissatisfaction. However, preventing such outcomes did not lead participants in one research study to identify nurses as giving excellent care [155], rather they were giving participants the minimum care expected. Likewise, a “good” or competent nurse should not be confused with a vigilant nurse. Patients in this study often commented that the majority of nurses were good, but there were one or two that stood out as really vigilant.

Detractors from Vigilance Are Different for Healthcare Providers

Key Findings: Patients perceive vigilance detractors for healthcare providers as different than vigilance detractors for patients (from Theme Category 7).

Patients saw some healthcare provider (HCP) qualities and behaviors (e.g. perceived incompetence or keeping patients waiting) as detractors from vigilance. When healthcare providers exhibited indicators of such detractors, patients perceived the healthcare provider as less vigilant. Patients identified things that they perceived as detractors from HCP vigilance for patients, and these were different detractors than findings indicated about patients’ being vigilant for themselves. Detractors included healthcare providers who did not seem knowledgeable or competent, healthcare providers who kept patients waiting and HCP who missed critical signals. The last of these detractors was the only one that seemed compatible with detractors similar to task performance vigilance, as in not picking up on radar signals when they occurred [23, 24].

Healthcare Providers Who Perform Beyond the Minimum Level of Vigilance

Key Finding: In order for patients to readily identify healthcare providers as vigilant, the healthcare providers must consistently perform beyond the call of duty and beyond patient expectations (from Theme Category 11).

Healthcare providers whom patients identified as vigilant were persons who consistently performed beyond the minimum. Indicators that healthcare providers, and particularly nurses, were highly vigilant included a highly professional demeanor and very competent care. Such highly vigilant nurses were used by patients as the benchmark for evaluating other nurses who may not be as watchful.

Patients benefited from such highly vigilant nurses. Patients who received care from highly vigilant nurses perceived they felt more rested, connected, respected, and protected, and it is likely that such perceptions contributed to patient satisfaction and quality of life. Yet, there was little in the literature that could be used to link vigilance to patient satisfaction or quality of life. Researchers identified 6 themes of provider qualities that mattered to healthcare consumers [156]. Five of the 6 themes were directly related to vigilance findings in this dissertation study: treating patients like they matter, competence counts, being made a healthcare providers' priority, giving patients information, and efficient care process-which included consistently seeing the same healthcare provider. All these themes mimicked experiences that patients in this study had with vigilant healthcare providers. Although Jennings et al. [156] indicated what healthcare consumers desired from their healthcare providers, researchers did not examine the relationship between what patients wanted from their healthcare providers and patient satisfaction or quality of life.

However, this link may be made from another study in which oncology patients' perceptions of quality nursing care was examined. The researcher presented links between patient sense of well-being and patients' perceptions of quality nursing care [155].

In addition to other characteristics, patients in the study felt that nurses who were attentive provided quality care. Attention is often used as another term for vigilance [68, 69, 71, 72, 75, 76]. Thus one might infer that vigilant healthcare providers' are perceived as giving quality nursing care.

Other qualities identified in research, such as knowledge and connectedness were qualities that patients in this dissertation study also associated with vigilant nurses [155]. Another support for the idea that quality nursing care with vigilance was associated with vigilance was not receiving timely care, in which participants were told nurses would be back at a certain time, but never returned [155]. In relation to such behaviors participants used the words abandonment and neglect. In this dissertation study patient findings indicated that vigilant nurses could be counted on and were timely in their nursing care, while nurses who were not vigilant could not be counted on to give timely care.

Patients Are Aware of the Healthcare System and Its Role in Vigilance

Key Finding: Patients were aware that the structure and philosophy of the healthcare system influenced vigilance of healthcare providers and family members (from Theme Category 10).

Patients were surprisingly aware and vocal about the healthcare environments influences on vigilance. Patients' perceptions indicated a complexity inherent in vigilance as experienced in healthcare systems. Interestingly, the National Institutes of Health recommended that healthcare environments be viewed as complex adaptive systems [9] in order to more effectively address and prevent medical errors. Patients were concerned about issues that were related to the potential for errors or lapses in safety. For example, patients perceived that vigilant systems provided trained and competent healthcare providers, as well as ancillary support staff, such as housekeeping. Additionally, patients wanted healthcare systems to accommodate families, so patients had an extra layer of vigilance available through family members. Patients believed that

systems should have facilities available for patients' families to use, such as laundry so that families did not have to leave patients to attend to things. In essence, having facilities available for families allowed them to remain present and watchful for patients a greater percentage of time, as compared to time family would have to be away, when facilities were unavailable.

Patients specifically identified issues that indicated the system was not vigilant: if there was short-staffing, over reliance on standardized measurements (e.g. single-item pain scales) without critical thinking, and unclear protocols for responding to medical errors. Surprisingly, patient perspectives of system problems which indicated lack of vigilance, or interference with vigilance, were rarely found in the literature.

Healthcare Errors as an Example of the Importance of Patients' Perceptions of System Vigilance

Key Finding: There was an unclear relationship between vigilance behaviors and errors. Patients had insights into the presence or absence of vigilance indicators that were potential antecedents to medical error that were ignored in medical error research (from Theme Category 10).

There was an assumed link between lack of vigilance or things that interfered with vigilance, and medical errors. Error literature and error reporting forms often included reasons for errors in terms of lack of vigilance. Although researchers developed error reporting forms or error classification forms, it was unclear how researchers derived the error classifications. Classifications on error reporting forms included terms such as inattention, lack of attention, thoughtlessness, and failure to check equipment, which were terms clearly indicative of a lack of vigilance [12-14]. Patient perspectives on error or error classification were absent in the development of such forms.

In this dissertation research, patients indicated a level of critical thinking about system vigilance. Patients perceived that things such as short staffing could lead to

lower levels of staff vigilance, and thus a potential for higher error risk. While it seems prudent to understand patients' experiences and concerns with system vigilance and make connections with why these perceptions of system vigilance were so important to patients, few research articles were found that included patient perspectives on medical error [157-159]. In the one study in which patients partnered with nurses to try and prevent medication errors, the researchers did not find any significant difference between their intervention (which consisted of giving patients a current medication list to double check with nurses) and the control group, who did not have a current medication list [159]. Although the researchers felt such interventions could be promising strategies to reduce error, there was no evidence that such a strategy would produce results. Researchers suggested several limitations in the study and suggested modifications that may improve future studies.

The majority of research on error generally addressed patient perspectives of what or how much patients want to be told about errors. All the research found was based off of surveys, focus groups, or vignettes. Only one research article was located that investigated patient experiences of actual medication errors [159]. While there was a plethora of information about healthcare errors in general, when patients' perspectives were included, researchers minimized the importance of the patient perspective [158].

In one research study which examined patients' perceptions of errors, researchers concluded that patients could not reliably identify medical errors [158]. Researchers indicated that 65% of the issues that patients identified as medical errors could be attributed to misunderstandings, and behavior, or communication problems on the part of medical providers. Interestingly, another study, on physician and patient perspectives of error disclosure also indicated that patients do see things like behavior problems and lengthy waiting for communication of test results as medical errors [157]. While researchers agreed that patients needed to be surveyed about their experiences, they also concurred

that patients could not accurately identify medical errors. Researchers did not think past the research question or instrument to identify why things such as communication, behavior, and misunderstandings might have led patients to be concerned an error had occurred.

Findings from this dissertation study indicated that patients believed vigilant healthcare providers were good communicators who listened. Further, vigilant healthcare providers were seen as professional. Lastly, vigilance was about making sense of things, not about misunderstandings. The bottom line issue was not whether or not the errors actually occurred in the aforementioned studies, but the emphasis should have been on recognizing that the patients believed the errors occurred.

Despite the lack of patient perspectives on actual errors or the lack of validation of patient perspectives, healthcare organizations have suggested ways patients might participate to prevent errors. There has been encouragement for patients to "speak up" about potential errors [160, 161]. One must question why it is okay for patients to be encouraged to speak up, and yet not be included in research related to system errors. Additionally, there was an important thought regarding patients being encouraged to speak up about potential errors. Although patients in this dissertation study indicated they would speak up to prevent an error, they also perceived speaking up to be energy-draining. Patients felt that if they had to speak up, this meant that healthcare providers were not functioning at the minimum level of vigilance, which was viewed by patients as careless or negligent practice.

Patients Experiences with Family Member Vigilance

Family members served a crucial role in the patients' experiences of vigilance. Patients saw family members as vigilant, in order to protect patients. Family members took on additional duties and roles, so patients could focus on being vigilant to fight cancer. Family vigilance helped patients feel more rested and protected. Families are

seen by patients as guardians of dignity and as making the hospitalization tolerable. Discussion of findings in this section will focus on: 1) the importance of the patient perspective of caregivers; and 2) The benefits of family member vigilance.

The Importance of the Patient Perspective of Caregivers

Key Finding: Patients did not discuss feeling like a burden for family members being vigilant (from Theme Category 6).

The vast amount of research regarding patients and family was focused on caregivers perspectives of burden [162-165] There was surprisingly little in the literature about the patient perspectives of family caregivers [166]. Patients were aware of the sacrifices family made for them and the new or additional roles family members took on. However, despite research focus being on caregiver burden, patients did not see themselves or discuss themselves as burdensome to family. Rather, family involvement in vigilance was a 'matter of fact' kind of experience for patients.

The Benefits of Family Vigilance

Key Finding: Evidence supported the patients' perspectives that family member vigilance was beneficial to patients (from Theme Category 6).

Research supported that patient and family members have a reciprocal effect on one another in several domains which studies have measured, such as quality of life, mood, and mental health [38, 167-169]. Self-efficacy, or the belief in one's ability to be effective in management of different aspects of life or illness, is one such reciprocal domain. Patients' self-efficacy about their ability to manage cancer symptoms was correlated with caregiver benefits and visa versa [168]. Perhaps one of the reasons that patients in this dissertation study benefited from vigilant family members was because family members felt efficacious when giving care, which in turn, lead to improved quality of life for both symptoms and mental health of the patients. Campbell et al. [168] noted in their study that interpersonal aspects of self-efficacy, or how patients' and caregivers'

individual self-efficacies could benefit each other, seemed to lend some credibility to the idea that vigilance may be a phenomenon that provided reciprocal benefits to both patients and family members. If both quality of life and mental health of patients and family members were positively linked to one another, then the importance of both patients and family members feeling efficacious in being vigilant could not be overstated.

Another way in which patients benefit from family members vigilance was by family members being watchful for information. Patients expected family members to be 'good thinkers', being vigilant for all kinds of information which in turn helped patients make healthcare decisions. Other research indicated that family members (spouses and children) were almost as important in influencing patients' medical decisions as their primary care physician [170]. Considering the level of importance that families played in healthcare decisions for patients, it seems reasonable that patients would expect family members to remain vigilant for information that could assist patients in such decision making.

The Idea of Shared Vigilance and Related Concepts

The last perspectives to be examined in the discussion of patient findings are unique in that they are related to experiences of vigilance as a shared phenomenon. Three topics will be discussed: 1) Vigilance as an implicitly shared phenomenon; 2) the issue of trust as a concept related to shared vigilance; and 3) the issue of hope and its relation to vigilance as a shared phenomenon.

Vigilance as an Implicitly Shared Phenomenon

Key Finding: There were indications that patients' experienced vigilance as a reciprocally shared phenomenon (from Theme Category 10).

Patient findings indicated that patients saw the need for vigilance to be a reciprocally shared phenomenon. Patients were aware that it was impossible for them to watch out for everything, and therefore, patients relied on family members and

healthcare providers to share vigilance. Previous oncology studies implied that vigilance was a shared process, but the process appeared to be more linear- the patient relied on family to be vigilant, who in turn relied on nurses to be vigilant [17]. In part, findings from previous research studies about the linearity of sharing vigilance were not surprising. Previous studies only examined one perspective or lived experience of vigilance, that of the participants themselves. For example, Carr's study was about family member vigilance and only asked about and examined vigilance of family members over hospitalized patients [171], therefore the patients' or others' perspectives of sharing vigilance, or vigilance as an interactive phenomenon, was not be detected. Therefore, to recognize shared vigilance, more than one participant perspective must be researched.

As differing participant perspectives were recognized, the complexity involved in shared vigilance emerged. Patients indicated that both family members and nurses were involved in an implicit sharing of vigilance. In attempt to construct a shared vigilance, patients tried to make sure that healthcare providers shared vigilance among one another, as they cared for the patient, by verifying if communication occurred among all involved healthcare providers. In one research study regarding patient perspectives of quality nursing care, patients wanted to share in the process and decisions regarding their own healthcare [155]. The research further indicated that nurses could perform in such a way as to influence whether or not patients felt they were partners with the nurses in their own care. Patients in this current study expressed relief when vigilance was a group effort shared by patients, families, and healthcare providers.

In regards to sharing vigilance with family members, patients had narrow perspectives. While patients indicated they watched over their families, and they are appreciative of family member vigilance, they did not seem to grasp a holistic picture of shared vigilance with family members. Patients indicated a sporadic discomfort in sharing vigilance with family members because it made the patient feel dependent.

In the literature, there were rarely examinations of patients' roles in interpersonal interactions with family members. However, one research study indicated that patients could be supportive of family caregivers by recognizing what the family caregiver did and actively participating to help ease the family caregivers' burdens. When patients were supportive of family caregivers in this way it was suggested that the burden of caregiving was eased because patients reciprocated the support they got from the caregiver [172]. While patients' findings in this study did not indicate an awareness or belief of burden, the idea that patients could do certain things to engage in supporting family member vigilance, such as being vigilant themselves, seems supported by other research [172].

Trust as a Concept Related to Shared Vigilance

Key Finding: Patients will share vigilance, but not just hand it all over to others. Trust is a potential moderator of sharing vigilance with others (from Theme Category 11).

Shared vigilance is a new idea emerging in this research. Experimental studies focused on vigilance as a task performance measured individual vigilance. In other research literature, vigilance was almost exclusively presented as a process conducted by one person. Only one research study was found in healthcare that indicated vigilance may be something patients pass off to trusted others [29]. In a study about the experiences of trauma patients, vigilance emerged as one of the strategies trauma patients used to stay alive. These study participants' maintained vigilance over themselves until someone they trusted, such as a healthcare provider, appeared. Then vigilance was handed off by the patient to the trusted other. For cancer patients, trust was a confidence patients had that they would be protected, and have reliable, timely care [155]. Further, patients indicated they did not feel the need to be vigilant because nurses would take this over for them. Thus, the issue of trust may be key to establishing shared vigilance among patients and healthcare providers or family.

Trust emerged in patient findings, but its role or relationship to vigilance was not clear. While trust was presented by patients as important, contrary to other research, cancer patients in this dissertation study did not hand off vigilance over themselves to anyone, trusted or not. Cancer patients described vigilance for self as a capability and personal responsibility. One explanation for why patients in this study did not pass off their vigilance to others may be related to issues of vulnerability.

Vulnerability was an ethical concern, addressed by Sellman who proposed that all people were vulnerable [173]. Sellman believed that people faced exposure to 3 types of risk of harm: harm which an individual can take action and provide self-protection from; harm which individuals must rely on the protection of others; and finally, harm from which the individuals or others are powerless to be protected. Therefore, patients in the healthcare system were more-than-ordinarily vulnerable because they were additionally exposed to the second and third types of risk of harm: they must rely on others, such as healthcare providers to protect them from risks, and they were often in the healthcare system related to a serious illness, over which patients had little power.

Findings from this study indicated that cancer patients do not totally turn over their vigilance of selfto healthcare providers or family, although they seem willing to share vigilance. According to Sellman's risk of harm scenarios, perhaps one reason cancer patients did not turn vigilance over to others was because it increased their vulnerability to risk of harm. By turning over vigilance to someone else, patients would be giving up the potential to protect themselves from certain risks of harm.

The other consideration in patients turning over vigilance to others was related to trust. Trust involves vulnerability and, when there is no trust, persons must respond with continuous vigilance, anxiety, or withdrawal [174], which are feelings that preclude sharing vigilance. Mechanic and Meyer interviewed 3 different groups of patients, breast cancer survivors, patients with Lyme disease, and patients with a mental illness. Trust was

emphasized by the breast cancer survivors more so than by the other patients groups and the researchers hypothesized that the life-threatening nature of cancer magnified the need for trust. Trust was found to be a process that developed over time which was concurrent with patient findings from this study. In this dissertation study, patients found it helpful to be able to keep the same nurse and Meyer and Mechanic [174] indicated that trust was more likely found in long term, rather than short term relationships in healthcare. Thus it seems that trust is an important consideration, because it allows patients to bridge a vulnerability gap and share vigilance with others.

Hope and Shared Vigilance-Searching for the Link

Key Finding: Hope is a potential moderator for patients remaining vigilant (from Theme Category 9).

For patients in this study, hope was about a balance between reality, the hoped for, and hopelessness. Hopeful communication from healthcare providers helped patients achieve this balance. In the literature, the balance of hope was often achieved through spiritual relationships. However, in this dissertation study, spiritual relationships, did not contribute greatly to a balanced hope. Patients did indicate they felt a higher being was watching over them, yet at the same time, there were concerns that a higher being was punishing them for not being watchful enough, hence their cancer. While literature documented the relationship between hope and spirituality [175, 176], hope and the issue of spiritual meaning of vigilance was not something patients and families openly discussed in the literature [177]. The idea of a higher power being vigilant or punishing people for lack of vigilance was something unusual to find in the research literature on vigilance. While researchers identified perceptions of being punished by God or abandoned by God as negative religious coping [178, 179], participants in such studies usually indicated they were being punished for lack of devotion or lack of faith. In this dissertation study, the relationship between hope and vigilance was unclear. There was a large body of

literature regarding hope and cancer patients, however many of these studies focus on hope in the context of maintaining hope with a life threatening illness, e.g., [177, 180, 181]. While the patients in this study were certainly at risk for death, it was only considered immanently likely for one patient interviewed. Therefore, the link between hope and vigilance was confusing. However, findings from family member data directed a line of reasoning about a potential connection between hope and vigilance, which seemed to be supported by research literature. No articles were located related to hope and vigilance, however Lazarus [182] suggested that hope arose from threat. Since vigilance occurs as a response to threat, perhaps threat was the common factor that produced a link between vigilance and hope. Articles on hope, hopelessness, and positive thinking were analyzed and suggested additional links between hope and vigilance.

The literature was in agreement that patient hopelessness led to higher mortality rates than patients who remained hopeful [183, 184]. When patients were hopeless, it would stand to reason that there was no motivation to be vigilant. Vigilance and hopelessness are oppositional to one another. If a person felt there was no hope to recover from cancer, then being vigilant, in order to protect oneself would seem useless. The underlying belief in hopelessness is that one is powerless to change the outcome. An interesting possibility exists. Perhaps one of the reasons patients who were hopeless had significantly higher mortality rates, even when compared to patients at similar stages in disease [184], was because those who were hopeless ceased to be vigilant for threats which led to earlier deaths. Lazarus [182] provided additional support for the link between hope and vigilance. Lazarus suggested that persons took certain actions which were related to certain emotions. Lazarus [182] suggested that the action associated with hope may be vigilance which was a demonstration of not wanting to give up on a yearned for outcome. Thus, when patients were hopeless, and did not have a yearned for outcome, they were not vigilant. Although patient findings in this study did not demonstrate that

patients were aware of the potential links between hope and vigilance, family members' findings indicated they unwittingly made this critical link. Family members and patient hope will be discussed in the family member discussion section. The benefit of interviewing persons with multiple perspectives of a phenomenon is that one group may provide insights about the other group which would otherwise go unnoticed or be misunderstood.

Family Member Discussion

Family members' experiences with vigilance for hospitalized patients is qualitatively different than patients' experiences of vigilance. Although there are some similarities in the phenomenon of vigilance between patients and family members, the essence of the experience was different. While experiences of vigilance for patients mimicked experiences of mythological heroes on an epic journey, family members' experiences of vigilance were much more chaotic, like being sucked into a hurricane. Krumweide et al. [17] noted similar experiences in family members caring for neutropenic cancer patients at home, and termed the family experience as "turbulent waiting".

To place the findings of this study within the body of knowledge, the literature on family caregiving was examined e.g. [38, 185-188]. Many of the family caregiver studies are focused on families giving patients care at home e.g. [189-193]. Little research is available in which the focus is on family members experiences when patients are in the hospital [15, 194, 195], and only one of these studies was focused on the experiences of family member vigilance [15]. The families interviewed in each of these studies were recruited from neurological units. No studies regarding experiences of family members of hospitalized, adult cancer patients were found. Research demonstrated that cancer diagnoses affect the whole family [196]. Interventions aimed at helping families of cancer patients benefit not just the family members, but cancer patients benefit as well [197, 198]. Without an

understanding of family members' experiences of vigilance, it would be unlikely that meaningful interventions could be designed.

Although there are similarities in family caregivers vigilance at home, an assumption must be made that family members' vigilance in the hospital may have unique qualities that influence the experiences. From previously conducted research, Ronch [199] proposed that families who care for patients in homes give care based on the family as a social institution, and that the care is generally a collaborative, more feminine type of environment. Ronch compared such home environments to the hospital where it is generally hierarchical, male-oriented, and focused on power relationships. While a majority of family care is given in the home environment, it is important to understand that family caregiving is influenced by patient hospitalizations. Gould [200] pointed out that patient hospitalization is an indicator of the increase in burden family caregivers will face, once patients are discharged back home. In other words, patient acuity is greater if they have been recently hospitalized. In a large study of family caregiving, it was found that more than half of patients being cared for at home had been hospitalized in the previous year's time [200]. While evidence indicated a subsequent increase in caregiver burden if patients have a hospitalization, research has not investigated burden as it applies to family caregivers in the acute care setting.

Family members' vigilance experiences will be discussed in 4 sections. First, family members' experiences of being vigilant for the patient will be discussed. Second, family members' experiences of being watchful with and for healthcare providers will be discussed. Third, the way in which being watchful effects family members themselves will be addressed. Finally, indications of the concept of shared vigilance will be presented.

Family Members' Experiences of Being Vigilant for Patients

Family members described many ways they were vigilant for patients. Specific ways in which family members' conveyed watchfulness for patients will be discussed. Discussion includes: 1) family members creating environments conducive to vigilance; 2) vigilance and intimacy; 3) knowledge needed by family members in order to be vigilant; 4) special knowledge family members have that gives them a vigilance advantage; 5) circumstances that trigger family member vigilance; 6) family members being vigilant for patients' hope; and 7) family members and the issue of spiritual vigilance.

Family Members and Optimal Environments for Vigilance

Key Finding: Family members modify the hospital environment to create an environment more conducive to family member vigilance (from Theme Category 4).

When patients are initially diagnosed and hospitalized, family members reported a sense of being overwhelmed, or sucked into the cancer hurricane. Likewise, Carr [15] indicated that part of the experience of family vigilance was "emotional upheaval". Carr indicated that emotional upheaval was a part of the daily vigilance experiences of family members. Yet, family members in this dissertation study indicated that strong, negative emotions, chaos, and disorganization interfered with vigilance. Family members did several things to manage strong, negative emotions and create order which helped construct an environment within which they could be optimally watchful for patients. Family members stayed in the present, limited what they paid attention to, and created a routine which normalized the hospital environment for themselves and the patients.

Normalizing experiences surrounding chronic illness or potentially life-threatening conditions is not a new concept. Knafl and Deatrick [201] found that families of children with chronic illness do many things to try and normalize the experiences of being parents of a child with a chronic condition. However, Knafl and Deatrick found that families of children with chronic illness did not just create normal environments, in addition and

more importantly, they did things to think of their child as normal. Thus, in the case of chronic illness family members were not creating normal environments to aid in vigilance, but were creating them to help cope with the psychological and social dilemmas created when parenting a child with chronic illness. In another study, Hilton [202] indicated that family members of breast cancer survivors wanted to be normal, do normal things, or get back to normal. Normal was described as a place that was safe and free of disease. Such is not the case in these dissertation findings for family members. Normal, for family members in this dissertation, took on a different meaning and purpose. For family members of hospitalized cancer patients, creating a normal routine and environment helped them be more effectively vigilant. Family members identified dealing with things that were *not normal* as a detractor from vigilance.

Other studies indicated that family members actively work to normalize and control the environment in order to aid vigilance. In Carr's study of family member vigilance one of the themes that emerged was resilience [15]. Carr described family member resilience as the ways in which family members passed the time in the hospital, took care of themselves, and maintained hope. The conceptualization of resilience by Carr seems mismatched with how other researchers have perceived resilience. Haase [92] defined resilience as: "the process of identifying or developing resources and strengths to manage stressors flexibly and gain a positive outcome" (p. 125). Carr described such resilience of family members in the study as "reading, writing, and doing crossword puzzles" (p. 77). It seems that Carr's description confuses aspects of resilience with things families did to make the situation more normal, or more similar to routines they may maintain at home. Resilience is not just the passing of time, but part of a transcendent experience [203]. Maintaining a routine and participating in normal activities is a way of normalizing or creating environments within which family can be effectively vigilant. Participating in calm, organized activities such as reading or doing crossword

puzzles would seem more associated with creating a calm environment for optimal vigilance as described by families in this dissertation study.

Krumweide et al. [17] described activities families caring for non-hospitalized neutropenic cancer patients did to control the environment and make it more optimal for vigilance. Family members in Krumweide's study chose activities where patients were less likely to be exposed to germs and other risks, such as going to movies at unpopular times when the theater would be less crowded. Families also focused on keeping the environment as clean as possible through the development of routines.

While direct links have not been made in the research literature before, findings from this dissertation study and indirect links from other research indicated that families do create more normal routines in the hospital to decrease chaos and disorganization (two things that family member findings indicate interfere with vigilance). The development of routines may decrease the influence a chaotic environment has on emotions, thus allowing families to maintain more consistent, positively focused emotions, because negative emotions also interfere with vigilance. Thus, a picture emerges in which family members set up routines in the hospital to minimize the influence the environment has on their ability to be vigilant. By creating such environmental boundaries family members give themselves a vigilance advantage in watching over patients.

Family Members and Sacred Vigilance: Intimacy Needs

Key Finding: Family members are watchful about intimate aspects of theirs' and patients' relationships (from Theme Category 4).

Family members expressed vigilance over intimate aspects of theirs' and the patients' lives. By giving intimate care, such as bathing or foot massages, and for the spousal family members, attending to the desire to maintain a romantic link between one

another, family members carefully watched over very personal and meaningful moments in their relationships with patients.

Hodern [204] conducted a critical review of the literature and found that researchers often confused the terms intimacy and sexuality. The majority of studies indicating the topic is sexuality or intimacy are actually focused on the physical aspects of sex. Sexuality and intimacy have different meanings, with sexuality encompassing broad areas such as gender, emotions, physical sex, and reproduction, intimacy is subtler, encompassing touch, closeness, and communication which can be shared by both romantic and non-romantic partners [204]. Hodern found that a gap exists in the literature on issues of intimacy in relation to life-threatening illnesses. Since the little research that does exist addresses both sexuality and intimacy, these are the terms that will be used to describe the research.

Patients diagnosed with cancer in indicated they really wanted information about sexuality and intimacy [205], however healthcare providers rarely, if ever addressed such needs. Healthcare providers indicate they are embarrassed, lack knowledge, and do not find sexuality or intimacy a priority to address with cancer patients [206, 207]. No literature was located that discussed intimacy or sexuality and family members of cancer patients, or which addressed intimate needs of either the patient or family member during hospitalization.

There was one research article located in which intimacy for family members could be implied. The research study proposed teaching nurses and then family members how to perform foot massage on patients at an inpatient facility [208]. The focus of the massage intervention was to decrease patient pain. Researchers cited recruitment difficulties and were unable to fulfill any meaningful data collection. One family member in this dissertation study relayed stumbling upon giving her husband, the patient, a foot massage and how this relaxed her husband and gave her a way to connect intimately

with him. If family members do not know whether intimate contact, such as hand-holding, is harmful, they will forego intimate contact in order to protect the patient from harm, as indicated by one family member in findings from this dissertation study.

Family Members and Knowledge Needed for Vigilance

Key Finding: Family members place a high value on knowledge accrual and connect knowledge with their ability to be effectively vigilant for patients (from Theme Category 1).

In this dissertation study, family members described having to grab knowledge wherever they could as if grabbing for information being blown around by a hurricane. Family members believed it was crucial that they possess knowledge in order to be effectively vigilant. Eggenberger [16] implied similar conclusions about educating patients so they can recognize and interpret cancer patients' symptoms and take appropriate action. Perhaps family members' awareness that knowledge and information allow them to be effectively vigilant for patients is one reason that in other research, family exhibit so much interest in gaining knowledge, at times at higher levels of interest than patients [209]. Schumacher et al. [210] studied family caregiving skill, and interestingly the first four "skills" addressed by researchers were monitoring, interpreting, making decisions, and taking action. Each of these skills are embedded within findings from this dissertation study and another study [17] as key elements of family member vigilance. Schumacher's [210] findings seem to support the notion that family members recognize the importance of accruing knowledge, experience, and skill, as a means to be effectively vigilant.

Research indicates that being prepared for the caregiver role is associated with better family caregiver mood, well-being [188], better patient quality of life and health promotion [211], and reduced caregiver burden [187, 188]. While research is often focused on preparing family to give patients care at home [193, 211, 212], Glajchen [213] indicates that families should receive information at diagnosis, initial hospitalization, the start of new

treatments, and to enhance end of life care. Wong et al. [209] found families want different information than patients, while both want information on symptom management, families also want information about emotions of and communication with the patient . Additionally, the majority of caregivers in their study preferred one on one delivery of information or brief amounts of information in pamphlet format, as opposed to other methods of delivery such as internet, books, or seminars. When given an opportunity, at least 75% of family members cooperated with nurses to learn new caregiving skills [214]. Despite the desire to know and learn studies indicate that only 25-50% of family members were informed about what they could do to care for patients, either during hospitalization [195] or in home care settings [200]. When family members do not have the opportunity to learn it is likely that their quality of life will be negatively affected [38].

Special Knowledge Gives Family Members a Vigilance Advantage

Key Finding: Special knowledge about the patient gives family members a vigilance advantage in being able to identify “different than normal” in the patient rather quickly (from Theme Category 1).

Family member findings indicated they were aware of the special knowledge they had about the patient. While there are many things family members feel they need to know about the patients’ disease and treatment, their special knowledge gives family members a vigilance advantage over healthcare providers. Knowing the patients well gives them an advantage in interpreting patient signs and symptoms. Family members base their actions on the knowledge they have of the patients’ usual way of thinking and expressing themselves. For example, such knowledge allows family members to make decisions about whether patients really want family members to leave and go home, or stay in the hospital with patients. Family members also know what patients’ frames of mind or usual emotional states were before cancer. The years of coming to know who

patients are allows family members to form a picture of who patients are “normally”. Family members can quickly recognize when patients are acting different than normal.

While family members are aware of their special knowledge of the patient which gives them a vigilance advantage, it appears from other research findings that healthcare providers often do not recognize or value family members’ input or insights about patients [214, 215]. Family members’ expectations and desires to be involved in patient care was recognized years ago in research [215], yet family members’ expertise and skill continues to go unrecognized by nurses [214]. Tensions between healthcare providers and family members grow because of disparate expectations for patient treatment and outcomes [214]. Some previous research findings indicate that family members provide care related to mundane tasks that anyone could do, and are passively watchful as they stay with patients in the hospital [15, 194]. Family members have been described as doing 80% patient care tasks, such as toileting or shaving, and spending 20% of their time giving patients emotional support [194]. Other research describes family members dealing with emotional upheaval in themselves and passing the time by doing crossword puzzles or reading [15]. Such findings are not indicative of the complexity or depth involved in family member vigilance and such lack of knowledge about the complexity of family member vigilance leads to a lack of appreciation, value, or respect about what family members really do to watch over patients, particularly while they are in the hospital setting.

Triggers for Family Member Vigilance

Key Finding: Family members are specific in their watchfulness and there are certain issues which trigger family member watchfulness (from Theme Category 4).

Findings from this dissertation research indicate that family members are actively watchful for any kind of threats, potential or actual. Family members are definitely on duty when they are at the hospital. Family members pay close attention to blood

products, lab results, medications, and particularly chemotherapy. Additionally, family members are especially watchful of healthcare providers who appear inexperienced and for any indications that potential for errors are high. Similar to Astedt-Kurki [194] family members in this dissertation study also spent time monitoring patients' emotional states; however unlike Astedt-Kurki's findings, this monitoring was not just 20% of the time, but was a continual and central focus of family members.

Family Members Monitoring Patients' Levels of Hope

Key Finding: Family members spend a majority of their time monitoring patients' levels of hope (from Theme Category 5).

One important patient emotional state that family members monitor is hope. Family members pay constant attention to patients' levels of hope and push patients to maintain positive attitudes. Family members will go to great lengths to hide negative emotions from patients and to prevent others from being negative around patients.

There is little evidence in research about hope in family members [177, 216, 217]. Interestingly, in this dissertation study, little of the family member data addressed hope within the family members. The family member findings indicated that the focus of the family members was monitoring hope or hopelessness in the patients. Perhaps, one reason family members did not talk about hope in themselves was related to the topic of this study, which was vigilance. Family members did not tolerate hopelessness or negativity in patients for extended periods of time.

There may be two prominent reasons that family members did not tolerate hopelessness in patients. First, family members equated hopelessness with death. Patients who score high on hopelessness die at almost twice the rates of patients who score high on hope, even if their illness trajectories are similar [184]. Somehow, family members are aware of the threats and dangers associated with hopelessness, without any evidence or training about such dangers. Second, when patients exhibited

hopelessness, they were not as likely to be vigilant and a greater burden was felt by family members to be doubly vigilant. While family members could sustain such “double” watchfulness for a period of time, it took exorbitant energy to do so. There was a limit to how long family members could or would take on this double burden of watchfulness. Family members expected patients to maintain a level of hope, and thus vigilance. When patients maintained hope and vigilance, it relieved family members of some of the burden of watching; in other words, there was an indication of shared vigilance.

Family members’ expectations that patients will share in being vigilant might be supported by research on the concepts reciprocity or mutuality. In examining the concept of reciprocity, Tarlow [218] found that participants in a research study described reciprocity as a “mutual interchange, give and take…across time” (p. 76). Reciprocity involved a sense of responsibility felt by all parties involved and negotiations about the interchanges. Other research findings indicated that family caregivers are actually vigilant for signs of patient reciprocity [219] and that a mutual exchange between caregivers and patients does indeed seem to give caregivers some protection from the negative demands of caregiving [187]. Such research findings indicate the need and importance of family and patients entering into a shared or reciprocal vigilance partnership.

Family Members Differ from Patients on Spiritual Vigilance

Key Finding: Spiritual issues were not associated with vigilance experiences of family members as they were with patients (from Theme Category 5).

Lastly in regards to hope and family members, it needs to be noted that, surprisingly, family members in this dissertation research said almost nothing about spirituality. While both positive and negative spiritual perspectives were more prevalent in patient findings, family members did not indicate that spiritual issues were associated with vigilance experiences. Although little research was located that addressed family

members spiritual needs, one research study pointed to a potential reason family members may not have focused on spiritual issues. Kuuppelomaki [3] conducted research on nursing assessments of cancer patients' families. In this study nurses expressed that one barrier they identified in supporting family members' spiritual needs was the perspective that "spiritual needs are often associated with death" (p. 213). Such results could provide a plausible explanation for why family members are not vigilant about spiritual issues in the acute phase of illness. If paying attention to spiritual issues is associated with death, then a tension would be created between hope for cure or remission and spiritual needs of patients or family members.

Family Members' Watching Healthcare Providers

Family member findings indicated that family members watched healthcare providers closely. Two specific family member perspectives will be discussed: 1) the issue of trust of healthcare providers (HCPs) and its relationship to family member vigilance; and 2) family member perspectives of the healthcare system and its role in family member vigilance.

Vigilance, Trust and HCPs

Key Finding: Healthcare providers must exhibit vigilance is order for family members to develop a trust relationship with them (from Theme Category 3).

The experience of vigilance for family members with healthcare providers seems to be associated with being able to establish trust with healthcare providers. Previous research has indicated that family members of hospitalized patients begin the healthcare provider-family member relationship with a naïve trust, which is ultimately shattered [220] and must be rebuilt with individual providers. In this dissertation research, family members did not exhibit the kind of naïve trusting of healthcare providers as previously researched. Findings indicated that trust in healthcare providers occurred when family members believed healthcare providers exhibited vigilance, and as others have

indicated, occurred over time [221, 222]. Family members view healthcare providers as vigilant if they perform beyond the expectations of family members. Although minimum levels of vigilance are the least family members expect from healthcare providers, those who perform beyond the call of duty are the healthcare providers that family members label as vigilant. Such vigilant healthcare providers are the ones with whom family members will develop trust relationships.

Other research conducted on relationships between healthcare providers and family members or patients offers some interesting support for the notion vigilance is a cornerstone that is essential in developing such kinds of trusting relationships. Hupcey [221] indicated that relationships between intensive care nurses and families developed when nurses spent time with patients and family members, provided explanations for care, and anticipated family members' needs. Family member findings from this dissertation study indicated that vigilant nurses were those who were present and listened, got to know the family members, and patient, gave family members information beyond what they expected, and prepared family members for what was coming. Such findings seem to indicate that healthcare providers who are perceived to exhibit vigilance have trust relationships with family members. Although vigilance was not linked directly to trust in Hupcey's research it was indicated that if families trusted nurses, they would relinquish some of their own vigilance in order to take breaks or go home. In this dissertation research family members took breaks once they had determined a vigilant nurse was on duty and had built a trust relationship based on the nurse exhibiting vigilance.

Additional support was found for the idea that healthcare provider vigilance is necessary to create trust with family members. Lynn-McHale [222] found that things nurses did that interfered with developing trust were, not listening and not taking the time to develop relationships with family members. In this dissertation research healthcare

providers who were less than vigilant were described as lacking responsiveness, being in a rush, and short on staff members. Based on these dissertation findings, it seems that vigilance is phenomenon that must be exhibited by healthcare providers in order to develop trust relationships with family members.

Family Member Perspectives on Healthcare System Support of Vigilance

Key Finding: Family members recognize the healthcare systems responsibility in supporting their vigilance (from Theme Category 9).

In these dissertation findings, family members indicated that healthcare systems were confusing. From how medication systems work to how patients are assigned to floors creates uncertainty and concern in family members trying to be vigilant for patients. Family members described ways in which the healthcare system both exhibits vigilance and can support family member vigilance. Examples included; information on how the healthcare system works, having appropriate levels of staffing, basic supplies, facilities for family to use, such as laundry, and attention to safety concerns, such as parking for family members.

Some of family members' concerns from this dissertation are mirrored by other research findings. Environmental design has been investigated recently with a focus on healing environments [223]. Some healthcare organizations recognize that considering family in the healthcare environment design is necessary because family members contribute to patients' healing [224]. Recommendations include home-like facilities and parking facilities for family members [225, 226]. Other facilities have made such recommendations a reality by creating roomy, safe parking areas and patient rooms that contain family zones [227]. Despite all the care put into making recommendations a reality, Lowers [226] notes that in order for healthcare environments to be family-friendly, the philosophy of staff has to match the intent of the environmental design. In other words,

the design alone makes no difference if healthcare providers and staff do not support the inclusion of family members in patient care.

Because oncology patients often have lengthy and numerous hospital stays, family member needs must be considered. The Planetree Model of patient-centered care is one example of considering the healthcare environment and its ability to positively influence patient outcomes by offering comprehensive family member access to amenities [228]. However, none of the research on healing environments made a link between healthcare system design, family member vigilance, and patient outcomes. The findings from this dissertation study indicated that family members used healthcare facilities amenities such as laundry and internet access as means to remain present with and vigilant for the patient. Without such amenities, family members would have to leave patients and be less able to be effectively vigilant.

The Effects of Vigilance on Family Members

Caregiver burden is often discussed in the research literature. Family member findings indicated there may be a link between caregiver burden and family member vigilance. This possible link is the focus of this discussion section.

Key Finding: There are indications that vigilance may be highly relevant to caregiver burden (from Theme Category 7).

As length of stay in acute care has decreased, the demands of family caregiving has increased [164, 229]. Such changes in caregiving have intensified researchers' focus on caregiver burden e.g. [162, 188, 191, 230-233]. There have been inconsistencies in the way in which caregiver burden has been defined and measured [200, 212], however time on task (or amount of time spent giving care) appears to be a somewhat consistent concern and focus in measuring caregiver burden [27, 188, 198].

A reminder that in Chapter II of this dissertation, historical studies of vigilance indicated that the longer persons are on duty, being vigilant, the less vigilant they are

able to be [23, 24]. If caregiver burden is measured as time on task, it would stand to reason that the longer family members are caring for patients, the less able they are to be vigilant. Perhaps this is why when caregiver burden is high, there are unmet patient needs [233].

Findings from this dissertation would suggest that things that interfere with vigilance such as strong emotions, lack of knowledge, negative interactions with the patient, and fatigue are closely associated with findings from studies which indicated high caregiver burden results in issues such as depression [163, 191] and fatigue [188, 234] and that lack of preparedness [187, 188, 212] and lack of reciprocity [219] contribute to higher caregiver burden. Other research findings have demonstrated that optimism and quality of life of both caregivers and patients have reciprocal effects on each other [38, 198, 212]. Therefore, it would not seem unreasonable to believe that caregiver burden, may have outcomes, such as decreased family member vigilance, which produces negative effects on the patient, which in turn produce reciprocal negative effects on family members.

Mahoney seemed to associate vigilance with caregiving burden. Mahoney [27] developed the Caregiver Vigilance Scale to measure time caregivers spent either giving care or just being present with the patient. Mahoney developed the instrument from a qualitative study from which 5 themes were derived, specific to caregiver vigilance; “watchful supervision, protective intervening, anticipating, on duty, and being there” (p. 26). Mahoney only used 2 of the 5 themes in developing the 4-item instrument; “on duty” and “being there”. These two themes represented a time on task perspective of vigilance, similar to historical vigilance studies. Statistical testing did not support the instrument as representative of vigilance as uni-dimensional, or time on task only.

There is a link between time family members spend giving care to patients and their ability to be vigilant. However, the complexities involved in family member vigilance have not been recognized. In this dissertation study, findings indicated that vigilance for family

members was a complex, multi-dimensional phenomenon. Schumacher [188] found that family member research, which includes multiple variables, is too complex to yield any meaningful findings without complicated analyses. It is possible that one explanation for such difficulties is a lack of sensitivity or meaningfulness of instruments. Gould [200] indicated that most instruments do not reflect the complexities and difficulties involved in giving care to patients with complex disease processes.

Hints of Shared Vigilance

Family member findings indicated that family members shared vigilance with healthcare providers and expect patients to contribute to shared vigilance as well. Family members' perspectives of shared vigilance are the focus of this discussion section.

Key Finding: Family members implied that there was a need to share vigilance with patients and healthcare providers (from Theme Category 8).

Family member findings indicated that family members felt as if the healthcare team, family members, and patients working together seemed to influence patients' sense of well-being. When issues such as knowledge, respect, and access to nurse managers were addressed, family members felt they had the footing needed to share more equally in vigilance with healthcare providers. On the contrary, family members indicated that patients' refusals to honestly share emotions or symptoms with family or healthcare providers blocked the ability for vigilance to be shared among the group.

Although the idea of sharing vigilance is new, there are some indications in the literature that including family members in patient care is beneficial. Family-centered care is being promoted as a way to increase patient safety [235] and improve patient and family satisfaction [236]. However, the majority of evidence for family-centered care is based in pediatrics or is anecdotal. Sisterhern et al. [236] proposed that performing interdisciplinary, medical resident rounds promoted communication and learning for both the healthcare team and the patients and families. Although the Institute for Family-

Centered Care [237] indicated that collaboration between healthcare providers, patients, and family can improve safety, there is no research evidence to support these claims. At the policy level, some institutions are including patient and family input into healthcare delivery systems, but there is not an indication that this is translated to the bedside [235].

Additionally, there are barriers of power that seem in impede views of success collaboration between patients, families, and healthcare providers. Sisterhern et al. indicated that nurses do not see collaboration in medical rounds as highly successful as physicians do [236], and Johnson [235] indicated that patients and families sometimes are intimidated in working with healthcare providers who have much higher educational backgrounds. In findings from this dissertation family members implied knowledge about power imbalances, but indicated as above that knowledge, respect, and access to those in power gave family members a basis from which to share vigilance with healthcare providers.

Nurse Discussion

Research has not previously focused on nurses and vigilance. Although reported to be a core of nursing performance from the time of Florence Nightingale [84] researchers have not investigated nursing vigilance. Only one nurse researcher, Meyer, suggested a model of nursing vigilance, however, the model suggested was derived from a sample of women with migraine headaches. Without further reported testing, the researcher used findings from women with migraine headaches and converted them into a model of nursing vigilance [84]. Nurses' findings from this dissertation research did support the idea of a phenomenon of nursing vigilance, however there are some marked differences in these findings when compared to Meyer's research. The most obvious difference being, nurses' findings in this dissertation study indicated that nursing vigilance was interactive between and among patients, family, nurses, and other healthcare providers. Meyer's

research indicated that nursing vigilance was something conducted by one person and no interactive components were identified in the model.

Nurses' findings supported vigilance as a complex, multidimensional, and interactive phenomenon. The discussion of nurses' findings is qualitatively different than for patients or family members. As findings were reviewed, it seemed that nursing vigilance was its own perspective, in addition to vigilance for patients, families, and healthcare providers. Nursing vigilance was primarily focused on patients, but functioned as an ingrained part of how nurses perform their jobs. Therefore, key findings are grouped into five perspectives presented in this discussion: 1) Nursing vigilance; 2) Nursing vigilance for family members; 3) Nursing vigilance for patients; 4) Nursing vigilance for other healthcare providers; and 5) Nurses' perspectives on shared vigilance.

Nursing Vigilance

Key findings for discussion of nursing vigilance are indicative of issues which may interfere with or promote nurses' abilities to be vigilant. Each of the key findings in this section seemed to create a picture of nursing vigilance that is representative of vigilance being part of nurses' work lives. Discussion of nursing vigilance includes: 1) the complexity of nurses describing vigilance; 2) issues nurses identified as interfering with their abilities to be vigilant; and 3) nurse behaviors that promote their abilities to be vigilant.

The Complexity of Describing Nursing Vigilance

Key Finding: Although vigilance is recommended as the solution to many clinical issues and lack of vigilance is a common category on error reporting forms, nurses struggled to understand and describe vigilance, despite their knowledge that it was a daily part of their practice (from Theme Category 1).

When the search terms vigilance and nurses were used, thousands of abstracts were located which indicated that the solution to many patient problems is to be more

vigilant e.g., [238-240]. There seems to be an assumption that nurses and other healthcare providers understand what vigilance is and can simply increase the amount of vigilance they use in order to be more protective of patients. Yet, in this dissertation study nurses clearly struggled to relay experiences of vigilance. For the participant nurses, who were identified by patients as vigilant, vigilance was such a routine part of their jobs that it was difficult to recognize what nurses did that constituted vigilance. Nurses' findings also indicated that they were uncertain how patients saw vigilance in nurses or families.

The difficulty in nurses being able to describe and recognize vigilance is concerning because assumptions are made that healthcare providers understand vigilance and can adjust it as needed. When nurses have difficulty understanding and recognizing vigilance, it seems unlikely that they could easily recognize vigilance or lack of vigilance and the part it may play in error. For example, as reviewed in Chapter II of this dissertation study, nurses' behaviors on error forms hint at, or in some cases specifically indicate the problem that caused the error was lack of vigilance [12, 13, 231]. However, without an explicit framework for vigilance, the classification of terms such as inattention, seem to hold little promise for explaining or correcting errors.

Studies conducted in healthcare, thus far, specific to nurses and vigilance have presented a more simplistic view of nursing vigilance as a task performance. Previous vigilance studies of nurses focused on the role that fatigue played in nurses' abilities to remain vigilant and respond to stimuli [28, 241]. Such studies have a limited view of nursing vigilance, and indicated nursing vigilance could be improved if nurses got more rest and worked less hours. However, in this dissertation study, findings indicated that vigilance was complex and despite there being a myriad of issues that nurses relayed as interfering with their vigilance, fatigue was a minor interference mentioned.

Nurses' Perspectives about Vigilance Interferences

Key Finding: Nurses identified specific issues which were viewed as interfering with their abilities to be vigilant (from Theme Category 6).

Nurses' findings in this dissertation study indicated that there are multiple things that may interfere with nurses' abilities to be vigilant and they are influenced by patients, families, or healthcare providers. Other studies have not identified such interferences with nursing vigilance. As reviewed in Chapter II of this dissertation study, historic studies of vigilance as a task performance indicated that certain things interfered with or detracted from the ability to be vigilant. Detractors from vigilance included: 1) Long tasks; 2) Boredom; 3) Increased number of false alarms; 4) Isolated work environment; 5) No evaluation of efficiency; 6) Difficult tasks; and, 7) Long response times [23].

Nurses work in environments that are significantly different than the environments in which such task performance studies were conducted. Nurses monitor multiple patients, family members, other healthcare providers, the environment, and a multitude of machinery. Ebright noted that when nurses' work is not studied in the actual environments within which it takes place, and therefore not understood, the science of nursing cannot improve patient outcomes, including safe passage [55]. Task performance vigilance studies failed to capture the complexity encountered by nurses in their everyday, complicated work environments.

Nurses and Interference with Vigilance Associated with Patients

In this dissertation study nurses indicated that certain patient characteristics and behaviors could produce interference with vigilance. When patients did not want to watch out for themselves, were really ill, had no support, or had vague symptoms, nurses perceived that their vigilance was impeded.

Nurses cannot be as vigilant when patients are not vigilant for themselves. Hagerty and Patusky [242] indicated that nurses expect patients to engage in managing their own

health and follow healthcare advice. When patients do not meet these expectations nurses label them “unmotivated, ignorant, and oppositional” (p. 147).

Key Finding: When patients are not watchful or knowledgeable about their care, nurses’ ability to be vigilant for that patient is impaired (from Theme Category 8).

Findings in this dissertation study did not indicate nurses were judgmental of patients who did not participate in watching out for themselves, but nurses were exasperated because they felt they could not be as vigilant when patients contributed nothing to the relationship. Nurses also indicated a concern that patients who took little or no initiative in their own care would be unable to protect themselves from untoward outcomes.

Vague patient symptoms interferes with nursing vigilance. Nurses also mentioned vague patient symptoms made it difficult to be vigilant.

Key Finding: Vague patient symptoms impeded nurses’ abilities to be effectively vigilant (from Theme Category 6).

One task performance vigilance theory may contribute to the issue of vague, difficult to detect symptoms. The Signal Detection Theory hypothesized that weak signals are missed more often, and nurses seem to have an awareness that vague symptoms, like weak signals, create potential for missing critical, yet almost imperceptible indicators [26]. Nurses often describe efforts to interpret and act on vague symptoms, but are uncertain how they knew what was wrong, or sometimes what to do. Benner [243] proposed that intuition, a rapid, unconscious process in which the holistic nature of a problem is grasped, explains abilities of nurses to recognize and interpret vague symptoms. Benner’s theory is not without criticism as it was based entirely on qualitative studies and has little empirical support, yet nurses and others use it to explain the previously unexplainable ability of nurses to sense and interpret patient distress [244].

Interferences in Nursing Vigilance Associated with Doctors

Key Finding: When doctors are inexperienced or unfamiliar with patients, nurses perceive a threat for vigilance interference, and therefore heighten their vigilance for these particular physicians (from Theme Category 8).

Nurses perceived that doctors who were unfamiliar with patients and who were inexperienced interfered with nursing vigilance. Nurses particularly mentioned a monthly physician switch that occurred on their unit as interfering with vigilance. There is some support in the literature for nurses' concerns of both physician inexperience and being unfamiliar with patients creating potential for complications. In a study examining physicians cross-covering several hospital units (physicians covering for one another to decrease hours worked) researchers found that cross coverage of physicians increased the number of preventable, adverse events for patients, especially if the physician was inexperienced (an intern) [245]. Nurses in this dissertation study responded to inexperienced, unfamiliar physicians with heightened vigilance, because they perceived there was a higher likelihood of errors, in the form of missing orders or orders that were inappropriate for the particular patient.

Two Major Interferences with Nursing Vigilance

Of all the issues mentioned by nurses as interfering with their ability to be vigilant, two seem especially compelling. When physicians do not address end of life (EOL) with patients and families, and when critically ill patients are not transferred to the intensive care unit (ICU), nurses' abilities to maintain a balance of vigilance for all their assigned patients was disrupted.

When EOL is not addressed it interferes with nursing vigilance. A unique and potentially important finding in this dissertation study is the perception that nurses have about the failure of physicians to address EOL with patients and families and the potential for unaddressed EOL status to interfere with nurses' vigilance.

Key Finding: When physicians do not discuss EOL with patients and families there is a dramatic potential for nurses' balance of vigilance to be disrupted (from Theme Category 6).

While nurses in this dissertation study indicated that EOL knowledge was a right that should be accorded to patients and families, and this knowledge and awareness allowed families to be vigilant for EOL issues for the patient, when EOL status was not addressed, nurses could be left in untenable circumstances.

If physicians did not address EOL with patients and families and the patient became critically ill, nurses had no choice but to shift all their vigilance to maintaining the patients' life. Essentially, nurses had to shift into critical care mode, which meant one on one nursing care, despite the fact that nurses have several patients assigned to them. Therefore, the nurse could not pay attention to all patients assigned to them in a balanced kind of way, but had to shift a majority-if not all attention-to one critically ill patient. In addition to caring for the now full code status critically ill patient, nurses were were distracted by thoughts of whether this patient would even want to be full code status. When living with a terminal illness, and when properly prepared, patients and families can at least choose whether or not a full code status is desirable. Without such knowledge and decision-making, nurses are left with no choice but to respond as full code.

Therefore, one of the things nurses in this study were particularly watchful for was whether or not physicians had addressed EOL with patients and families and what symptoms patients might exhibit that led nurses to suspect EOL issues needed to be addressed emergently. Nurse findings strongly indicated that rather than be left with a critical situation in which EOL went unaddressed; nurses would take it upon themselves to introduce the topic earlier. However, nurses also indicated that addressing EOL was

often met with resistance from physicians who felt it was not within the nurses' scope to address.

Although McSteen and Peden-McAlpine [246] indicated nurses were advocates for discussing EOL, research supports the notion of barriers to nurses discussing EOL, and nurses' perceptions that physicians often do not address EOL in a timely fashion. In one study, Jezewski et al. [247] investigated what oncology nurses felt they needed to assist them in addressing advanced directives with patients and families. Nurses indicated that nurses wanted physicians to communicate EOL with patients and families, but also wanted physicians to support the nurses' roles in EOL. Nurses did not want retribution from physicians when nurses chose to discuss EOL with patients and families, particularly when physicians had not discussed EOL.

Critical care and vigilance interference. Whether or not EOL life status is addressed, oncology nurses are not staffed to safely care for critically ill patients who require one on one attention.

Key Finding: When patients become critically ill oncology nurses do not feel they are adequately prepared to safely care for them and a critically ill patient detracts from the nurses' vigilance for all other assigned patients (from Theme Category 6).

Nurses in this study requested that patients be transferred to ICU, but physicians sometimes refused to transfer or the ICU refused to take the patient. When critically ill patients were not transferred to ICU, nurses had no choice but to give one on one attention to the critical patient, which took attention away from all other assigned patients. Such instances were "worst case scenarios" for nursing vigilance.

Research seems to support nurses concerns about lack of expediency in transferring inpatients to ICU. Young et al. [248] found that when inpatient transfers to ICUs were delayed, patients had a much higher mortality rate than those transferred immediately. Dilemmas must exist for oncology nurses in relation to oncology patients

who become critically ill because Hull and O-Rourke [249] addressed the topic of critical care and oncology collaboration. Although the focus of the article was continuity of care, the authors clearly identified different strengths in nurses for each of these specialties. Oncology nurses were thought to possess expertise in symptom management, oncologic emergencies, and immunosupression, while ICU nurses focused on physiologic stabilization. The authors proposed collaboration between both ICU and oncology to provide patients with better care and reduce patient mortality and morbidity. While the authors implied the potential for ill-prepared nurses forced to care for patients they are unfamiliar with contributing to stress and burnout, there was no link made to the potential for oncology nurses' attention being wholly shifted to critically ill patients as detracting from nursing vigilance for other patients, thus increasing a risk for potential error.

Behaviors which Promote Nursing Vigilance

Nurses' findings indicated that certain behaviors promoted nursing vigilance. Three compelling key findings will be discussed: 1) Nurses develop routines to promote vigilance; 2) Being present in patients' rooms is a signal to patients that nurses are vigilant; and 3) Nurses purposely develop connectedness with patients to be more vigilant.

Routines and nursing vigilance. Nurses in this dissertation study perceived that routines helped them to be vigilant.

Key Finding: Nurses develop routines in order to be more effectively vigilant (from Theme Category 2).

Routines seemed to provide a focus structure the nurses needed in order to be vigilant .When routines were interrupted by for examples, hospital policy changes with the way medication was administered, or interruptions by patients' families, nurses became frustrated and somewhat anxious.

In order to remain vigilant at a high level, nurses felt their routines needed to be maintained. Literature supports the notion that interruptions in work routine increases the likelihood of error [250] and these dissertation findings indicate it is because interruptions distract nurses from a routine of vigilance. Interruptions in routines are a regular part of nurses' work [11], but they often add to an already high level of work demands which affects nurses' quality of work life [251] as well as decreases nurses' perceptions of patient safety [252]. Ebright et al. [11] recommended that when nurses are assigned to patients, the environment should be considered, because even the distance between patient rooms can increase non-patient interruptions.

Nursing presence and vigilance. Presence is an important indicator of nursing vigilance.

Key Finding: In order for patients to appraise the nurses as vigilant, nurses perceived they need to be present in patients' rooms (from Theme Category 2).

The literature is replete with articles about nursing presence. In examinations of the concept of presence, most authors indicated that presence can be physical, psychological, or spiritual [253, 254]. In a meta-synthesis of existing research, Fingfeld-Connett [253] indicated that antecedents to nursing presence included a patient need for a nurse's presence and a willingness on the part of a morally conscious nurse to be present as the environment allowed. Nurses in this dissertation study felt they needed to be present in patients' rooms in order to develop connectedness with them, in order to assess patients' conditions themselves, and in order to perform nursing actions which would overtly indicate to patients that nurses were being vigilant.

Nursing presence [255] and vigilance [15] have both been couched within the concept of caring and caring has been purported to be the basis of nursing; however, based on the findings of this dissertation, presence is more about vigilance than it is about caring. Caring as a central concept for nursing is not without criticism. Paley [256], Tarlier [257] and

Aranda [258] have criticized caring research from the perspective that it is no more nurse-like to be caring than it is to be competent. Although caring is a bonus if it occurs, caring is not the most important or necessary element in providing interventions [256]. Presenting caring as the primary function of nurses detracts from the complexity involved in nursing [258]; thus, caring distracts nurses from focusing on what is most important, which is the relationship between the nurse and the patient [257]. What patients want is for their nurses to be responsive to provide meaningful interventions [259]. As indicated by nurses in this dissertation study and implied in the literature, responsive relationships that result in meaningful interventions were indicators of nursing vigilance [257].

Connectedness and vigilance. Developing relationships with patients gives nurses a vigilance advantage.

Key Finding: In order to enhance their ability to be vigilant, nurses intentionally develop connectedness with patients (from Theme Category 4).

Connectedness appears to be an important and essential part of productive, satisfying relationships between patients and healthcare providers [260, 261]. Connectedness often emerges as an important concept in qualitative studies, from patients' perspectives. In other research, nurses reported they have purposeful relationships with patients [262], in order to meet needs important to the specific patient [263]. When patients felt connected with their healthcare providers they felt as if the healthcare providers were 'on top' of the patient's condition [260], supporting findings in this dissertation study that indicated, in order to be effectively vigilant, nurses purposely developed relationships and connected with patients. Nurses felt that if they got to know patients well, especially by being the appointed primary nurse, they learned what was normal for a particular patient, and then they could more quickly identify "different-than-normal", thus increasing their ability to be vigilant.

While nurses' findings revealed that connectedness is something nurses develop in order to be more effectively vigilant, findings also indicated that nurses' sometimes are not sure what appropriate levels of connectedness with patients are. Oncology nurses' certainly indicated a high level of commitment to cancer patients and even noted that some people may view their relationships with patients as 'crossing boundaries'. Nurses also commented that this uncertainty with connectedness boundaries began in nursing school, where they relayed they were told to not get too close to patients.

Discussions exist in the literature about boundary uncertainty and issues of distance and intimacy in nurse-patient relationships [258, 264]. Nurses reported that when they violated the unit culture by having patient relationships that were deemed too intimate, they were penalized [258]. However, uncertainty arises because nurses must engage in a level of intimacy to develop connected relationships. The remedy for overinvolvement is not lack of involvement and nurses who are self aware are more likely to balance a connected relationship with patients without being overinvolved, both personally, and emotionally [258, 264].

Nursing Vigilance and Family Members

Although nurses had many perspectives about family members and vigilance, the perception that nurses rely on family member vigilance, which in turn helps nurses be more vigilant is a compelling and unique finding. Nurses' reliance on family member vigilance is the focus of this discussion section.

Key Finding: Vigilant nurses rely on and encourage family member vigilance (from Theme Category 8).

In this dissertation study, to be more effectively vigilant, nurses recognized, valued and used family member's intimate knowledge of patients. Because family member vigilance was so beneficial to nurses, nurses looked for signs family members were being vigilant and encouraged such vigilance. When nurses could identify vigilant family

members, nurses were less anxious about discharging patients from the hospital because they felt as if the patient would have vigilant care, therefore better outcomes.

Outside of pediatric literature, there is little research about nurses and families' relationships, particularly in acute care [194, 195, 220, 221, 235]. In relation to one another, both nurses and family members are in odd and somewhat undefined positions. The nurse is present to care for the patient and what the acute care nurse's responsibility is in relation to the family is often undefined. Soderstrom et al. [265] found that nurses felt unprepared to assess family needs and provide support to families and felt they needed more education on the best ways to conduct interactions with families. Yet, nurses recognized benefits to family members' involvement and nurses based nurse-family relationship development on underlying beliefs of whether families improve or hinder patient care and the nurses' abilities to care for patients [221, 265]. Nurses felt as if families who were present in the acute care setting improved nurses' quality of performance [265] and patient outcomes [266].

Despite the benefits of family involvement, and in contrast to the findings in this dissertation, the literature indicates family members in acute care settings who asked a lot of questions or were overly observant of nursing activities were viewed as interfering with patient care and nurses' jobs [220, 221, 265]. In response to perceptions of family interference, nurses did uninviting actions that were perceived as controlling, unemotional, or exclusionary of family involvement and these action prevented development of connectedness with families [221, 265]. In contrast to these literature findings, vigilant nurses in this dissertation study indicated that families who asked questions, kept track of information in a journal, or watched the nurse closely, were not interpreted as threatening or interfering: These family members were considered vigilant, which contributed to nurse-family connectedness.

Nursing Vigilance and Patients

Nursing vigilance is deeply ingrained in nurses' work. The primary focus of nursing vigilance as a whole is on patients and nursing duties such as assessment and treatments. Nurses' findings however indicated that nurses are especially watchful of patients' emotions and energy levels which is discussed in this section.

Key Finding: Nurses are particularly watchful over patients' emotions and energy levels (from Theme Category 8).

Nurses perceived that both extensive medical testing, such as CAT scans, and negative patient emotions, such as anxiety or anger, drained patient energy and prevented patients from being effectively vigilant. Thus, nurses indicated that they were especially watchful in respect to patients' emotions and energy levels.

Research indicated that cancer patient fatigue and emotions were related to one another and affected one another, either positively or negatively [267, 268]. For example, positive attitudes and hope were strongly related [269]. Nurses perceived that patients, family members, and nurses who had positive emotions and outlooks contributed to patients' having better disease and treatment outcomes, therefore contributing to hopefulness. Alternatively, nurses labeled patients who were angry or questioning as having negative emotions or attitudes, thus worse outcomes, such as hopelessness [269]. As discussed in a previous section, patients who scored higher on hopelessness measures died at higher rates than patients who scored higher on hope measures [184]. The emotions, hopelessness and depression, were highly correlated with sleeplessness, compounding issues with patient fatigue. Further, the combination of such negative emotions with symptoms of sleeplessness led to higher patient death rates when compared to patients who did not score highly for depression, hopelessness, and sleeplessness [270].

Nursing Vigilance and other Healthcare Providers

Nurses' findings indicated that nurses are vigilant for other nurses and healthcare providers. Often vigilance directed at other healthcare providers is a means of indirectly protecting patients. Two key findings guide this discussion section: 1) Ways in which nurses try and solicit orders from doctors; and 2) Nurses' extra watchfulness for inexperienced nurses.

Nursing vigilance and doctors' orders. Nurses' findings in this dissertation research indicated that nurses spend time monitoring doctors.

Key Finding: Nurses approach doctors in different ways to try and get vigilant responses from the doctors (from Theme Category 8).

Nurses were vigilant for doctors' interactions with patients and doctors' awareness of current patient status, particularly lab results. For example, nurses identified a low platelet count, which produced a threat for patient bleeding, so nurses expected to see physicians write an order for transfusion of platelets. Nurses relayed checking continually for doctors' orders. If the orders were not written in a timely manner, the nurse would approach the doctor.

Nurses indicated a preference for getting doctors to write orders for patients through an indirect approach. Before approaching doctors to get patient orders, nurses perceived they had to "have their ducks in a row" (Nurse 001). To make their requests for patient orders seem non-demanding nurses often used humor or a displayed an attitude of deference. In attempts to get doctors to write orders for patients, or intervening when a doctor was insistent on a course of action that nurses felt may be harmful to patients, using assertiveness was a last resort for nurses.

Tanner et al. [271] described a similar kind of indirect communication that nurses used with physicians to get them to seriously and immediately attend to patients. While Tanner et al. concluded that the nurses communicated in indirect ways because they

had a good rapport, developed over years, with familiar physicians, other authors indicated that hierarchical relationships promoted indirect and deferential communication and was a game doctors and nurses played [272]. In order to get what the patient needed, nurses approached doctors submissively. More recently, authors suggested that higher nursing education levels reduced doctors' hierarchical power. In turn the amount of indirect and submissive communication from nurses to doctors decreased because nurses communicated more assertively [110, 273]. However, other research reported findings similar to these dissertation findings, in that nurses preferred to communicate indirectly first, and then became more direct if indirect communication did not achieve nurses' goals [274].

Nurses' goals were often aimed at protecting patients. Much like the above example with low platelets and risk of patient bleeding, nurses pursued orders from doctors to decrease the risk of threat and preemptively protect patients. Research indicated nurse-physician communication and medical errors or patient safety were related [275, 276]. Findings in the literature indicated that the whether nurses spoke up or how nurses communicated was strongly influenced by healthcare cultures and environments. Nurses in magnet facilities were more likely to communicate with physicians, which reduced error [275], while nurses who perceived work environments had low levels of procedural justice often chose to remain silent, even in light of potential patient safety concerns [276].

Nurses watch out for inexperienced nurses. Nurses in this dissertation study indicated that they watched over each other and each others' patients, but particularly knew they needed to be watchful for inexperienced nurses.

Key Finding: Nurses are especially vigilant for inexperienced or novice nurses (from Theme Category 8).

Despite their knowledge of the need to be watchful, even experienced nurses were sometimes surprised by inexperienced nurses' lack of knowledge and inability to make

critical connections, which interfered with their ability to be vigilant. Experienced nurses could more readily identify and correctly interpret threats, whereas inexperienced nurses often failed to correctly assess threats. However, inexperienced nurses engaged experienced nurses when things did not make sense or when inexperienced nurses felt uncertain. Thus, because experienced nurses attended to inexperienced nurses' concerns, they took on a greater share of vigilance burden when working with inexperienced nurses.

Nurses have long been aware of the difference between inexperienced, or novice, nurses and experienced nurses through such theories as Benner's. The literature is rife with articles about Benner's novice to expert nursing theory e.g. [277-279]. Benner's theory was used to structure preceptor or mentoring programs in hospitals for the purpose of transitioning novice nurses into practice [278, 279], decreasing their stress [280], and therefore improving retention of new nurses [281].

However, outside of stress and retention, there was little found in the literature which addressed concerns about novice nurses. Nurses in this dissertation study perceived that novice nurses lacked the knowledge they needed to be effectively vigilant, and were therefore at higher risk for errors. Other research supports the perceptions of nurses in this dissertation study. Novice nurses generally did not have the expertise to deal with heavy patients loads, particularly when time to perform duties was limited, and they were unfamiliar with all procedures [282, 283]. The pressures associated with lack of knowledge and workload increased near miss errors and produced higher potential for failure to rescue patients [282, 283]. Novice nurses cannot selectively put pieces of information together to create a clinically correct and meaningful 'big pictures' [283].

In this dissertation study, experienced nurses described vigilance as a way to 'sift through' incoming information and use what was relevant to create a 'big picture' that was used to make decisions about patients and interventions. Novice nurses seemed to

have difficulty in ‘sifting’ through data in this manner. Other research indicated that novice nurses become overwhelmed and therefore stressed [280, 282]. In this dissertation study vigilant nurses indicated that strong, negative emotions, lack of knowledge, hurried care, and hypervigilance were things that were oppositional to effective vigilance, and novice nurses seem especially susceptible to conditions that produce interference with vigilance, such as these.

In this dissertation study, experienced nurses indicated they were engaged by inexperienced nurses for help. For years, hospitals systems, both formally and informally, have relied on experienced nurses to help inexperienced nurses. Yet, little is known about the mechanisms that contribute to such help and what affects this has on the experienced nurses. There was very little in the literature that addressed the realities of experienced nurses working with inexperienced nurses in an informal way. However, research on preceptor experiences was used to better understand underlying issues of experienced nurses working with inexperienced nurses [284-286].

Precepting inexperienced nurses was stressful [284-286]. Preceptors indicated that instead of the number of patients cared for being reduced when precepting inexperienced nurses, preceptors were actually assigned more patients because two nurses would be caring for them [284-286]. The lack of experience for one of these nurses was not considered when giving extra patient assignments. Thus, preceptors had to both watch over and teach the inexperienced nurse, while providing care for a surplus of patients, which reduced the actual amount of time nurses could devote to giving direct care [284-286]. Preceptors seemed aware of the extra vigilance burden evidenced by comments that they had to be vigilant for inexperienced nurse and potential errors which could lead to patient harm [284].

Overall, there appears to be little formal concern about safety or errors related to inexperienced nurses and precepting. The lone indicator acknowledging the importance

of overseeing the practice of inexperienced nurses was in relation to the administration of chemotherapy [287]. Chemotherapy errors can produce death or horrific damage to patients, and the administration of it is tightly controlled. Thus a dichotomy exists in research in recognizing some concerns about novice nurses and potential danger in practice, while ignoring others.

Nurses and Shared Vigilance

Key Finding: Nurses indicated that they relied on patients, family members, and other nurses to share in vigilance so nurses be more effectively vigilant (from Theme Category 10).

In this dissertation study, nurses indicated that they relied on others to be vigilant in order for nurses to be more effectively vigilant. When patients, family members, or other healthcare providers did not participate in being watchful, nurses were frustrated because they were left at a vigilance disadvantage. Nurses addressed perceptions of shared vigilance by group, and it was rare for nurses to present shared vigilance as a team process wherein, patients, healthcare providers, and families all contributed. The nurse was more of a central hub linking vigilance of patients, families, and healthcare providers with their own and others' vigilance.

Ideas underlying the need for shared vigilance were found in literature on relationships, but divided much the same away as nurses in this study divided it among groups [214, 220-222, 240, 242, 262-266, 288]. The literature did not reflect a focus or concern for relationships that occur between families, patients, and healthcare providers together.

Reciprocity was most often noted as a means of sharing responsibility for certain elements in relationships [220, 242, 263, 264]. Trust was a cornerstone in persons being able to reciprocate in relationships [220, 242] and reciprocal relationships had elements of constancy and purposefulness [262]. When reciprocity existed the relationship was viewed as positive with a sense of well-being as an outcome [242]. Much like the elements

described in reciprocal relationships, nurses in this dissertation study indicated that trust, constancy in getting to know patients, families, and other healthcare providers were important elements of shared vigilance.

When further considering such elements of reciprocal relationships, inferences may be drawn concerning shared vigilance. For example, when patients do not allow nurses to be involved, care is made more difficult [263]. Findings from this dissertation study indicated that nurses relied on patients participating fully in their own vigilance, which informed the nurses' vigilance. Thus, when patients did not participate in vigilance for themselves, and with nurses, care was more difficult because the nurses had to try and guess what might be wrong.

Another element to consider in the development of shared vigilance was constancy. When nurses are able to get to know patients, families, and other healthcare providers, nurses are more able to be vigilant, because there is more opportunity to share vigilance. One reason nurses in this dissertation study may have found the monthly physician change on their unit so disturbing was because the switch produced an interference with reciprocal relationships that were developed over a month. Those physicians were no longer available and a new of physicians entered, necessitating the development of or renewal of relationships, which for a time, reduced the potential for shared vigilance.

Clinical and Research Implications for Vigilance

The matrix analysis identified commonalities of vigilance across groups from this dissertation research. Because of the large amount of data, the five most compelling commonalities were chosen as the focus for implications from the dissertation findings. The five themes identified as key points for discussing implications were: *Shared Vigilance, Vigilance is Beyond the Call of Duty-More than the Minimum, Knowledge is Imperative, Hope and Vigilance*, and *Connectedness as a Signal of Vigilance*.

Discussion of implications is structured in the following ways: 1) The matrix commonality is identified, followed by a brief synthesis of across group findings for the specific commonality; 2) Clinical implications for the commonality are discussed; and 3) Research Implications for the commonality are discussed.

Matrix Commonality 1. Shared Vigilance

Shared vigilance emerged as a new phenomenon in this dissertation research. All participants indicated that vigilance occurred at some level between persons. While all groups recognized the need and importance of shared of vigilance, the expectation of shared vigilance was not adequately expressed, but often implied. All three groups expected the other two groups to share vigilance by being watchful on the other's behalf and then to communicate what was observed, but the expectation of that sharing was not often expressed to the other parties. Patients relied on family members to be vigilant, but the actual expectation for sharing vigilance was unspoken. When expectations were not met, the result was frustration, experienced by all groups. When considering these dissertation findings about shared vigilance, it seems nurses and other healthcare providers might consider explicitly discuss expectations of shared vigilance among patients, family members, and nurses.

Clinical Implications

Patient implications for shared vigilance. Healthcare providers can make clear for patients what kinds of things are realistic to watch for, while reinforcing what nurses and other health professionals will specifically watch. Patients need to know that healthcare providers have communicated with one another about patients' concerns or condition, so patients do not have to feel responsible to check if all providers have the same information. When such information is conveyed to patients, they can relax and save their vigilance energy.

Nurses can help patients recognize specific kinds of family member watchfulness. Such recognition will be necessary for shared vigilance to work more synergistically among patients, family, and nurses. If nurses could be explicit about patients and families vigilance roles, together, it may be easier for patients to recognize the contribution family members make with their vigilance.

Family member implications for shared vigilance. Nurses can be mindful of the awkward position family members often experience in acute care settings. Families need to be included in all aspects of patient education, while at the same time being given respect for the superior knowledge they possess about patients.

Family members were very vigilant for patients; however, their expectations of patients sharing in vigilance were implicit. Nurses need to have an awareness of the reciprocal nature of shared vigilance between family members and patients. Family members who assume the patients' vigilance responsibilities in addition to their own become exhausted and negative after a period of time. Nurses can try and recognize when patients are not sharing in vigilance with family members. Nurses may suspect that patients cannot or will not participate in shared vigilance if family members become negative and extremely tired. Investigating barriers to such sharing and encouraging patients to be watchful, even in small ways relieves family of total responsibility and helps them renew their ability to be vigilant.

Nurse implications for shared vigilance. Shared vigilance seems a critical concept about which healthcare providers need to be explicit. Nurses can inform patients and families that nurses rely on them to indicate concerns or share symptoms. Nurses can reinforce that patients and families do not have to have all the answers or even know what is wrong, but that in shared vigilance, that is where nurses can help. Because of their knowledge and experience, nurses can often put puzzle pieces of information together, if patients and families at least share the puzzle pieces. Instead of being

frustrated with patients, nurses could share with patients the importance of what patients contribute to nurses being able to be effectively vigilant. Nurses can recognize that such frustration likely comes from anxiety, because they are trying to be vigilant without all pertinent information. If patients are not forthcoming, it seems even more critical that nurses engage family members to share in vigilance.

Research Implications

Findings from this dissertation research supported the idea that vigilance is more than just an individual response to a stimulus, but rather is a complex phenomenon that is shared among individuals. There are benefits in researching multiple perspectives at one time. One possible reason shared vigilance has not before been identified is because researchers have focused on single population perspectives. Thus, it seemed that vigilance was something that a person did by him or herself. Conducting additional studies which examine specifics of shared vigilance seems warranted. Additional perspectives of shared vigilance, such as those of doctors may further inform this phenomenon.

Models of shared vigilance need to be developed and tested, as well as instruments to measure perspectives of shared vigilance. When models and instruments are developed, intervention studies could be implemented and comparison of control and experimental groups could then be made. Particular attention needs to be paid to levels of analysis, with a focus on group perspectives of shared vigilance, with the group consisting of a patient, family member, and nurse. An example of varying levels of analysis is Phipp's study of infertility in which she studied wife and husband experiences individually, and then their experiences as a couple [289]. Findings indicated clear differences in experiences within and across these groups.

Matrix Commonality 2. Vigilance is Beyond the Call of Duty

Across all participant groups, healthcare provider vigilance was identified through performance beyond the call of duty. As a minimum, patients and family members expected healthcare providers, and especially nurses, to do their job. However, highly vigilant healthcare providers were identified as nurses who performed beyond patient and family expectations, through extra and unexpected actions, beyond routine care. Nurses clearly indicated that nursing vigilance was not optional and required a whole-hearted investment, beyond just a desire for a paycheck. Implications will be discussed that may help nurses improve perceptions of their level of vigilance and implications for levels of vigilance on potential for healthcare errors.

Clinical Implications

Implications for being perceived as highly vigilant. The quality of care provided in hospitals may be improved when nurses are aware of the importance patients and families place on going beyond the minimum-going the extra mile-in their job performance. These “little extras” can be easily overlooked as insignificant; yet these small, extra actions lead to views of nurses as highly vigilant. In fact, patients and families rank order nurses from most to least vigilant based on their observations of nurse going beyond the call of duty. In addition, the higher level of perceived vigilance is key to patients feeling protected, connected and respected.

Based on findings of our study, nurses who want to increase the likelihood of being perceived as highly vigilant can consider the following.

1) Adopt a demeanor that does not appear to be rushing when providing care and interacting with patients and families.

2) Be present in patients’ rooms as often as possible.

3) Respond to patient or family needs in a timely fashion or at a minimum communicate an accurate timeframe for being able to respond.

4) Communicate a willingness to be flexible with routines.

5) Use creative strategies to get to know patients and families personally. An example is having families put up pictures that are especially meaningful to them and that precipitate discussions about the patient and family outside the context of their illness and hospitalization.

6) Actively listen to patient and family concerns.

7) Perform accurate and meaningful assessments of patient symptoms and family needs.

Implications for levels of vigilance on potential healthcare errors. Findings from this dissertation study related to levels of vigilance have important implications for prevention of medical errors. There may be a protective factor in performing at a highly vigilant level; conversely minimally vigilant nurses may be more likely to make errors. When nurses are performing at the minimum level of vigilance-just doing their job-, findings indicate there is a danger of slipping below that level into perceived or actual negligence.

Research Implications

This dissertation research has just begun to identify ways in which patients identify highly vigilant healthcare providers. Observational studies and studies where technology was employed, in which patients could, in real time, note vigilant healthcare providers behaviors would be helpful in identifying additional behaviors or actions that signal high levels of healthcare provider vigilance patients.

Identifying such behaviors could further inform error research from patient or family perspectives. Existing error research minimized patients concerns about errors, indicating that patient could not appropriately identify errors [158]. What is clear from this dissertation study is that patients and families are able to identify behaviors and actions associated with healthcare provider vigilance and lack of vigilance. What patients identified in previous error studies were behaviors or concerns which indicated lack of

vigilance, which patients interpreted as potential for error. Further research needs to be done to see if relationships exist between behaviors and actions patients and families see as lack of vigilance and near miss or actual errors.

Lastly, this dissertation research leads to questions about the relationship of patient satisfaction and quality of life to levels of healthcare provider vigilance. Research needs to be conducted to examine potential relationships between highly vigilant nursing care with both patient and family satisfaction and quality of life.

Matrix Commonality 3. Knowledge is Critical to Effective Vigilance.

Across all three participant groups, knowledge was identified as essential for the ability to be vigilant. When participants lacked knowledge, they could not be effectively vigilant. Patients and families actively sought knowledge from many sources, though families seemed to have a harder time accruing knowledge related to the chaos of patients' diagnoses and subsequent hospitalizations. Nurses were aware that initially, patients and family members lacked knowledge; therefore nurses were more vigilant for newly diagnosed and newly admitted patients. Clinical implications for knowledge will be discussed for patients and families together, and then discussed for nurses.

Clinical Implications

Implications for patient and family knowledge. Findings from this study suggest that nurses should explicitly help patients and families link knowledge with the ability to be vigilant as a way to underscore the importance of patient education. Patient education becomes a much more serious undertaking when viewed as a means to watch out for and protect oneself or one's loved one. Sometimes patients or families in the study were overwhelmed by too much information, while too little information left them unable to be as vigilant. To address the potential for too little or too much information, individualized patient and family education is recommended. To assure patients and families have the

requisite knowledge to be vigilant, basic principles of patient education, such as asking patients or family to explain or demonstrate what they have learned, should be used.

Family members are often at a knowledge disadvantage because they may not be present for many patient education sessions and incorporating ways in which family members can gain knowledge, even when they are not present, will help family members participate fully in vigilance for patients. Nurses may find it helpful to identify family members who exhibit actions indicative of vigilance, such as those who journal, ask a lot of questions, or are particularly attentive of nursing actions. Such vigilant family members will be more likely to engage in knowledge acquisition and use it to enhance their existing ability to be vigilant.

Access to patient and family knowledge helps nurses be more effectively vigilant. If patients and families lack knowledge, and are unable to therefore be vigilant, they are also unable to effectively contribute to shared vigilance. As such, vigilant nurses became more highly watchful of newly diagnosed or newly admitted patients. Thus, it is in nurses' best interests to increase patients and families knowledge levels so they can make meaningful contributions to shared vigilance, allowing nurses to be more effectively vigilant. Because of cancer patients' memory impairments, nurses need to recognize the role of family members as keepers of knowledge. If families are as informed as patients, then family members can support nurses by helping reinforce critical pieces of knowledge, which promotes patients' abilities to be vigilant for themselves and families to be vigilant for the patient.

Research Implications

The kinds of knowledge minimally needed to produce effective vigilance needs to be identified. Research needs to be conducted that indicates how much information, over what amount of time seems to produce the greatest retention of knowledge, particularly for patients experiencing side effects of cancer treatment, such as memory impairment.

Research is primarily focused on knowledge family members need in order to give care at home: The research is virtually nonexistent for family information needs in acute care settings. Because treatment for leukemia often results in long-term hospitalizations, it seems prudent to develop and test educational interventions for family members that progresses from acute care knowledge needs to knowledge needed for home care. Since previous research indicated significant numbers of family members feel unprepared to care for patients at home, differing types of education could be measured and compared for effectiveness, perceptions of unmet needs, quality of life, family member vigilance, and caregiver burden.

Matrix Commonality 4. Connectedness and Vigilance.

Patients and family members perceived that nurses who went out of their way to connect with them and accommodate them were more vigilant nurses than those who did not connect with them. In these dissertation findings, vigilant nurses confirmed that they purposely connected with patients and family members to become familiar with what was normal for that specific patient or family. Knowing what was normal, allowed nurses to be more effectively vigilant, by more quickly identifying 'different than normal" behaviors or symptoms for specific patients and family members. Implications for connectedness are primarily relevant for nurses and hospital administrators, therefore implications are presented for these two groups.

Clinical Implications

Nursing implications for connectedness. To increase nurses' ability to be vigilant, strategies may be considered to enhance connectedness with patients and families. Strategies to foster connectedness include: 1) Getting to know patients and families on a personal level; one way to increase personal knowledge of families is through primary nursing; 2) Accommodating family members' needs; 3) Explicitly recognizing patients and families unique strengths; and, 4) Help patients to sense a home-like environment.

One example of such a strategy that also illustrates going “above the call of duty”, was when nurses ordered out food and asked long-term hospitalized patients or families if they would like to place an order also. Such actions led patients and family to feel as if they were being watched over as a part of the “family”.

Hospital administrators and connectedness implications. In these dissertation findings, nurses expressed some concerns about boundaries and what might be viewed as boundary violations as they connected with patients and families. Such concerns seem especially problematic for oncology nurses as they are dealing with life and death of patients, and often repeated, long term hospitalizations. Hospital administrators need to be aware of and provide education and exploration of such concerns. Unconnected or disconnected nurses will not be viewed as vigilant, so clarification of connectedness boundaries would help nurses enact appropriate connectedness, which in turn enhances patient and family perceptions of nursing vigilance.

Research Implications

Connectedness among healthcare providers, patients, and families is a little researched and little understood phenomenon. In order to better understand connectedness and its relationship to vigilance, more research about connectedness is recommended. How nurses develop connectedness with patients and family members needs to be delineated, particularly in light of the discouragement to develop connected relationships nurses receive in nursing school and in acute care settings. In addition, healthcare provider behaviors that act as barriers to connectedness need to be identified. More specific information about the ways in which connectedness informs nursing vigilance should be researched.

Matrix Commonality 5. Hope and its Relationship to Vigilance.

Hope emerged as an important and previously unrecognized element related to vigilance. Patient findings indicated patients wanted to be hopeful and have others instill

hope, while family members focused almost entirely on monitoring patients' levels of hope. Nurses felt there was a need to support realistic hopefulness in patients, families, and themselves. The across group perspectives allowed a connection to be made about the meaningfulness of hope for vigilance. Essentially, if patients become hopeless, they will cease to be vigilant. Other research indicated when patients are more hopeless, they die at higher rates. Our findings indicate that when patients are hopeless, they are at risk to cease being vigilant for threats, and because of this expose themselves to dangerous conditions, contributing to greater death rates.

Clinical Implications

Patients, hope, and vigilance. Lazarus believed that when people were hopeful, the corresponding action was vigilance [182]. Thus, nurses can assess patients' levels of vigilance or hope indirectly. If nurses notice patients are not being vigilant at all, nurses may want to question the patient about their hopes or hopelessness. Likewise, if patients are exhibiting signs of hopelessness, nurses need to suspect that patients may not be vigilant for themselves. Nurses can help patients identify what to be hopeful for, which may change, based on the course of the cancer and its treatment. When one thinks of hopelessness as a trigger for lack of vigilance, the importance of maintaining some kind of hope, thus vigilance, becomes extremely important.

Family members, hope, and vigilance. As family members remained highly focused on maintaining patients' levels of hope, they often ignored or suppressed their own concerns or needs. When nurses become aware of family members' sacrifices in relation to encouraging hope in patients, they may consider offering family members safe places to express negative emotions, away from patients. Referrals to social workers or chaplains may be necessary for family members to engage in such self care. If nurses identify family members as becoming hopeless themselves, nurses may suspect patients are dwelling in hopelessness as well. There is strong research evidence for

reciprocal effects of family members and patients on one another. Where there is a potential for reciprocal effects of hopelessness, vigilance is likely to be diminished.

Nurses, hope, and vigilance. Nurses are in a pivotal position to monitor patient and family emotions, particularly hope. While hope has always been an important focus for oncology nurses, these dissertation findings magnify the importance of hope and its influence on vigilance, and on the possibility of decreased mortality.

Given the study findings on nurses' difficulty adjusting their foci of hope from remission to hospice, they need safe places to express their disappointment, difficulties making adjustments in foci and emotional responses. Nurses additionally need help changing their own and their patients' and families' hoped for goals from cure or control of the cancer to goals that are realistic at the end of life. Hoped for goals directs the focus of patients, families and nurses vigilance.

Research Implications

Hope and its relationship with vigilance needs to be further established. Why people who score higher on hopelessness scales die at almost twice the rates as people who score higher on hope scales need to be examined from a vigilance perspective. It is feasible that patients who are hopeless become less vigilant and do not or cannot effectively protect themselves from threat.

Methodological Implications

As indicated in Chapter II of this dissertation study, levels of analysis need to be considered when constructing studies, collecting data, and measuring concepts. Often, research studies are conducted from the individual level of analysis. Certainly that has been the case in the study of vigilance, as both a task performance and a complex phenomenon. Only one perspective has been measured in past vigilance studies, whether patients, family members, nurses, or physicians. When only one perspective is measured, the complexities in a phenomenon may not be fully recognized. In this

dissertation study, one interesting example of examining data at individual and across group levels emerged. Connectedness was a commonality identified in each participant group and emerged as across group commonalities as well. If only one perspective was measured in this dissertation research, the complexities of connectedness and its relationship with vigilance would likely have been diminished. Connectedness as a commonality provides an example of the value of multiple group perspectives for methodological considerations.

Perceptions of vigilance and connectedness were especially interesting in this dissertation research because of the confirming evidence from across group perspectives. The value of more than one participant group perspective enhanced the understanding of connectedness as related to vigilance. Patients and families felt that nurses who connected with them were more vigilant. Nurses confirmed these perceptions by indicating they purposely connected with patients in order to be more vigilant. Without participation of all groups, such important links would likely have been missed. More research which takes into account multiple perspectives may produce more complex, yet meaningful connections among concepts.

Summary

In this dissertation study vigilance emerged as a complex, multidimensional, interactive (between persons) phenomenon. Examining perspectives from multiple samples allowed a more wholistic picture of vigilance to emerge and revealed complexities previously undiscovered. Vigilance in healthcare is not just a response to stimuli, rather is a phenomenon that depends, in part, on the relationships between nurses, patients, families, and other healthcare professionals. The environment seems to influence the ability to be vigilant for each of the participant groups.

From a clinical perspective, vigilance among nurses, patients, and family members has been mostly implicit. Vigilance is such an ingrained part of what healthcare

professionals do on a daily basis that, as a phenomenon, vigilance is not recognized nor consciously examined in order to improve performance. Explicating vigilance will do two things: 1) Adds to the growing body of knowledge about nurses' work. Such knowledge will allow nurses to support the value of what nurses uniquely contribute to the healthcare industry and patient care; and, 2) Will strengthen the ability of vigilance to influence patient outcomes. Vigilance needs to become a more explicit part of interactions among nurses, patients, and families. When each partner understands what is expected of them from a vigilance perspective, less room is left for missing crucial knowledge links within the partnership, which also decreases the likelihood of error.

Vigilance, as conceptualized within this dissertation research, requires more examination through research. Vigilance has not previously been conceptualized as a complex, interactive phenomenon. Models of shared vigilance need to be constructed and tested. In order to carry out this level of research, instruments need to be developed that are constructed to measure vigilance from individual and group levels of analysis. In particular, the measure of vigilance from a group level would allow the testing of interventions and the ability of the intervention to strengthen shared vigilance through vigilance partnerships among nurses, patients, and family members. Lastly, vigilance needs to be further examined in light of healthcare errors and how the perspectives of patients and families may inform error research. Patients and families clearly seem to recognize healthcare provider and healthcare environment contributions to and interference with the ability to be vigilant. As such, their perspectives may provide valuable insight into preventing healthcare errors.

APPENDICES

Appendix A

Examples from Literature Suggesting Increased Vigilance as a Solution to Healthcare Issues

The incidence of tuberculosis in Western countries is rising, and continued vigilance together with an awareness of its protean manifestations is essential (from: Saral Y. Coskun BK. Ozturk P. Bulut Y. Cobanoglu B. Multiple metastatic tuberculosis abscesses in a patient with Pott disease and lung tuberculosis: a case report. [Case Reports. Journal Article] Journal of Cutaneous Pathology. 32(9):629-33, 2005 Oct).

These cases demonstrate the need for continued vigilance and education regarding lead poisoning in children (from: Florin TA. Brent RL. Weitzman M. The need for vigilance: the persistence of lead poisoning in children.[see comment]. [Journal Article] Pediatrics. 115(6):1767-8, 2005 Jun).

Opportunistic screening and vigilance for clinical presentations suggestive of DM is encouraged (from: McIntyre RS. Konarski JZ. Misener VL. Kennedy SH. Bipolar disorder and diabetes mellitus: epidemiology, etiology, and treatment implications. [Review] [100 refs] [Journal Article. Review] Annals of Clinical Psychiatry. 17(2):83-93, 2005 Apr-Jun).

First, as the central component of all patient safety activities, communication requires constant vigilance (from: Lindblad B. Chilcott J. Rolls L. Mary Lanning Memorial Hospital: communication is key. [Journal Article] Joint Commission Journal on Quality & Safety. 30(10):551-8, 2004 Oct).

Hospital departments should maintain a high level of vigilance towards such incidents as this, and should routinely undertake a direct measure of the saturation of haemoglobin by CO, i.e. blood carboxyhaemoglobin or breath CO (from: Gallagher F. Mason HJ. Carbon monoxide poisoning in two workers using an LPG forklift truck within a coldstore. [Case Reports. Journal Article] Occupational Medicine (Oxford). 54(7):483-8, 2004 Oct).

Appendices B, C, D, and E

Protection of Human Subjects

Appendix B

Scientific Review Committee Approval

SCIENTIFIC REVIEW COMMITTEE

Indiana University Cancer Center

SRC Approval Date: February 10, 2006
Principal Investigator: Joan Haase, PhD, RN

Project Title: Vigilance Experiences as Described By Cancer Patients Receiving Treatment for Cancer, Their Families, and Their Nurses

Sponsor: IU
Study Number: IUCRO-0138
Building/Room Number: RT 380
Department: Behavioral
The study listed above has received **final approval with stipulations** from the Scientific Review Committee. As the principle investigator of this study, you assume the responsibility of following the Indiana University Cancer Center Data Safety Monitoring Plan guidelines. The responsibilities start at the time of IRB approval.

1. ADVERSE EVENTS
Internal Adverse Events:
Definition:
Expedited Reports: Adverse events that must be reported per protocol in an expedited manner for timelier monitoring of patient safety and care. Expedited reports include AdEERS reports, MedWatch, IRB SAE forms, and additional SAE forms required by the sponsor.
24 HOUR Reporting
For all studies, internal adverse events requiring expedited reporting by phone within 24 hours (as described in the protocol) will be reported to the CTMC, within one business day, by email to Theresa Nguyen at thenguyye@iupui.edu. Follow-up information such as hard copies or electronic versions of NCI Adeers forms, MedWatch and/or other required forms required by the company along with a copy of the IRB SAE form should be provided within 10 working days. Forms will be sent to IUCC CRO RT 380 attn: CTMC.

3-10 DAY REPORTING
For all studies, internal adverse events requiring expedited AE reports in writing within 3-10 working days (as described in the protocol) require hard copies or electronic versions of NCI Adeers forms, MedWatch and/or other required forms required by the company along with a copy of the IRB SAE form. Forms will be sent to IUCC CRO RT 380 attn: CTMC. Cumulative reports of expedited reporting will be reviewed quarterly.

External Adverse Events:
Investigator Initiated Trials' external serious adverse rates will be reviewed by the CTMC on a monthly basis. Provide a list of all external serious adverse events that were **reported to the IRB,** sorted by protocol to include protocol title, IRB number, PI, event #, date received, event description, and if it was an initial or follow-up report. Reporting

time frame is the 1st of the month to the last of the month. Reports will be sent to IUCC CRO RT 380 attn: CTMC by the 15th of each month.
**If you are using the AE database in ECT this report is automatically generated monthly.*

2. PROTOCOL DEVIATIONS:
Investigators are required to submit Protocol Deviation Forms, using the standard IRB forms, to the CTMC concurrent with their submission to the IRB. Reports will be sent to IUCC CRO RT 380 attn: CTMC

3. ACCRUAL
Quarterly reviews of accrual per protocol will be reviewed by the CTMC. Reports should include PI, protocol title, IRB number, date opened to IRB, total accrual to date, quarterly accrual, and targeted accrual of each study. Accrual reports will be submitted to the CTMC for review. Reports are due the first of January, April, July, and October. Submit reports to IUCC CRO RT 380 attn: CTMC
**If you are using the ECT Registration database this report will be automatically generated quarterly.*

4. PHASE 1 SUMMARY REPORTS
For Phase I trials **without an external DSMB**, weekly review meeting summaries will be reviewed by the CTMC. Summaries should include review of data and patient safety by including for each dose level: the number of patients, significant toxicities as described in the protocol, dose adjustments and responses observed. Weekly summaries will be submitted to the CTMC for quarterly review. Submit reports to IUCC CRO RT 380 attn: CTMC by the 15th of each month.

***5.* PHASE I/II AND PHASE II SUMMARY REPORTS**
For Phase I/II and Phase II studies **without an external DSMB**, monthly review meeting summaries will be reviewed by the CTMC twice yearly. Summaries should include review of data, the number of patients, significant toxicities as described in the protocol, and responses observed. Summaries will be submitted to the CTMC, and reviewed at least twice yearly and no more frequently than quarterly. Reports will be sent to IUCC CRO RT 380 attn: CTMC by the 15th of each month.

6. QUALITY ASSURANCE REVIEWS (QAR)
The Clinical Trials Monitoring Committee will conduct quality Assurance Review (QAR). Quality Assurance Review is performed on **all therapeutic clinical trials** conducted at IUCC. The Quality Assurance Review concentrates on data management and system procedures, quality of data collection and protocol adherence. The Biostatistics core randomly selects five patients for QAR every quarter. The CTMC auditor will contact the PI at the time of the review.

7. INTERNAL AUDITS
Internal audit should be conducted by each program. Internal audits are a formal, comprehensive source document review of any institutional study not otherwise audited by an external agency. Two trials from each IUCC program that meet these criteria should be selected for audit. Ten percent of the cases from these trials are randomly selected for

review. Internal Audit reports will be submitted to the CTMC for review. Reports are due by the 15th of each month July and January. Submit all Internal Audit reports to IUCC CRO RT 380 attn: CTMC.

8. CONTINUING REVIEWS

All Continuing Reviews will be reviewed annually or as dictated by the Institutional Review Board. Approved continuing review reports will be provided by the IRB.

9. AMENDMENTS

All protocol amendments must be submitted to the SRC.

Appendix C

Internal Review Board Approval: Initial

INTERDEPARTMENTAL COMMUNICATION
Research Compliance Administration
Indiana University - Purdue University Indianapolis

DATE: May 25, 2006
TO: Joan Haase
Nursing Research NU 330 IUPUI
FROM: Tara Bateman
Research Compliance Administration
SUBJECT: Final Approval
Study Number: 0602-65
Study Title: Vigilance Experiences: Cancer Patients, Families, and Nurses
Sponsor:
The study listed above has received final approval from the Institutional Review Board (IRB-05). IMPORTANT NOTICE: The Institutional Review Board (IRB) requires that the consent statement given to subjects have the IRB approval stamp on the last page – OR – include information regarding granting of waivers.
Please note that although this study has been granted final approval by the IRB, special requirements apply if the principal investigator becomes aware that an individual enrolled on the study either is a prisoner or has become a prisoner during the course of his/her study participation (and the study has not been previously granted approval for the enrollment of prisoners as a subject population). In such cases, all research interactions and interventions with the prisoner-participant must cease and if it is wished to have the prisoner-participant continue to participate in the research, Research Compliance Administration (RCA) must be notified immediately. In most cases, the IRB will be required to re-review the protocol at a convened meeting before any further research interaction or intervention may continue with the prisoner-participant. Refer to the IUPUI/Clarian Standard Operating Procedure [232] on *Involving Prisoners in Research* for further information.
As the principal investigator of this study, you assume the responsibilities as outlined in the SOP on *Responsibilities of Principal Investigators,* some of which include (but are not limited to):

1. CONTINUING REVIEW - A status report must be filed with the Board. The Research Compliance Administration (RCA) staff will generate these reports for your completion. This study is approved from **May 25, 2006** to **May 25, 2007.**

2. STUDY AMENDMENTS - You are required to report on these forms ANY changes to the research study including protocol design, dosages, timing or type of test performed, population of the study, and informed consent statement. An amendment form can be obtained on our website. See link http://www.iupui.edu/~resgrad/spon/amendment-irb.htm.

3. UNANTICIPATED PROBLEMS INVOLVING RISKS TO SUBJECTS OR OTHERS AND NONCOMPLIANCE - You must report to the IRB any event that appears on the **List of Events that Require Prompt Reporting to the IRB.** Refer to the SOP on "Unanticipated Problems Involving Risks to Subjects or Others and Noncompliance" for more information and other reporting requirements. The SOP can be found at: http://www.iupui.edu/~respoly/human-sop/human-sop-index.htm. NOTE: If the study involves gene therapy and an adverse event occurs which requires prompt reporting to the IRB, it must also be reported to the Institutional Biosafety Committee (IBC).

4. UPDATED INVESTIGATIONAL BROCHURES, PROGRESS REPORTS and FINAL REPORTS - If this is an investigational drug or device study, updated clinical investigational brochures must be submitted as they occur. See link http://www.iupui.edu/%7Eresgrad/spon/cibrequire.htm for requirements. Three copies of progress or final reports must be provided to the Board with your written assessment of the report, briefly summarizing any changes and their significance to the study.
5. ADVERTISEMENTS - If you will be advertising to recruit study participants for a drug or device study regulated under FDA requirements, i.e., investigational drugs or devices will be used, and the advertisement was not submitted to the Board at the time your study was reviewed, a copy of the information contained in the advertisement and the mode of its communication must be submitted to the reviewing board as an amendment to the study. These advertisements must be reviewed and approved by the Board PRIOR to their use.
6. STUDY COMPLETION – You are responsible for promptly notifying the IRB when the study has been completed. This is done by contacting RCA staff to request that a continuing review report be generated for your completion within 90 days after termination or completion of the investigation or the investigator's part of the investigation.
7. LEAVING THE INSTITUTION - If the principal investigator leaves the Institution, the Board must be notified as to the disposition of EACH study.

PLEASE REFER TO THE ASSIGNED STUDY NUMBER AND THE EXACT TITLE IN ANY FUTURE CORRESPONDENCE WITH OUR OFFICE. In addition, SOPs exist which cover a variety of topics that may be relevant to the conduct of your research. See link http://www.iupui.edu/~respoly/human-sop/human-sop-index.htm. All documentation related to this study must be neatly typed and must also be maintained in your files for audit purposes for at least three years after termination of the research; however, please note that research studies subject to HIPAA may have different requirements regarding file storage after termination. If you have any questions, please call RCA at 274-8289.
Enclosures: Documentation of Review and Approval Advertisement(s)
Expedited Review Checklist 1 Authorization form(s)
1 Informed Consent Statement(s)
Other:

Appendix D

Consent Form

IUPUI and CLARIAN INFORMED CONSENT STATEMENT FOR

Vigilance Experiences: Cancer Patients, Families, and Nurses

STUDY PURPOSE:

You are invited to participate in a research study that involves interviewing patients, one of their family members, and nurses about their experiences of vigilance. Vigilance is a process by which persons watch out for themselves or others. Vigilance can be a means of protection and it is something we all do to some extent as part of daily living. The purpose of this study is to gain an understanding of what persons feel – as they experience the process of vigilance.

NUMBER OF PEOPLE TAKING PART IN THE STUDY:

If you agree to participate, you will be one of 30 individuals total (made up of 3 individuals in 10 groups of a patient, a family member, and a nurse) who will be participating in this research (locally and nationally).

PROCEDURE FOR THE STUDY:

If you agree to be in the study, you will do the following things:

You will be asked to participate in an interview with the primary researcher about your experiences of vigilance. You will receive some questions ahead of time that may help you be able to think ahead and answer the questions as fully as possible. You may also be able to think of some stories about your care and vigilance. The interview will be audio tape recorded to ensure the researcher does not miss what you are saying. Tapes are only heard by the research team. This recording will be typed word for word so it can be examined by the researchers, but no names will be attached to those typed transcriptions of the interviews. They will only be identified by a code number that will be kept in a separate, locked file in the investigator's office. The interview will last approximately 1-2 hours. You may be contacted after the initial interview, to give further information, or to make clear what you have already told the researcher. The audio tapes will be erased and destroyed after the study is completed.

RISKS OF TAKING PART IN THE STUDY:

While participating in the study, the risks are minimal.

The risks of completing the interview could include feeling uncomfortable answering the questions or you may feel too tired to complete an interview. You may request that the interview be stopped at any time. You also may refuse to answer any questions that you feel too uncomfortable talking about.

Another risk is the possibility of the loss of confidentiality. However, your information will be kept confidential by not having your name associated with the interviews or their transcriptions (written version of what was said). To reduce the risk of the loss of privacy, your signed consent form will be kept separate from the interview information. Your name will not appear on the interview transcription. All information related to the study will be kept in locked file cabinets or in password protected computers, with only investigators having access. See below for further information on confidentiality.

BENEFITS OF TAKING PART IN THE STUDY:

The benefits to participation are minimal for you. The research may benefit patients, families, and nurses in the future through deepening an understanding of the vigilance process and how nurses and family members may best participate in that process with the patient. This information will be used to develop and clarify the understanding of vigilance.

ALTERNATIVES TO TAKING PART IN THE STUDY:

You are free to refuse to participate in the study- which will not affect your care in any way.

_____Participant's Initials

CONFIDENTIALITY:

Efforts will be made to keep your personal information confidential. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Your identity will be held in confidence in reports in which the study may be published.

Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the investigator and his/her research associates, the study sponsor, the Office of Human Research Protection (OHRP) and the IUPUI/Clarian Institutional Review Board or its designees.

COMPENSATION FOR INJURY

In the event of physical injury resulting from your participation in this research, necessary medical treatment will be provided to you and billed as part of your medical expenses. Costs not covered by your health care insurer will be your responsibility. Also, it is your responsibility to determine the extent of your health care coverage. There is no program in place for other monetary compensation for such injuries. However, you are not giving up any legal rights or benefits to which you are otherwise entitled.

COSTS/COMPENSATION:

You will not receive payment for taking part in this study.

CONTACTS FOR QUESTIONS OR PROBLEMS:

For questions about the study, contact the researcher Wendy Kooken at 309-677-3704.

In the event of an emergency, you may contact Wendy Kooken at 309-370-1297.

For questions about your rights as a research participant or complaints about a research study, contact the IUPUI/Clarian Research Compliance Administration office at 317/278-3458 or 800/696.2949.

VOLUNTARY NATURE OF STUDY:

Taking part in this study is voluntary. You may choose not to take part or may discontinue participation in the study at any time which will not result in any penalty or loss of benefits to which you are entitled. This would not affect the quality of care you receive, either.

In consideration of all of the above, I give my consent to participate in this research study.

I acknowledge receipt of a copy of this informed consent statement.

SUBJECTS SIGNATURE:_____ Date:_____
(must be dated by the subject)

SIGNATURE OF PERSON OBTAINING CONSENT:_____ Date:_____

Study No. 0602-65

IRB Approval Date: APR 12 2007

Continuing Review Due: APR 12 2008

Appendix E

Release of Health Information for Research Form

IUPUI–CLARIAN
AUTHORIZATION FOR THE RELEASE OF HEALTH INFORMATION FOR RESEARCH

Introduction: You have the right to decide who may review or use your Protected Health Information ("PHI"). The type of information that may be used is described below. When you consider taking part in a research study, you must give permission for your PHI to be released from your doctors, clinics, and hospitals to the research team, for the specific purpose of this research study.

What does this authorization relate to? This authorization relates to the following study:

PRINCIPAL INVESTIGATOR (in charge of Research Team)	*IRB PROTOCOL # 0602-65*
Joan E. Haase	*SPONSOR #*
NAME OF RESEARCH PARTICIPANT	*BIRTHDATE*
STREET ADDRESS	*CITY, STATE & ZIP CODE*

What information will be used for research purposes? The PHI that will be used for research purposes may include some or all of your health records. This includes, but is not limited to: information provided by you directly to the Research Team, hospital records and reports; admission histories, and physicals; X-ray films and reports; operative reports; laboratory reports; treatment and test results; immunizations; allergy reports; prescriptions; consultations; clinic notes; and any other medical or dental records needed by the Research Team.

Specific Authorizations: I understand that this release also pertains to records concerning hospitalization or treatment that may include the categories listed below. I have the right to specifically request that records NOT be released from my health care providers to the Research Team. However, I understand that if I limit access to any of the records listed below, I may not be able to be in this research study. Check limitations, if any, below:

- ☐ Mental health records
- ☐ Psychotherapy Notes
- ☐ HIV (AIDS)
- ☐ Sexually transmitted diseases
- ☐ Alcohol / Substance abuse
- ☐ Other: _____

Who will be allowed to release this information?

I authorize the following persons, groups or organizations to disclose the information described in this Release of Information/Authorization for the above referenced research study:

- ☐ **Treating providers**
- ☐ **Hospitals, clinics or other places where I have received treatment**
- ☐ **Other:** _____
- ☐ **The Principal Investigator and the Research Staff**

Who can access your PHI for the study? The people and entities listed above may share my PHI (or the PHI of the individual(s) whom I have the authority to represent), with the following persons or groups for the research study: the Research Team, Institutional Review Board, Research Sponsor and its representatives, Research Organizations, the Department of Health & Human Services or other US or foreign government agencies as required by law, and to the Food and Drug Administration (FDA) or a person subject to the jurisdiction of the FDA in order to audit or monitor the quality, safety or effectiveness of the product or activity.

The **Research Team** includes the Principal Investigator, his/her staff, research coordinators, research technicians and other staff members who provide assistance to the Research Team. If there is a **Research Sponsor(s),** this shall include: _____ and any **Research Organizations** who provided assistance to the **Research Sponsor(s)** including, but not limited to: _____.

IUPUI–CLARIAN
AUTHORIZATION FOR THE RELEASE OF HEALTH INFORMATION FOR RESEARCH

Expiration date of this Authorization: This authorization is valid until the following date or event:

☐ Specify Date ___/___/____ ☐ End of the Study ☐ None
☐ Other: _____ ☐ Indefinitely, or until such time as authorized by the sponsor to destroy study documents

Efforts will be made to ensure that your PHI will not be shared with other people outside of the research study. However, your PHI may be disclosed to others as required by law and/or to individuals or organizations that oversee the conduct of research studies, and these individuals or organizations may not be held to the same legal privacy standards as are doctors and hospitals. Thus, the Research Team cannot guarantee absolute confidentiality and privacy.

I have the right:

1. To refuse to sign this form. Not signing the form will not affect my regular health care including treatment, payment, or enrollment in a health plan or eligibility for health care benefits. However, not signing the form will prevent me from participating in the research study above.

2. To review and obtain a copy of my personal health information collected during the study. However, it may be important to the success and integrity of the study that persons who participate in the study not be given access until the study is complete. The Principal Investigator has discretion to refuse to grant access to this information if it will affect the integrity of the study data during the course of the study. Therefore, my request for information may be delayed until the study is complete.

3. To cancel this release of information/authorization at any time. If I choose to cancel this release of information/authorization, I must notify the Principal Investigator for this study **in writing** at: _____ *(provide organization name and address)*. However, even if I cancel this release of information/authorization, the Research Team, Research Sponsor(s) and/or the Research Organizations may still use information about me that was collected as part of the research project between the date I signed the current form and the date I cancel the authorization. This is to protect the quality of the research results. I understand that canceling this authorization may end my participation in this study.

4. To receive a copy of this form.

I have had the opportunity to review and ask questions regarding this release of information/authorization form. By signing this release of information/authorization, I am confirming that it reflects my wishes.

_____
Printed name of Individual/Legal Representative

_____
Signature of Individual/Legal Representative *Date*

**If signed by a legal representative; state the relationship and identify below the authority to act on behalf of the individual's behalf.*

***Individual is:** ☐ a Minor ☐ Incompetent ☐ Disabled ☐ Deceased

***Legal Authority:**

☐ Custodial Parent ☐ Legal Guardian ☐ Executor of Estate of the Deceased
☐ Power of Attorney Healthcare ☐ Authorized Legal Representative
☐ Other: _____

APPROVED
APR 12 2007

Appendix F

Potential Participant Benefits

Appendix F

E-mail from Family Member Participant

I am saddened to inform you that my wife passed away after a difficult battle with [an] infection that took her life because she had MDS and was neutropenic. I remember seeing you on [the unit] but I was too distraught to stop and say "Hi".

Tomorrow marks the first month anniversary of her passing. I am doing pretty well and am doing the best I can with my healing and grieving process with a healthy frame of mind.

During our discussion, I spoke about how vigilance is a process. Interestingly, vigilance does not end when a loved one passes away. The vigilance process continues because one needs to watch out for other
loved ones who are now in shock and grief. Vigilance now takes itself to the next level which is caring, comforting and watching out for one's living loved ones:

- To help them get through the difficult days that lie
ahead
- To inspire them and to remind them that there are
still dreams and hopes to be achieved
- To lift their spirits so that they continue to live
instead of retreating into an emotional withdrawal
- To know that all things will pass, and
- To live life to its fullest, each and every day.

I believe you probably have a good read on me – the type of person that I am. I am a very strong person and I will overcome many of these challenges of losing a spouse. As difficult as it is some days (and there are days when I cry me in my own little quiet time of prayer), it is [my wife's] strength and perseverance that gives me the fortitude and courage to look to the bright side of things and to live life to its fullest- even when some days are dark and gloomy.

I will always remember your wonderful compliments of [of my wife] - her beautiful "blue" eyes and her stunning looks. These were such beautiful compliments. After our conversation and when I got back to her room, I took a long deep look at [my wife]and I appreciated the beauty that you had described and how true that is. This will forever be an everlasting memory - every time I think of [my wife] and that how I will remember [her]. FYI..[my wife] passed away a couple of days later.

Wendy, I am glad that we had a chance to meet. I hope that I was able to contribute in an enlightening way to your study. If there is anything else you need, please feel free to email or call me.

Appendices G, H, and I

Data-Generating Questions

Appendix G

Questions to prepare for Kooken interview for the patient:

1) Please describe to me your experiences of vigilance. Vigilance is sometimes called “being watchful.” You may have another word that also fits this experience. We are interested in your stories and experiences of being watchful for yourself during your hospitalization and treatments for cancer. Please describe all you can remember about how you stayed vigilant or “watchful” for yourself—all your thoughts, feelings and actions. You might begin by telling a story about a specific time when you needed to be vigilant or “watchful” for yourself.

2) Please describe to me your experience of vigilance or being watched over by family members or nurses. Please describe all you can remember about how it was for you to be watched for by others—all your thoughts, feelings and actions about how others were watchful for you. Again, you might begin by telling a story about a specific time family members or nurses were vigilant or “watchful” for you.

Appendix H

Questions to prepare for Kooken interview for the family member

1) Please describe to me your experiences of vigilance. Vigilance is sometimes called “being watchful”. You may have another word that also fits this experience. We are interested in your stories and experiences of being watchful for your family member during his or her hospitalization and treatments for cancer. Please describe all you can remember about how you stayed vigilant or “watchful” for your family member—all your thoughts, feelings and actions. You might begin by telling a story about a specific time when you needed to be vigilant or “watchful” for your family member.

2) Please describe to me your experience of nurses being vigilant for your family member. Please describe all you can remember about how it was for you to see nurses watching over your family member—all your thoughts, feelings and actions about how others were watchful for your family member. Again, you might begin by telling a story about a specific time nurses were vigilant or “watchful” for your family member.

Appendix I

Questions to prepare for Kooken interview for the nurse

1) Please describe to me your experiences of vigilance that is sometimes called “being watchful” for your patients during their hospitalization and treatments for cancer. You may have another word that also fits this experience. Please describe all you can remember about how you stayed vigilant or “watchful” for your patient—all your thoughts, feelings and actions. You might begin by telling a story about a specific time when you needed to be vigilant or “watchful” for your patient.

2) Please describe to me your experience of vigilance of family members or patients being watchful. Please describe all you can remember about how it was for families or patients to be watchful—all your thoughts, feelings and actions about how they were watchful. Again, you might begin by telling a story about a specific time family members or patients were vigilant or “watchful”.

REFERENCES

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CURRICULUM VITAE

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Education

PhD in Nursing Science, Indiana University, Indianapolis, IN, Nursing, Health Systems, "Vigilance Experiences: Cancer patients, family members, and nurses". (2008).

Master of Science in Nursing, Bradley University, Peoria, IL, Nursing Administration, "Development of an Instrument to Examine Nurse Manager Hiring Practices". (2002).

Bachelor of Science in Nursing, Bradley University, Peora, IL, Nursing. (1999).

Associate Degree in Applied Science, Illinois Central College, East Peoria, IL, Nursing. (1985).

Professional Memberships

Oncology Nursing Society, ONS, International. (2004 - Present).
The Oncology Nursing Society (ONS) is a professional organization of over 35,000 registered nurses and other healthcare providers dedicated to excellence in patient care, education, research, and administration in oncology nursing. It's also the largest professional oncology association in the world.

National League of Nursing, NLN, National. (2002 - Present).
The National League for Nursing promotes excellence in nursing education to build a strong and diverse nursing workforce.

Sigma Theta Tau International-Epsilon Epsilon, (STTI). (1999 - Present).
The mission of the Honor Society of Nursing, Sigma Theta Tau International is to support the learning, knowledge, and professional development of nurses committed to making a difference in health worldwide.

Scholarship / Research

Kooken, WS, (Trainee); Haase, JE, (Sponsor). Indiana University School of Nursing T 32 Training Grant, NR 07066 National Institute of Nursing Research.

Kooken, WS, Haase, JE (Principal), Sponsored Research, "Vigilance Experiences: Cancer Patients, Family Member, and Nurses", Indiana University, Federal, National Institutes of Nursing Research, Federal, Funded. (Start: 2006, End: July 2008)

Intellectual Contributions

Russell, KM, Haase, JE, **Kooken, WC**, Ziner, KW, Lu, Y, Shedd-Steele, R, Storniolo, A M. African American Female Breast Cancer Survivors: Assessments ofCultural Validity of Quality of Life Measures. Submitted: *Psych-Oncology*.

Priest, CS, **Kooken, WS**, Ealey, K, Holmes, S, Hufeld, P (2007). Improving Baccalaureate Nursing Students Understanding of Fundamental Legal Issues through Interdisciplinary Collaboration. *Journal of Nursing Law, 11*(1), 35-42.

Kooken, WC, Haase, JE, Russell, K M (2007). I've Been Through Something: Poetic Explorations of African American Women's Cancer Survivorship. *Western Journal of Nursing Research, 29*(7), 896-919.

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Kooken, WC, Haase, JE, Russell, KM. "I've Been Through Something-Poetic Exploration of African American Women's Cancer Survivorship." 12th Annual International Qualitative Health Research Conference. Edmonton, Alberta Canada, April 2-5, 2006-podium).

Russell, KM, Lu, YFY, **Kooken, W**, Ziner, KW, & Haase, JE. A Litany of Symptoms and Their Effects on Quality of Life of African-American Breast Cancer Survivors. Symposium at the 8th World Congress of Psycho-Oncology, Venice, Italy, October 19, 2006-podium).

Russell, KM, LU, YFY, **Kooken, W**, Wager, KW & Haase, JE. The Process of Becoming a Breast Cancer Survivor. Symposium at the 8th World Congress of Psycho-Oncology, Venice, Italy, October 19, 2006-podium)

Haase, JE, Russell, KM, Ziner, KW, **Kooken, W**, & Lu, YFY. Not Encompassing My Experiences. Symposium at the 8th World Congress of Psycho-Oncology, Venice, Italy, October 19, 2006-podium).

Ziner, KW, **Kooken, W**, Russell, KM, Haase, JE & Lu YFY. Surviving Poor Communication. Symposium at the 8th World Congress of Psycho-Oncology, Venice, Italy, October 19, 2006-podium).

Kooken, W, Haase, JE & Russell, KM. I've Been Through Something-Poetic Explorations of African American Women's Cancer Survivorship. Symposium at the 8th World Congress of Psycho-Oncology, Venice, Italy, (October 19, 2006-podium).

Ziner, KW, Russell, K, **Kooken, W**, Haase, JE, Lu, YF (Feb, 2007). Poster: Surviving Poor Communication: Non-verbal communication experiences of African American women breast cancer survivors. American Cancer Society/Oncology Nursing Society 9th Cancer Nursing Research Conference, Hollywood, CA.