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GIVING VOICE TO THE VULNERABLE:
ADVOCACY AND ONCOLOGY NURSING

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GIVING VOICE TO THE VULNERABLE:

ADVOCACY AND ONCOLOGY NURSING

By

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DEDICATION

This work is dedicated to the nurses who provide

expert care and a lifeline of love for people affected by cancer.

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GIVING VOICE TO THE VULNERABLE: ADVOCACY

AND ONCOLOGY NURSING

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Despite common use of the term, there is no consensus among nursing professionals on a definition of advocacy, how to teach it, measure it, and determine its effectiveness. The purpose of this grounded theory study was to generate descriptions of the cognitive and social processes of advocacy as it is practiced by a purposely selected group of expert oncology nurse clinicians. Informants, nineteen registered oncology nurses working in direct care roles, participated in semi-structured interviews which were audio-recorded and transcribed verbatim to comprise data collection. Informant recruitment and data collection continued until saturation was apparent. Analytic techniques of constant comparative analysis, theoretical coding, and development of theoretical concepts were consistent with grounded theory methodology. Oncology nurses as voices for the vulnerable, the core finding, characterizes the lived experience of advocacy among the study sample. Identified themes were: 1) The meaning of advocacy as a component of ethical practice; 2) Nurses' ways of being combine holistic philosophy, expertise, knowledge and personal values; 3) Nurses' ways of knowing includes recognition of patients' inherent vulnerabilities, knowing the population, and modeling patients' worlds; 4) Nurses' ways of doing incorporates the nurse-patient relationship, informing, educating and navigating; and 5) Value of nurses' advocacy to the health care system, individual patients, and nurses. Interpretation of findings suggest that core components of advocacy are nurses' 1) Intention to give voice; 2) Provision of a lifeline of love; and 3) Fulfillment of a moral covenant with patients. Nurses recognize patients' needs and intentionally enter into relationships with patients, acting on the knowledge that their advocacy can assist patients with directing their energy to their healing work rather than being diverted to surviving the health care system. The data-driven theory can serve as a basis for defining, teaching, measuring, and supporting advocacy among students and practicing nurses, contribute to codifying advocacy competencies for clinical practice, and could serve as a catalyst for additional research and translation into practice of this complex and still immature construct.

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CHAPTER ONE

OVERVIEW OF ADVOCACY

During my medical-surgical student rotation one of my patient assignments included a young man, husband and father. According to his medical chart and the nursing care Kardex, he was dying from cancer, and his plan of care focused on comfort measures. One of the routine nursing tasks was the physician-ordered "daily weights", which in 1969, meant transferring, tugging and pushing the patient onto the hard table of the monstrous bed-scale. I had already witnessed the toll that this procedure took on this man, and asked the nurse assigned to the patient, as well as my instructor, why a daily weight measurement was needed for this patient who was so near to death. Neither offered a logical response, other than that the doctor ordered it, adding that the patient's doctor was the chief cancer doctor at University Hospitals. I decided to delay weighing the patient for a while and hoped that the doctor and medical students would be making their rounds soon.

My instructor was not pleased with my plan; in fact, I think she was appalled that I intended to question the doctor's order. We were in the midst of talking about this when the doctor and his group of students arrived at my patient's door. I introduced myself as the student nurse assigned to Mr. H., and then simply and humbly asked the rationale for the order to have Mr. H. weighed on a daily basis – adding that the procedure was an excruciating experience for him. Dr. B. seemed taken aback – not at my audacity to ask the question, but instead, that his patient was still getting weighed at all. Apparently, he

had instructed an intern to discontinue the daily weight order some time before, and this had not been done. Dr. B. thanked me for bringing my concern for his patient to his attention, and immediately changed the order himself. My patient and his wife were obviously relieved, and thanked me for my thoughtfulness and for speaking on their behalf. I remember feeling validated, proud, and elated. My instructor was still unhappy with me, fearing (I believe) that my behavior would reflect negatively on her ability to control her students. I cannot say with certainty that this incident was a factor in my dismal mid-term grade for that course, but I cannot discount the episode either. This was my first exposure to advocacy on behalf of a patient, and also an initiation into the risks and rewards presented by nurses' advocacy efforts.

Throughout my nursing career, I have been drawn to cancer care. Within that specialty area, my knowledge, skills, competencies, and confidence increased, and I often found myself in situations that seemed to call for a nurse to speak on behalf of patients, situations that were – and often still are – common in oncology care settings: patients lacking full understanding of posed treatment options; patients whose pain or other symptoms are inadequately controlled; family members insisting their wishes be considered over those of the patient; physician referrals based on personal relationships as opposed to matching physician skills to patient needs; the mismatch between nursing staff skills and numbers and patient acuities – to list just a few scenarios. Contemporary cancer care is more complex and fast-paced than ever, and the need for nurses to speak on behalf of patients – to advocate for patients - appears to be more critical to positive patient outcomes than ever before.

Introduction to the Problem

Historical Perspective

Advocacy, in which the patient is the central focus of concern, is offered by many past and contemporary nursing leaders as the philosophical foundation of the nursing profession. The image of Florence Nightingale, depicted as a leader of valiant efforts to introduce basic hygienic conditions into the miserable Crimean War hospital at Scutari and to the masses in Victorian London and India, is that of the quintessential patient advocate. Indeed, her work could be interpreted as advocacy on behalf of those populations (Grace, 2001).

Acceptance of Nightingale as the exemplary advocate is not universal. In an historical examination of nurses' loyalties, Winslow (1984) argues against Nightingale's image as a nurse advocate, citing her adherence to a military service model for nursing in which nurses committed loyalties first and foremost to physicians.

The nursing and allied health literature documents interest in patient advocacy for nearly four decades. Numerous editorials, interviews, opinion papers and case studies during this time frame refer to patient advocacy as an element of professional nursing care (Copp, 1986; Miller et al., 2000; Segesten, 1993). Some authors infer that patient advocacy is a philosophical foundation for the nursing profession (Curtin, 1979; Gadow, 1980), while others warn that nursing's assumption of patient advocacy roles presents a slippery slope to paternalism (Mitchell & Bournes, 2000). Still others predict – and even promote - the evolution of an entirely new patient advocate career that may or may not include nurses (Annas & Healey, 1974; Mallik, 1997, 1998).

It was not until 1973 that the International Council of Nurses' (ICN) code deleted mention of loyal obedience to physicians' orders. In 1976, the American Nurses Association (ANA) *Code of Ethics for Nurses* was revised to advise nurses to protect "the client" from "incompetent, unethical, or illegal practice of any person" (ANA, 1976). Since then, nursing leaders in the United States (US) increasingly advance the notion that patient advocacy has been and continues to be a core value or ideal of the nursing profession.

In a theoretical paper of patient advocacy, Donahue (1985) posited that concerns of ethical health care practices were the driving force behind a call for patient advocates, health service roles in which a foundational philosophy emphasizes human worth, dignity, and rights within health care settings. The phenomena of democracy and technological advances, according to Donahue, were twentieth century societal trends that escalated interest in advocacy (1985). Democracy focuses on human rights and obligations while technological advances further complicated health care delivery. Erosion of the health care professions' monopoly on knowledge and declining trust in professional decisions are noted as additional significant societal trends of the last century that served as catalysts to a growing advocacy movement in the United States.

Donahue noted that early nurse leaders including Florence Nightingale, Lavinia Dock, and Lillian Wald were patient advocates, "concerned about and committed to human rights, dignity, humanitarianism, and accountability" (1978, p. 146), ideas consistent with a contemporary, holistic approach to nursing. Donahue concluded with

the suggestion that over time, nursing lost the advocacy role and the profession is
attempting to reclaim it as a vital component of nursing. She proposed that:

> An advocacy model for nursing would need to encompass the total individual
> (patient) rather than one aspect of concern, would need to consider long-term or
> projected outcomes, and would need to focus on helping the patient to ultimately
> become his own advocate when appropriate" (1985, p. 345),

and noted that reports of conducted research are "nearly impossible to find. (p. 346).

<center>Philosophical Models of Advocacy</center>

Over time, description, support, and criticism of models of nurse advocacy have
been posed, influenced by variations in philosophic perspectives of nursing. Models most
often cited in the literature are proposed by Curtin (1979), Kohnke (1980), and Gadow
(1980), each directed toward nurses' facilitation of patient decision-making, with
variations in information-giving processes. Curtin's (1979) human advocacy model
proposed the nurse as advocate as a philosophical foundation for nursing based on the
nurse-patient relationship and our common humanity, needs, and rights. In Kohnke's
model the role of the nurse advocate has "only two functions: to inform and to support"
(Kohnke, 1982, p. 2). Gadow (1980) proposed the existential advocacy model, with its
basis in patients' freedom of self-determination. These models will be discussed in more
detail in Chapter Two.

In a philosophical analysis of advocacy, Grace (1998) proposed that Nightingale's
definition of nursing - "what nursing has to do,.. is to put the patient in the best condition
for nature to act upon him" (Nightingale, 1946, p. 75) - is in fact, a conceptual definition

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of nurse as advocate. Although Nightingale did not use the term *advocacy,* Grace (1998) contends that this perspective of nursing's role is the essence of advocacy.

Advocacy and Contemporary Oncology Nursing

In the early years of the 21st century, the idea of oncology patient navigation and designated patient navigators entered the lexicon of American health care, as a service that could lessen the disproportionate burden of cancer, including higher incidence, higher mortality, and lower survival rates noted in poor, elderly and other underserved populations (Haynes & Smedley, 1999; President's Cancer Panel, 2001; Schwaderer & Itano, 2007). Many nurses regard patient navigation as an advocacy role within traditional oncology nursing practice that is increasingly acknowledged as a vital service to patients who must simultaneously cope with the bewildering American health care system and the chaos imposed by cancer diagnoses (Bruce, 2007).

Gosselin-Acomb and colleagues (2007) acknowledge the paucity of research in the clinical specialty of oncology nursing despite the increasingly dynamic and complex cancer care environment. They suggest these circumstances will expand oncology nurses' roles and that understanding how oncology nurses advocate and use resources may well enhance patient care. In their report of a statewide survey intended to identify ways oncology nurses advocate for patients, Gosselin-Acomb and colleagues (2007) conclude that advocacy is a key component of oncology nursing practice but that nurses often lack the resources, background, education, and time to do so.

Contemporary Status of Advocacy

Even after some forty years of philosophical and theoretical description and debate, a great diversity of opinion about advocacy remains. The philosophers, theorists, and other nursing leaders have yet to craft a consistent definition, any recognized methodology for teaching and learning advocacy roles, come to consensus about practices considered to be advocating ones, devise clarity regarding practice settings or environments that support advocacy, or the ability to test and assess outcomes of nurses' advocacy efforts. It is imperative that the value of this role component of professional nursing in contemporary and evolving health care environments be confirmed or refuted. If in fact, advocacy is a core value for the profession, then it is essential that its attributes, antecedents, and consequences be defined so that these elements are promoted in the identification and selection of those who might enter the profession, education and socialization of professional nursing students supports successful advocacy, and that health policy fosters health care environments that allow nurse-advocacy to flourish. The present study was undertaken to explore questions cited most recently 2007 by Gosselin-Acomb and colleagues, and the still unanswered, but crucial question, posed by Donahue in 1978: "What must nurses possess to adequately assume such a responsibility?" (p. 150).

Background and Significance

Professional Nurse Advocacy as a Late Twentieth Century Phenomenon

Increased recognition of the need for patient advocacy coincides with the civil rights movement, higher educational levels and subsequent rise in consumerism among

the general American population, along with growing distrust of experts, and awareness of the growing dangers associated with medical technology (Annas & Healey, 1974; Donahue, 1985). Teresa Christy, considered "nursing's historian" (Schweer, 1982, p. 66) and one of nursing's foremost 20th century leaders, charged that nurses "should and can become patients' advocates in the truest sense, the intermediaries for the befuddled civilian who is thrust into the maze of an alien world – the American health care system" (1973, p. 8). Christy equated the advocate with sponsor, supporter, and counselor (1973). Annas and Healey proposed the Patient Rights Advocate system and Patient Rights Advocate role as mechanisms to increase patients' abilities to participate in medical decision-making, stipulating the purpose of an advocate is to "assist the patient in exercising his rights" (1974, p. 30). The advocate, according to Annas and Healey, should be a person whose only responsibility and loyalty is to the patient.

In 1976, the American Nurses Association *Code of Ethics for Nurses* was revised to oblige nurses to protect the client from "incompetent, unethical, or illegal practice of any person" (ANA, 1976). The nurse's role as patient advocate is specifically stipulated in the *Code of Ethics for Nurses*: "The nurse promotes, advocates for, and strives to protect the health, safety, and rights of the patient" (ANA, 2001, p. 12). Donahue (1978) noted that the traditional meaning of advocacy "involves concern for and defined actions in behalf of another at both the individual and the system's organizational level" (p. 144). Between 1970 and 1980, nursing leaders increasingly advanced the notion that patient advocacy is a core value of the nursing profession and philosophical contributions to the

American nursing literature throughout the decade reflect this position (Christy, 1973; Curtin, 1979; Donahue, 1978; Gadow, 1980).

Diffusion of the concept of the nurse as patient advocate from America to Europe was at least a decade in the making, and in the process, advocacy took on a somewhat altered meaning. Nurse-as-advocate papers started to appear in the nursing literature, authored by nurses in the United Kingdom (UK), specifically Great Britain, during the 1980's. UK authors tended to view patient advocacy by the nurse as a distinct role, different than other nursing roles (Mallik, 1997), and there are claims to an advocacy career both within and outside of nursing. The professional patient advocate role, sometimes called *hospital patient representative*, was commonplace in American hospitals in the 1980's and a similar phenomenon occurred in UK in the 1990's. Mallik (1997) characterized the literature on advocacy in nursing as a "large body of conceptual work which predominantly proselytizes the role with little empirical investigation…" (p. 130).

<center>*Nurse Advocacy and Risks*</center>

In a comprehensive review of the literature, Mallick (1997) concluded that advocacy is a potentially risky role and that acts of advocacy reflect a nurse's moral choice. It is increasingly apparent that the role of nurse as advocate is indeed fraught with risks for nurses, including risks of job loss (Hekkers, 2005), career setback (Baldwin, 2003), and conflicts with physicians, administrators and managers, and peers (Bennett, 1999; Grace, 2001; Hewitt, 2002). Perceived advocacy obligations are, according to Grace (2001), most often confined to individuals or groups in the immediate practice

setting, creating confusion among practicing nurses about their responsibilities to be patient advocates despite serious risks to the advocate. Grace (2001) noted that anecdotally and from personal experience, nurses' "inability to take action on behalf of needy patients" (p. 152) can engender a sense of failing the patient and subsequent emotional turmoil. In these circumstances, nurses are left "feeling powerless and in a condition of moral distress" (p. 152).

Bennett (1999) stipulates that until there is a universally accepted definition, the personal and professional risks will continue to be barriers to meaningful and successful nurse advocacy. Indeed, definitions vary considerably. As a noun, "Advocate", according to the Oxford English Dictionary (1997), is defined as: 1) "a person who supports or speaks in favor"; 2) "person who pleads for another"; or 3) "professional pleader in a court of justice." As a verb, "advocate" becomes: 1) "recommend for argument (a cause, etc.)"; and 2) "plead for; defend." The ways in which "advocate" is applied within professional nursing practice is not so straightforward. Of all the definitions offered thus far, the one that is most consistent with my world view is Gadow's (1980) notion of existential advocacy:

> That individuals will be *assisted* by nursing to *authentically* exercise their freedom of self-determination. By authentic is meant a way of reaching decisions which are truly one's own – decisions that express all that one believes important about oneself and the world, the entire complexity of one's values. (1980, p. 85)

Significance of Advocacy for the Nursing Profession

Nurses' abilities to provide consistent, compassionate and safe care, the most basic tenets of the profession, are impaired by compassion stress, fatigue, and moral distress – now recognized as costs of caring (McNeely, 2005). Compassion stress and fatigue are inversely related to nurses' professional satisfaction, patient safety, patient satisfaction and patient outcomes (Gray, 2002; Mrayyan & Huber, 2003; McNeely, 2005; Weisman & Nathanson, 1985). Additionally, there is a global shortage of nurses that is attributed to difficult working conditions in many health care settings, expanded career options for women and subsequent declining enrollment in nursing education programs, changes in workplace ideals, values and motivators, and overall dissatisfaction with the nursing profession being among the most commonly cited factors (McNeely, 2005; Rivers et al., 2005). Considerable multifaceted financial impacts linked to the nursing shortage include crises of Baccalaureate and Associate Degree nursing programs, costs to health care facilities to absorb temporary staffing costs, malpractice premiums and recruitment and retention, and costs of overtime and overworked nurses (Rivers et al., 2005). A nursing workforce composed of healthy, highly motivated, committed, skilled, knowledgeable, competent and empowered nurses is imperative if nursing is to fulfill its social obligation as a profession. It appears that nurse advocacy is an important if not essential component of professional practice, and it is therefore, essential to achieve conceptual and behavioral clarity around advocacy.

Grace (2001) offers a more open and broad conceptualization of professional advocacy as ways in which nurses foster 'health' for their patients, including exploring

and challenging potential environmental obstacles, political activity, and intra- and interdisciplinary collaboration. The concept and acts of advocacy characterize the thoughts, thinking patterns and actions of leaders who designed nursing as a vocation for women and continue to influence the evolution of the profession today (Hamilton, 1994). Advocacy is consistently offered as a desirable model of professional nursing practice that is potentially an indicator of excellence (Benner, 1984; Gadow, 1980; Millette, 1993; Murphy, 1979). Falk-Rafael (1995) made a credible argument that existential, relational ethics, centrality of mutuality and the nurse-patient relationship, a unitary-transformative approach to caring, and empowerment are synchronous concepts. Likewise, Wade (1999) defined professional nurse autonomy as "belief in the centrality of the client when making responsible discretionary decisions…that reflect advocacy for the client" (p. 310), and includes proactive advocacy for clients among its critical attributes. Educational and personal qualities, according to Wade (1999), are antecedents that promote professional nurse autonomy.

Murphy (1979) suggested three models of the nurse as advocate: *bureaucratic advocacy* (the nurse is loyal primarily to the institution while patient and nurse needs are secondary); *physician advocacy* (the physician gets primary consideration with all other factors subordinate); and *client advocacy* (the client is the primary focus). Segesten (1993) defined *patient advocacy* as informing patients about their rights, making sure they have all necessary information, supporting patients' decisions, and protecting and safeguarding patients' interests. At the time of her study, Segesten (1993) noted that the need for patient advocacy was recognized as an activity outside of nursing that was

largely assumed by appointed patients' ombudsmen in full-time positions: advocacy as a part of a nurse's responsibility had not been considered.

Despite favoring the advocate role as a philosophical foundation for professional nursing, Curtin (1983) recognized the ambiguities inherent in the role definition: "I found the nurse as patient advocate depicted as a combination lawyer-theologian-psychologist-family counselor and dragon slayer wrapped up in a white uniform" (p. 9).

The nursing advocacy literature can be summarized as focusing on three central themes:

- Questions remaining about whether nurses have the authority to challenge physicians or the bureaucratic health care system;
- Professional codes, licensure statutes and employment contracts are inconsistent in recognition of advocacy; and,
- Accountability for advocacy among nurses is not explicit.

Significance of Advocacy for the Oncology Nursing Specialty

Acting as advocate through assisting with information seeking, assurance of informed consent, and promotion of maximal patient independence is central to the defined scope of oncology nursing practice (ANA & ONS, 1996). The Oncology Nursing Society (ONS), representing over 35,000 nurses worldwide, asserts that nurses play critical and essential roles in the provision of quality cancer care and to a limited extent, stipulates desired outcomes of nurses' advocacy efforts (ONS, 2008). Empiric data delineating oncology nurses' advocacy behaviors, factors that facilitate or impede effective advocacy, and related outcomes are essential to incorporating advocacy into

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oncology nursing preparation and role expectations and may augment nursing's contributions to cancer care.

Complex, state-of-the-art health care, cost-containment, managed care, centralized planning and reimbursement for expensive procedures, and access to care issues contribute to increased vulnerabilities on the part of persons in need of professional health care services (Marck, 2000; Weston & Lauria, 1996). There is overwhelming evidence that people affected by cancer - regardless of time since diagnosis and therapeutic intervention - have a host of unmet physical, informational, psychosocial, emotional, financial, and spiritual needs (Adler & Page, 2008; Freeman & Reuben, 2002; Ganz, 2001; Hewitt, Greenfield, & Stovall, 2006; Hewitt & Simone, 1999; Rowland et al., 2001). Poverty, culture, social injustice and race/ethnicity are just some of the many determinants of cancer-related disparities among Americans (Freeman, 2004; Ward et al., 2004). A gap exists between what experts believe should be offered to people affected by cancer and what is actually made available to them (Freeman & Reuben, 2002; Hewitt & Simone, 1999). Oncology nurses, despite psychosocial risks associated with chronic compounded grief, frequent crises, intense emotional experiences and resultant moral distress (Medlund et al., 2004) can and often do develop close, long-term relationships with patients, families, and caregivers - the client population - throughout the cancer trajectory. These nurses can observe and assess clients, and collaborate with clients and colleagues to devise strategies to address the unique needs of the oncology client population. Recognition of the nature of oncology nursing and clarity about advocacy role expectations may enhance oncology nurses' abilities to cope with

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workplace-related stress, experience optimal satisfaction in their work roles (Medlund et al., 2004), contribute to the establishment and maintenance of the needed skilled oncology nursing workforce (Lamkin et al., 2001, 2002) and ultimately to the overall quality of cancer care.

<p style="text-align:center">Purpose of the Study</p>

As noted previously, the American Nurses Association *Code of Ethics* (ANA, 2001) prescribed advocacy as a role function of nurses, yet failed to provide a consensus-derived definition of advocacy for nursing. At the present time, there is as yet, no universally agreed upon definition of the construct and no consensus among nursing professionals about how to practice it, teach it, measure it, and determine its effectiveness. Nevertheless, available literature supports the notion of advocacy as a foundation for nursing (Curtin, 1979; Donahue, 1985; Gadow, 1980; Gaylord & Grace, 1995; Kohnke, 1982) and anecdotal reports suggest that successful advocacy is a critically important element of nurse work satisfaction and provision of quality care regardless of practice setting or specialty arena (Carpenito-Moyet, 2003; Gary, 2002; Grace, 2001; Falk-Rafael, 1995; Wade, 1999).

The purpose of this grounded theory study was not to define, rather, to explore and describe advocacy as it is perceived and operationalized by oncology nurses practicing in direct care clinical settings. The specific aim of this study was to create new and theory-based understanding of the construct of practicing oncology nurses' advocacy behaviors and actions by eliciting these descriptions from oncology nurse clinicians. Therefore, the overall purpose of this research was to delineate a grounded theory of

advocacy as practiced by oncology nurses as they provide nursing care to people affected by cancer.

It is proposed that outcomes of the study will contribute to identification of social processes and theory development of advocacy among nurses. The resulting data-driven theory can serve as a basis for defining, teaching, measuring, and supporting advocacy among students and practicing nurses, contribute to codifying advocacy competencies for clinical practice, and serves as a catalyst for additional research into this complex and still immature construct.

Sensitizing Framework

Modeling and Role-Modeling Nursing Theory

The study is informed by healing as a central nursing construct, historical precedent, philosophical prescription, the nursing theory perspective of Modeling and Role Modeling (Erickson et al., 1983) and the investigator's tacit knowledge and professional experience. Grace (1998) contends that Nightingale's differentiation of nursing and medicine - that nursing must "put the patient in the best position for nature to act on him" (Nightingale, 1946, p. 75) - is Nightingale's interpretation of patient advocacy, inferring that 'patient advocacy' is akin to putting the patient in the best condition for nature to act, and is therefore, a guide for nurses' promotion of healing.

Curtin (1979) theorized the outcome of the nurse's role as patient advocate is the creation of an atmosphere in which human values, respect, and compassion are realized. This outcome is similar to those noted by Kritek and others (1997a) in their work on healing as a central nursing construct. Kritek (1997b) says that nurses "attend to both

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subjective and objective meanings of healing and wholeness and engage in interactions with others where both meanings guide nursing responses" (p. 14).

Erickson and colleagues (1983), in proposing Modeling and Role-Modeling (MRM) as a theory and paradigm for nursing, define nursing as "the holistic helping of persons with their self-care activities… an interactive, interpersonal process that nurtures strengths to enable development, release, and channeling of resources for coping with one's circumstances and environment… [and the] goal is to achieve a state of perceived optimum health and contentment" (Erickson et al., 1983, p. 49). MRM is a good fit for the practice of oncology nursing, the central focus of this study. MRM, a theory derived from existing scientific and philosophic perspectives, is a useful guide to assessing the complex interplay of physical, social, psychological, emotional, and spiritual needs of people affected by cancer, and for guiding collaborative efforts to enhance healing undertaken by oncology nurses, other health care professionals and the people they serve.

Research Questions

Guided by the conceptual orientation and sensitizing frameworks described here, grounded theory methodology was employed to answer the following research questions:

1) How is advocacy described by oncology nurses working in clinical practice settings?

2) What are the social and cognitive processes used by oncology nurses' when deciding to advocate?

3) How is advocacy operationalized by nurses?

4) What are the client-focused outcomes nurses describe as being influenced by their advocacy efforts?

Design Overview

Given that the aim of this study was to create new and theory-based understanding of the construct of practicing oncology nurses' advocacy behaviors and actions, the theory-building methodology, Grounded Theory, described by Strauss and Corbin (1998a) was the research method of choice. Grounded theory is valuable in the study of interpersonal processes that characterize nursing and is therefore a good fit for this qualitative study (McCann & Clark, 2003a). This methodology offers opportunities to enhance understanding of the construct of advocacy and guide subsequent action, and is particularly useful when a topic is largely unexplored (McCann & Clark, 2003a). Provisional hypotheses are formed during initial data collection, verification occurs through additional data collection, and theory is derived deductively from general principles (Carpenter, 1999; McCann & Clark, 2003a).

Data collected during participants' semi-structured interviews was the primary source of data in this study. Data analysis incorporated constant comparative analysis and ongoing theoretical sampling, coding and categorizing interview data, field notes and memos. Throughout the data collection process, data were examined and used to inform and focus subsequent interviews. Level I, II, and III coding (also known as open, axial, and selective coding respectively) occurred simultaneously, often shifting from one to another throughout the analytic process (McCann & Clark, 2003 b, 2003c). Theoretical saturation occurred within the sample. Core categories were identified and integrated

with the literature and the clinical and theoretical knowledge of the researcher to explain

relationships between categories – the theory - that emerged from the data. Methods and

emergent findings are described in greater detail in Chapters Three and Four.

Assumptions

The following assumptions influenced the study:

1. Advocacy as a component of direct care provided by oncology nurses is a
   complex social process.

2. The operationalization of advocacy by practicing oncology nurses differs in the
   various oncology nursing practice settings.

3. Individuals (patients, clients, family members) facing cancer-related challenges
   have a wide variety of complex physical, emotional, psychosocial, and spiritual
   needs.

4. Individuals (patients, clients, family members) facing cancer-related challenges
   represent a vulnerable population that benefits from the wisdom and guidance of
   expert oncology nurses.

5. Oncology nurses who provide direct care services have first-hand knowledge of
   the needs of individuals and communities affected by cancer.

6. Expert oncology nurses can articulate the needs of the individuals and
   communities they serve and can describe the social and cognitive processes that
   allow them to formulate holistic approaches to healing.

Limitations

The grounded theory method used in this study allowed for a beginning exploration of the social processes associated with advocacy among oncology nurses. It is acknowledged that all qualitative research is conducted with subjective bias that occurs as a result of researcher participation in the inquiry, data collection and analysis (Speziale & Carpenter, 2007). Nevertheless, the qualitative researcher is expected to engage in the process known as bracketing, in which efforts are made to put aside personal values and assumptions, thereby avoiding the imposition of the researcher's understanding on the data, data collection and analytic process (Ahern, 1999). Speziale and Carpenter suggest that the bracketing process begins with the researcher making clear her thoughts, ideas, suppositions, and personal biases about the topic. They infer that explication of personal beliefs enhances the researcher's awareness of potential judgments that could occur based on the researcher's beliefs as opposed to data collected from participants. A way to make personal beliefs known is to write them down before conducting the study, and conducting journaling throughout the research process, a practice that helps the researcher keep an open mind and differentiate her thoughts from ideas, activities, and comments offered by participants (Speziale & Carpenter, 2007). The cognitive process of bracketing can then occur, allowing the researcher to remain open to data as they are revealed (Speziale & Carpenter, 2007). Before this study was initiated, assumptions and personal beliefs were identified and entered into the researcher's journal, and are also reflected in the six assumptions listed earlier. Care was taken to eliminate or minimize researcher bias by crafting carefully worded questions as suggested by Kvale (1996) to be

used in the systematic questioning during semi-structured participant interviews, as depicted in the Interview Guide (Appendix F).

Although participants were recruited from varied geographic locations and practice settings and brought a variety of educational and experiential characteristics to the data, the purposively selected sample limits generalization of findings beyond this population. Nevertheless, findings depict complex social processes that are, at least for the study participants, central to their work, the professional and personal satisfaction derived from their work, and from their perspective, attainment of optimal outcomes among patients or clients, family members and loved ones, and communities facing the challenges imposed by cancer. Findings provide direction for additional research about how best to teach, facilitate, promote, operationalize, and codify advocacy among nurses. Other potential research questions center around exploration of health systems' economic outcomes and patients'/clients' expectations and perceived benefits of nurses' advocacy behaviors in general and specialty practice settings.

Summary

This chapter provided an overview of the background informing this study. Although great interest in the concept of nurse as advocate is reflected in historical and contemporary nursing literature, theorists, philosophers, ethicists, educators and clinicians have failed to establish a universally accepted definition nor has a systematic effort been directed at providing evidence to support the integration of advocacy within professional nursing. Further, an imperative was put forward for greater understanding of how advocacy is incorporated into everyday oncology nursing practice. Modeling and

Role-Modeling nursing theory (Erickson et al., 1983) and the context of healing in the cancer care setting provided the sensitizing framework of this study. Grounded theory methodology was used to explore how this population of oncology nurses consider, plan, and carry out advocacy behaviors in the context of their professional roles.

CHAPTER TWO

LITERATURE REVIEW

This chapter presents a review and critique of published works that influenced this study. Literature from various health-related disciplines contributed to the study and provided context for interpreting findings. As appropriate for grounded theory, review of the literature continued throughout the research process as a way to assess and evaluate emerging concepts and theory.

Historical Perspective of Advocacy and Professional Nursing

It is often assumed that Florence Nightingale's vision of nursing could be recognized as a modern-day equivalent to advocacy. However, Winslow (1984) described Florence Nightingale's adherence to a military service model for nursing in which nurses as loyal soldiers committed loyalties first and foremost to physicians, contradicting her image as a nurse advocate. It was not until 1973 that the International Council of Nurses' code deleted mention of loyal obedience to physicians' orders; and in 1976, the American Nurses Association *Code of Ethics* was revised to require nurses to protect the client from "incompetent, unethical, or illegal practice of any person"(ANA, 1976). Since then, nursing leaders, particularly those in the United States (US), increasingly advance the notion that patient advocacy has been and continues to be a core value of the nursing profession. Other authors warn that nursing's assumption of patient advocacy roles presents a slippery slope to paternalism (Mitchell & Bournes, 2000) and still others

predict – and some even promote - the evolution of an entirely new patient advocate career that may or may not include nurses (Annas & Healey, 1974; Mallik,1997, 1998).

Nursing's Social Policy Statement, Second Edition (2003), considered the fundamental document characterizing professional nursing practice in the United States, includes the social framework and obligations of nursing. The *Social Policy Statement* is a social contract between professional nursing and the broader society, acknowledging professional rights, responsibilities and mechanisms for accountability. For purposes of delineating these rights and responsibilities, nursing is defined:

> Nursing is the protection, promotion, and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through the diagnosis and treatment of human response, and advocacy in the care of individuals, families, communities, and populations. (ANA, 2003, p. 6)

While "prevention of illness and injury, and alleviation of suffering" (ANA, 2003, p. 6) can be more or less readily defined, "advocacy in the care of individuals, families, communities, and populations" (ANA, 2003, p. 6) is nebulous, and remains undefined and unexplained throughout the *Social Policy Statement.* The American Nurses' Association's *Nursing: Scope and Standards of Practice* (2004) describes "the who, what, where, when, why and how of nursing practice" (p. 1). This document maintains that registered nurses "promote, advocate for, and strive to protect the health, safety, and rights of those patients, families, communities, and populations"… and "value their roles as advocates in dealing with barriers encountered in obtaining health care" (p. 17). Standard 12 of the *Standards of Professional Performance*, charges registered nurses to

"integrate ethical provisions in all areas of practice" (p. 39) and suggests ethical standards are demonstrated when the nurse "serves as a patient advocate assisting patients in developing skills for self advocacy" and "delivers care in a manner that preserves and protects patient autonomy, dignity, and rights" (p. 39). The document fails to delineate "what, where, when, why, and how" nurses serve as patient advocates.

Despite the frequent application of the term "advocacy" in the health sciences literature, its prominence in the American Nurses Association (ANA) *Code of Ethics for Nurses* (ANA, 1976, 1985, 2001) and its inclusion in professional curricula, there is a diverse body of opinion about advocacy. There is no consistent definition of advocacy, no recognized methodology for teaching and learning advocacy roles, no consensus about practices considered to be advocating ones, no clarity about practice settings or environments that support effective advocacy, and no empirically demonstrated outcomes of nurses' advocacy efforts.

Defining Advocacy: An Ambiguous Concept

Search of the literature using key words "patient", "advocacy", "patient advocacy", "nurse" and "nursing", with limitations to English language and humans, a computer-assisted Medline® (1970-2007) search yielded 100,707 citations, and the Cumulative Index to Nursing and Allied Health Literature (CINAHL) (1982-2007) revealed 5,185 references. (Literature searches conducted during preliminary work for this study in 2002 revealed just over 90,000 citations in Medline and 400 citations in CINAHL, reflecting significantly increased interest and attention to advocacy over the past half decade.) Given the duplication of relevant citations between the two, and the

fact that most citations relevant to this study are authored by nurses, the CINAHL and the nursing literature specifically, provided the basis of the preliminary search. These computer-assisted searches revealed a small number of unpublished doctoral dissertations and masters theses. Of the 5,185 listed and accessible articles identified in the CINAHL, most are authored by nurses in the US, but nurse-authors in England, New Zealand, Australia, Canada, Wales, Ireland, France, Sweden, Italy, Thailand, Japan, and Israel are also represented in this body of literature. The majority of listed articles focus on patients' rights, patient abuse and/or management of patients' complaints around health care delivery issues, and nurses and whistle-blowing. More recent citations reflect current concerns including prevention of adverse events, end-of-life issues, mental health and other special needs populations, access to care and other public policy initiatives. Articles feature interviews, editorials, opinions, conceptual analyses and literature reviews focusing on ethics, professional scope of practice, discharge planning and patient care issues.

Adding the key word "research" to the search parameters reduced the number of citations to 312, but only fifteen reports of empiric inquiry, all published between 1993 and 2007, were relevant to this study. Because of the paucity of empirically based articles in the nursing literature, reference lists were used to provide additional data for this review. Additional literature searches in the 1983 (the publication date of Modeling and Role Modeling by Erikson, Tomlin, and Swain) - 2007 time frame were performed to address application of Modeling and Role Modeling nursing theory to further inform this study.

The literature search provides evidence of the ambiguities associated with the concept of advocacy and the need for clarity with regard to the meaning of advocacy in this study. Nurse philosopher Sally Gadow introduced the concept of *existential advocacy* in 1980, and influences ongoing philosophical and empiric exploration of nurse advocacy:

> … individuals will be *assisted* by nursing to *authentically* exercise their freedom of self-determination. By authentic is meant a way of reaching decisions which are truly one's own – decisions that express all that one believes important about oneself and the world, the entire complexity of one's values. (1980a, p. 85)

Philosophical Perspective

The word "advocate" is derived from Middle English *avocet* and *advocat* and from the Latin *advocatus*, meaning to summon, call to one's aid, from *ad-* and *vocare* to call (Webster's Third New International Dictionary, 2002). "Voice", derived from *vocare,* the Latin "to call", is defined as "wish, choice, or opinion openly or formally expressed; the right to express a wish, choice, or opinion." (Webster's Third New International Dictionary, 2002).

Advocacy takes many forms. Teasdale (1998) identifies self-advocacy, citizen advocacy, collective advocacy, and professional advocacy. In self-advocacy, individuals are informed and encouraged and supported to speak up for themselves. Citizen advocacy, or independent advocacy as it is termed in the United Kingdom (UK), focuses on instrumental needs (things needed for practicalities of everyday living) and expressive needs (issues of friendship, security, love, and belonging). Citizen advocates are

generally unpaid and unconnected to the services provided (Teasdale, 1998). Collective

advocacy involves an organized group of people campaigning for a selected cause at

policy development and political levels. Professional advocacy, according to Teasdale, is

advocacy by health care professionals that centers on professionals' availability,

relationships with clients or patients, and professionals' technical and personal

knowledge, in which professionals represent patients' views to colleagues, other

professionals or agencies.

Annas and Healey (1974, p. 25) proposed the *patient rights advocate* as a role that

serves to enhance patients' abilities to participate in medical decision-making. Their

proposal was devised in response to concerns about inconsistency of laws protecting

patients' rights and their enforcement and the rise of the consumer movement in the

United States. Annas and Healey suggested four areas in which patients' personal

interests can be translated into rights (p. 26):

- The right to the whole truth.

- The right to privacy and personal dignity.

- The right to retain self-determination by participation in the making of
   decisions regarding one's health care.

- The right of complete access to medical records both during and after the
   hospital stay.

Annas and Healey acknowledge several patient rights problems in regard to decision-

making generated by the traditional doctor-patient relationship as it existed in 1974:

1. Ambiguous identification of the decision-maker.

2. Ambiguous identification of the person or entity that commands the decision-maker's loyalty.

3. Control of pertinent medical information by the attending physician.

4. Lack of reporting or review of the ultimate treatment decision.

5. Justification of the decision on the basis of public policy.

Since 1974, changes in health care delivery have diminished or eliminated the ambiguous nature of some of these traits, while other characteristics are augmented. Patients or clients are clearly identified as decision-makers by virtue of informed consent and other forms of documentation. Technologic advances, specifically, existence of and patients' use of Internet-based resources and advances in consumers' literacy levels and abilities to find and understand health-related information serve to diminish physicians' control of information. State and federal statutes mandate patients' access to their medical records. Treatment-related decisions, particularly in health care facilities, are subject to ongoing peer review and quality assessments by institutional and regulatory authorities. Conversely, the impact of delivery systems and third party payers on information-sharing and decision-making may diminish transparency of assessment and care planning processes. Judicial and legislative bodies may impact health care providers' recommendations to patients, and patients/consumers are not always aware of these variables. Additionally, the transition of care delivery to ambulatory settings, including private clinics and physician offices, has the potential to diminish oversight of consistent attention to patients' rights.

The need for advocacy in health care has been supported both in theory and in practice for over three decades. What remains unclear and even controversial, are questions focusing on: "Who should perform the advocacy role?" "How is advocacy taught and learned?" "How is advocacy done?" "What are the goals of advocacy?" "What are outcomes of advocacy?" And even, "Who pays for advocacy-related services?"

Nursing and Advocacy

After nearly a decade of published theoretical and philosophical papers, Kohnke's *Advocacy: Risk and Reality* (1982), offered an approach to the study of advocacy and essential categories of knowledge needed for the enactment of the advocacy role. Kohnke (1982) calls "advocacy" the "act of loving and caring" (p. viii), and acknowledges that advocacy is NOT something we all do. Instead, she asserts that advocacy is an act of free will, and a "choice of a way to behave and to see ourselves in relation to others" (p. viii). Ironically, Kohnke acknowledges the cyclic nature of popular buzzwords, suggesting that in the early 1980's while writing her book, "advocacy is one of the popular buzzwords" (p. 2). She commented that in nursing education, we tell students to be patient's advocate, but do not tell them much more except that it is a good thing. Kohnke reduced the advocacy role to two functions: to inform and to support (p. 2), but identified 10 areas of proficiency necessary for learning and enacting the advocacy role: 1) informing and supporting; 2) systems analysis; 3) social ethic; 4) ethics; 5) issues; 6) medical-industrial complex; 7) social laws; 8) politics; 9) professional education; and 10) professional practice. Operationalization of these proficiencies for effective advocacy, according to Kohnke, is best viewed as a gestalt, in which each part intertwines with every other.

The earliest review of the nursing advocacy literature is provided in a textbook focusing on application of nursing diagnoses (Donahue, 1985). In an historical and theoretical perspective, Donahue contends that advocacy has been an underlying construct of nursing since its origin. She suggests that the question is not *whether* nurses should be patient advocates, but rather, how nursing lost this role (Donahue, p. 341). She notes the abundance of literature that defines and describes advocacy, and the lack of descriptive empirical investigations that offer a foundation for operationalizing advocacy in practice; no tools, instruments or guidelines. Donahue suggests that, while two nursing diagnoses, Powerlessness and Impaired Communication, are relevant to specific advocacy-related interventions, it must be considered in a broader context – "as a dynamic process which underlies the entire care philosophy of nursing and which provides the very structure basic to the nurse-patient relationship" (Donahue, p. 348). Finally, Donahue offers a set of five recommendations that she hopes will facilitate internalization of advocacy as a vital construct of nursing (Donahue, p. 350):

1) Refine and redefine advocacy as a concept related to nursing – including completion of studies to determine what advocacy is – an intervention, an interactional process, a conceptual framework, or a theory;

2) Identify characteristics of a nurse advocate and the process a person follows to become an advocate;

3) Develop curriculum offerings dealing with advocacy at undergraduate and graduate levels, integrating advocacy content into current course offerings;

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4) Resolve the question of the nursing community's commitment to incorporating advocacy into nursing practice – professionally sanction this component of nursing practice; and,

5) Identify, test and evaluate strategies of advocacy in nursing practice.

Two literature reviews on advocacy and nursing have been published in peer reviewed journals. Mallik's (1997) review addresses conditions that instigated a need for patient advocacy in health care settings, meanings and models of advocacy. She cited the influence of American nursing on British acceptance of the role, and highlighted the large body of conceptual work but the paucity of empirical study of the circumstances under which the advocacy role is operationalized. According to Mallik (1997), the writings of Curtin (1979), Gadow (1980a), and Kohnke (1982) established the foundation for the debate around advocacy among nurses. A second and more recent review is that of Finland's Vaartio and Leino-Kilpi (2005), in which "empirical research" published between 1990 and 2003 is reviewed and critiqued. These authors take exception to other authors' tendency to equate nursing advocacy with the advocate's role, instead contending that nursing advocacy must be viewed in terms of furthering health and nursing actions (p. 705). Vaartio and Leino-Kilpi's search process excluded editorial and theoretical pieces, position papers, and descriptions of individual experiences, leaving 89 articles to be included in their review. Their distinction of "empirical" papers is unclear, since many of the papers they included are philosophic or theoretical in nature, or are articles in which empiric findings are used to craft interventional strategies for various populations. Like Mallik (1997), they concluded that existing literature highlights the

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complexity and immaturity of the concept of advocacy, difficulties in operationalization of nurse advocacy, and primarily focuses on reactive advocacy from nurses' perspectives (Vaartio & Leino-Kilpi, 2005). Vaartio and Leino-Kilpi contend that concept clarification and validity testing in clinical settings remain as perquisites for quantitative research designs with larger samples.

A concept analysis of patient advocacy (Baldwin, 2003) based on methods suggested by Walker and Avant (1983), identified three defining attributes of patient advocacy: 1) A therapeutic nurse-patient relationship in which to secure patients' freedom and self-determination; 2) Promoting and protecting patients' rights to be involved in decision-making and informed consent; and 3) Acting as an intermediary between patients and their families or significant others, and between them and healthcare providers (Baldwin, 2003, p. 35). These attributes are summarized as valuing, apprising and interceding, and the nurse is both proactive and reactive. Identified antecedents included patient vulnerability - loss of control over his/her life as a result of entering the patient role – and nurses' willingness and feelings of responsibility toward patients. Consequences were both positive and negative and exist for both patients and nurses. A positive consequence of advocacy involves securing and maintaining patients' autonomy and self-determination. Patients who observe competition for the advocacy role among professionals are likely to experience discomfort, a negative consequence. A positive consequence of advocacy for nurses is job satisfaction, while negative consequences for nurses include perceived and actual career risks. Baldwin concludes that deliberate, logical and systematic assessments are required to identify situations in

which advocacy is appropriate and possible. The assessment process necessarily incorporates nurses' awareness of antecedents if opportunities are to be identified consistently, and consideration of consequences. Finally, Baldwin cautions that active patient participation in advocacy processes is fundamental and required.

The 1973 revision of the New York State Nurse Practice Act granted nurses the new privilege of action through the "diagnosis and treatment of human responses to actual or potential health problems through such services as casefiinding, health teaching, health counseling, and provision of care supportive to or restorative of life and well-being…." (New York, 2006). Teresa Christy, R.N., Ed.D., considered nursing's foremost historian, linked new privileges to new challenges, and new responsibilities of advocacy by nurses, and suggested that "our challenge is to prove that we [nurses] are *not* just adjuncts, but full, functioning colleagues to physicians" (Christy, 1973, p. 8). In what may be the earliest published specific call for nurses as advocates, Christy wrote:

> We should and can become patients' advocates in the truest sense, the intermediaries for the befuddled civilian who is thrust into the maze of an alien world – the American health care system. …the great nursing challenge of the 1970's is that of advocacy, to be the patient's sponsor, supporter and counselor. (1973, p. 8)

She alluded to the image of "proponent, defender and true professional who possesses all the necessary ingredients for delivery of nursing care" that had been identified by Dock and Stewart (1925). Christy amended the necessary ingredients slightly to fit her image of nurse advocate (1973):

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1) Motivation – a personal commitment to the patient without subjugation to the agency or obligation to the physician;

2) Skill and expertness to perform whatever tasks may be required with a minimum of discomfort to the patient; and

3) Knowledge to know how, when, where, and why.

Donahue (1978, p. 144) recounted a personal crisis occurring in a hospital emergency room, saying "At a time when I needed support, when I needed a nurse advocate, I had none." She offered a review of the scant support for nurse advocacy at the time, concluding that "before we can fully realize our potential as patient advocates, we must first become nurse advocates and proponents of nurses' rights." (Donahue, 1978, p. 147). Donahue described a 1977 conference during which nurse philosopher Sally Gadow offered a philosophical analysis of the nurses' ethical responsibilities to patients, which Donahue used to support her conclusion that the role of nurses as patient advocates is essential to the profession and to society. Gadow labeled her philosophical foundation of nursing - "existential advocacy" (1980). According to Gadow, advocacy is an ideal for nursing, expressing that

> Individuals be *assisted* by nursing to *authentically* exercise their freedom of self-determination…a way of reaching decisions which are truly one's own – decisions that express all that one believes important about oneself and the world, the entire complexity of one's values … [The nurse] helps persons become clear about what they want to do, by helping them discern and clarify their values in the situation, and on the basis of that self-examination, to reach decisions which

express their reaffirmed, perhaps recreated, complex of values.(Gadow, 1980, p. 85)

Gadow clearly differentiates "advocacy" from paternalism, patient's rights, and consumerism. She reasons that paternalism and advocacy are opposites. Gadow defines paternalism as the "use of coercion in order to provide a good that is not desired by the one whom it is intended to benefit" (Gadow 1980a, p. 82). She asserts that there are two principal elements in paternalism: 1) the intent – getting what is believed to be good for the other person; and 2) the effect of violating the person's known wishes in the matter" (p. 83). Paternalistic acts and attitudes, according to Gadow, limit the liberty or rights of individuals for their own interest and implies coercion.

Consumerism, according to Gadow (1980a, p. 84) is a "sophisticated form of paternalism" in which the professional provides technical assistance and information, leaving the individual to make important decisions alone. Likewise, patients' rights advocacy renders the advocate a troubleshooter willing to intervene when the system violates an individual's rights (p. 84).

Gadow (1980a) acknowledges the existence of positive interpretations of paternalism, in which decisions affecting an individual's well-being should be made by those most capable of knowing what actions are in the person's best interest. Accordingly, paternalism is a protection of the patient's right to the best possible care that can be given, as opposed to a violation of the patient's right of self-determination. Gadow claims that the positive interpretation of paternalism reduces it to a simplistic and inadequate meaning of advocacy – of acting on behalf of another.

Gadow (1980a) differentiates patients' rights advocates and consumer advocates from existential advocacy, for which she maintains that the nurse alone is uniquely suited. Existential advocacy is based on the principle of freedom of self-determination, the most fundamental and valuable human right. Accordingly, individuals are assisted by nursing to authentically exercise their freedom of self-determination, reaching decisions that are truly the patient's own and express all that is important about oneself and the world, incorporating the complexity of ones own values (Gadow, 1980).

A unique element of Gadow's perception of existential advocacy is her recognition of complications imposed by the dichotomy between personal and professional involvement of the practitioner, and the dichotomy between the lived body and the object body of the patient. These two discrepancies, she says, prevent authentic self-determination, and must be resolved if patients are to fully express their reaffirmed or recreated values. To accomplish this, Gadow calls for nurses to act as whole persons, allowing their individuality to enter into interactions with patients, as opposed to the personal and professional as mutually exclusive aspects of the nurse. The essential difference then, in the nurse's perspective and that of the patient, is related to the body, not to emotion. Professional involvement is a deliberate synthesis of all kinds of involvement with the patient – emotional, esthetic, physical and intellectual, using every dimension of the patient as a resource in the professional relationship. The notion of nurses' professional involvement as unifying and directing of one's entire self in relation to another's need, is entailed by the concept of existential advocacy.

In a philosophical analysis of advocacy, Grace (1998) accepted Gadow's (1980) concept of existential advocacy, and proposed that Nightingale's definition of nursing - "what nursing has to do, is to put the patient in the best condition for nature to act upon him" (Nightingale, 1946, p. 75) - is in fact, a conceptual definition of nurse as advocate.

Arguments against the role of nurse advocate

In addition to being an early proponent of advocacy as a basis for nursing ethics, Gadow (1980) recognized the potential for confusion about the advocacy role of nurses. Gadow argued that three potential guiding principles of nursing ethics – benefit, detachment, and autonomy – underlie alternatives for a philosophical foundation for nursing (Gadow, 1983). From these three positions, principles arise: paternalism, consumerism, and advocacy. The benefit principle, according to Gadow (1983), requires the nurse to align with other providers, especially the physician and the institution, concerned with benefiting patients, all assuming that professionals are better qualified than patients to determine benefit and harm. She also notes that most often, benefit is defined by medical criteria of reversing pathology and preventing death, as opposed to a nursing judgment of benefit. Following this philosophy, patient self-determination is a secondary consideration. This infringement of freedom, even though motivated by providers' concern for the patient's good, Gadow (1983) designates *paternalism*. She defines paternalism as meaning "all decisions concerning a patient made without ascertaining and respecting that individual's wishes" (p. 62). Only advocacy as a philosophical foundation of practice, according to Gadow (1983), respects patient autonomy.

Concern over the slippery slope toward paternalism is a recurrent and frequent argument against nurse advocacy. Once individuals are in the hands of healthcare professionals and enter roles as patients or clients, they are in positions of dependence and diminished power, risking loss of abilities to make decisions (decisional autonomy) and abilities to act on decisions (executional autonomy) (Haddad, 2003). Bennett (1999) warns that lacking a universally accepted definition of nurse-related advocacy and clarification of the skill set needed, the role of nurse as advocate will continue to be fraught with potential danger for nurses and patients. He claims that such ambiguity places nurses in vulnerable positions professionally and personally according to professional codes, practice statutes and employment contracts.

Issues resting with nurses' conflicting interests and loyalties, whether they lie predominantly with employing institutions, physicians, themselves, or with patients, add to the discourse over nurses' suitability for effective advocacy (Annas & Healey, 1974; Winslow, 1984; Woodrow, 1997). Contentious debate surrounds questions of intellectual competencies and educational preparation, including awareness of consequences of acting as an advocate and educational preparation to advocate safely and effectively (Mallik, 1997; Wheeler, 2000). Some critics argue that nurses lack power within the health care system and therefore, lack authority to challenge physicians and institutions (Martin, 1998; Winslow, 1984). The notion that patients are vulnerable, and forced to be dependent on nurses for fear of pain and suffering, results in health care professionals exercising benevolent paternalism and restricting patient self-determination, is a noted

concern as well (Castledine, 1981; Hewitt, 2002). Finally, in most health care settings, patients have limited or no choice of who is to act as advocate (Woodrow, 1997).

Despite the ongoing controversy around nurses as advocates, the professional nurse as advocate is viewed as a philosophical foundation of the discipline by many nurse leaders and considered by some to be not only a foundational element of nursing, but its very essence (Steeves et al., 1994).

<div align="center">Scientific Inquiry</div>

The meager yield from the computer-assisted search for empirically-based articles necessitated an additional search using reference lists from the few studies available, citations in literature reviews, conceptual frameworks, philosophical discussions, interviews and editorials. Sixteen articles describing scientific efforts to explore concepts of advocacy with regard to patients, nursing and nurses emerged from this extended search.

In the first published inquiry into advocacy among nurses, Segesten (1993) used nurses' narratives to describe the lived experiences of expert Swedish nurses. At the time this study was initiated, patient advocacy was not considered a nursing activity in Sweden and instead, it was assumed that specially appointed patients' ombudsmen fulfilled these needs – most of which were related to patients' dissatisfaction with care. In the process of exploring characteristics of expert nurses, many narratives involved actions that could be considered patient advocacy, leading Segesten to ask: "What are the characteristics of patient advocacy situations in which expert nurses are involved?" The elements of patient advocacy situations identified were: 1) a powerless patient; 2) a problem concerning the

patient's own will or what is good for the patient; 3) an adversary; 4) a trigger situation; and 5) a prompt decision and action by the nurse. Segesten's findings also suggested that nurses advocates act out of conviction, accept additional work, and assume risks of being punished (1993). Participants in this study attached a high degree of importance to their advocacy efforts.

Acting on the assumption that "client advocacy is an essential component of the professional nursing role", Millette (1993, p. 607) set out to describe nurses' views on advocacy and how it affects nursing practice. She posited that advocacy involved nurses acting on ethical principles, standards, and values, and also pursued exploration of nurses' moral development. Informed by the work of Murphy (1979), Benner (1984), Gadow (1980), and Millette (1993) explored nurses' preferences for various models of advocacy (client advocate, bureaucratic advocate, or physician advocate), and the relationship of preferred advocacy models to demographic factors, and nurses' moral development using Gilligan's (1977) instrument. Murphy (1979) constructed three models of advocacy: bureaucratic advocacy, in which the nurse owes allegiance primarily to the institution, and the needs of the patient and nurse are secondary; physician advocacy, in which the physician gets primary consideration and all other factors are secondary; and client advocacy, in which the client is the primary focus, with all health care providers collaborating to attain the client's self-determined goal. Using quantitative (mailed questionnaire) and qualitative (semi-structured interviews) methods, Millette's (1993) participants ranked the client advocate model highest of the three models, but few actually selected client advocacy actions as best responses to case examples. Bureaucratic

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and physician advocate actions were more often selected as best responses by these nurses. Millette (1993) concluded that while the concept of client advocacy appealed to practicing nurses, implementation posed problems that had yet to be addressed.

In a study using both qualitative and quantitative methods, Sellin (1995) asked nurse participants to define patient advocacy, to discuss advocacy experiences in institutions and their perceptions of risks attached to advocacy in these settings, and to identify a concept central to patient advocacy. Data were collected using semi-structured interviews, completed decision-making inventory, and a Likert-type scale was used to assess willingness to assume risks associated with patient advocacy. Several conceptual definitions of advocacy were identified and agreed with definitions present in nursing ethics literature. Participants opposed the notion of referring to advocacy in terms of whistleblowing. Participants identified information gathering as the primary advocacy activity; identified secondary advocacy activities included protecting patients from harm, reporting problems, supporting patients' decisions, educating patients, and guiding patients through the system (Sellin, 1995). More complex situations were thought to generate greater risks. Participants identified practice setting culture, nurses' personal and professional characteristics, and quality of the nurse-patient relationship as factors that influence patient advocacy, and also identified *caring* as the most essential quality necessary for effective advocacy. Caring properties specifically cited included respect for others, commitment, compassion, sensitivity to patients' feelings and needs, honesty and trust.

Snowball (1996) explored British nurses' understandings of the concept of advocacy through analysis of data from semi-structured interviews. Snowball noted that differences in health care contexts between the US fee-for-service context and that of the National Health Service System in the UK, would likely account for expected differences in observed advocacy actions reported from the two systems. Categories derived included the importance of the therapeutic relationship as the key to advocacy, shared common humanity between the nurse and patient, the cultural environment of the care setting in which advocacy occurs, and descriptions of reactive and proactive levels of advocacy. Reactive advocacy was described as specific or individual advocacy – *reacting* to immediate needs of patients who are the direct responsibility of the nurse, and was the predominant mode of advocacy noted here. 'Bigger picture" advocacy, taking place on a broader scale than at the bedside of individual patients or small ward groups of patients, was classified as "proactive advocacy" – advocacy on behalf of people who "aren't even in care yet, aren't even ill yet who will be" (Snowball, 1996, p. 73). Snowball concluded that nurse advocates need to have sound professional identity and high self-esteem and self-confidence if they are to effectively advocate in potentially risky situations. The key, Snowball asserts, is for nurses to be clear that the focus of nursing accountability is to the patient, and realizing their "security with others and in the personal and professional self" (p. 74).

In two related qualitative studies, Mallik (1997, 1998) outlined a functional model of patient advocacy among practicing nurses in London, and perceptions and attitudes among England's "elite" nurses respectively. Using qualitative data analysis techniques

attributed to Strauss and Corbin (1998a), data generated from practicing nurses revealed

five causal condition categories that prompted nurses to advocate: 1) patients' fear of

medical authority; 2) patients' vulnerability; 3) direct patient requests; 4) nurse trapped

by role – or duty to be the patient's advocate; 5) nursing judgment of need. Intervening

conditions included: 1) patient recognition of the role; 2) significance of the nurse-patient

relationship; 3) emotional responses (especially feelings of anger and frustration);

4) moral justification; and 5) knowledge, expertise and position legitimacy (Mallik,

1997). Good communication and negotiation skills were viewed as necessary traits for

the nurse advocate. Self-advocacy was under-utilized and respondents cited many

incidents in which the nurse assumed the advocate role instead of promoting patient

power (Mallik, 1997).

In the second of Mallik's studies, perceptions and attitudes of the nursing elite –

nurses occupying formally-defined positions of authority – were explored (1998).

Advocacy was viewed as good professional practice for nurses, but was not viewed as a

"nurse-only" role. The elite nurses recognized the risky nature of advocacy, but still

agreed that all nurses should be able to advocate and that no special education was

necessary. Mallik pointed out that at the time of this study, there was little legal

protection for nurses and that loss of employment was indeed a possibility for nurses who

choose to advocate. As a result, Mallik concluded that support among the elite for an

advocacy model of nursing is tentative.

Vlasses (1997) explored the caring aspects of nurses' work that are difficult to

articulate in a case study at an urban U.S. rehabilitation center. According to Vlasses

(1997), the caring aspects of nurses' work is often a covert phenomenon, is denigrated as simply emotional, and taken for granted. This case study was designed to increase the understanding of patterns of nurses' care and work in the context of the client situation. Unstructured interviews were analyzed, revealing previously unaccounted for aspects of nursing work that when combined, comprise full-scale interventions. Vlasses (1997) concluded that nurses must take into account numerous clinical assessments as well as patient, family, and organizational assessments in relation to one patient.

The effects of ritual actions and routines that pervade nurses' daily activities were explored for their effects on the advocacy role of nurses by Martin (1998). Martin employed a form of participatory inquiry called *new paradigm research* in which results arise from the research process and are formulated by participants, and interpretation is left to the researcher. Participants, registered nurses enrolled in a death and dying continuing education course, provided feedback from a classroom exercise and a written reflection of practice. Findings indicated that the ritualized nurse-doctor relationship and other ritualized actions diminished the abilities of nurses to act as advocate. Power of the doctor was perceived as central to nurses' abilities to act as advocate, leading Martin to conclude that the rigid status structure in health care settings limits and defines responsibility of individual nurses (1998). Professional distancing via ritual behaviors associated with a task-orientation and what Martin saw as the "busy nurse syndrome" protected nurses from the need to talk to patients (p. 193). Limited interactions precluded occurrence of advocacy, but also appeared to help nurses overcome anxieties commonly associated with work in end-of-life care settings.

In another qualitative descriptive study, Chafey and colleagues (1998) sought to identify characterizations of advocacy among practicing nurses, including how nurses exercise the advocacy role and characteristics that promote or impede the role. Categories that emerged from these data were "characteristics of the client", "characteristics of the environment", and "characteristics of the nurse." Nurse traits of self-confidence, conviction, and personal beliefs and values were found to be influences to advocate. Unapproachable and uncommunicative physicians and sociolegal and economic environmental conditions stimulated nurses' advocacy actions. Influences not to advocate included nurse-client relationship and interpersonal relatedness – for example, the nurse did not sense the patient's need. For the 17 informants recruited by Chafey's research group, interpersonal relatedness, including elements such as listening, being there, taking time and effective communication, was viewed as the cornerstone of nurse advocacy. Issues of accountability, ethics, and professional autonomy were not viewed as central forces in the advocacy process in this group of nurses. These authors offered a conceptual model of advocacy categories and characteristics that influence advocacy interactions.

Ambler and colleagues (1999) compared outcomes of an advocacy approach utilizing specialist nurse counselors to outcomes achieved in conventional approaches to women newly diagnosed with breast cancer under the UK's National Health Service. Data collection methods included administration of standardized scales and semi-structured interviews conducted with 103 subjects. Subjects in the advocacy group rated themselves as better informed, having greater comprehension of treatment options, and

being more involved in treatment decision-making than did women in the conventional care group.

The experiences of military nurses engaging in advocacy practices, their shared practices and common meanings were explored by Foley and colleagues (2000) using Heideggerian hermeneutic phenomenology. Twenty-four U.S. Army nurses deployed during the military operation in Bosnia and Hungary volunteered participation in the study. Of all the studies reviewed here, this study alone offered educational and experiential demographics: By virtue of Army Nurse Corps requirements, all participants had at least a bachelor's degree in nursing, with nursing experience ranging from 2.5 years to 26.5 years. These nurses felt strongly about caring for patients the way they would want to be cared for, or would want members of their families cared for. Safeguarding emerged as the constitutive pattern, encompassing immediate physical protection, anticipation of future problems, planning for contingencies, speaking up for the patient, and preserving patients' human dignity. Four advocating practice themes were identified: 1) advocating as protecting; 2) advocating as attending the whole person; 3) advocating as being the person's voice; and 4) advocating as preserving personhood. Consistent with theoretical literature (Copp, 1986, 1993; Mallik, 1997) participants identified patient vulnerability as a key component of situations where advocacy practices occurred. Caring, indicated by respect and concern for patients and fostered by the nurse-patient relationship, was identified as a key characteristic.

Previously unpublished data from the work of Foley and colleagues (2000) and an expanded participant sample were used to describe how nurses learn advocacy skills

(Foley et al., 2002). Again, a Heideggerian hermeneutic phenomenological approach was used in this study in which 62 active duty Army nurses were interviewed. The single constitutive pattern that emerged from data was Developing Advocating Practices, with three themes: 1) Who I Am; 2) Watching Other Nurses Interact with Patients; and 3) Gaining Confidence. Participants often revealed that establishing advocacy in their nursing practice was deeply rooted in who they were and how they were raised, as opposed to a specific learning process. Participants also indicated that the mentoring process, watching other nurses interact with patients, offered meaningful lessons, and underscored the importance of role modeling in learning how to deal with and care for patients. Last, confidence acquired by working with mentors and the resulting supportive environment were identified as important aspects of learning advocacy. For participants in this study, learning advocacy was not systematically taught, but instead was haphazard and situationally dependent.

MacDonald (2006) analyzed themes from accounts of nurses' advocacy experiences using a synthesis of qualitative studies published from 1993 to 2005. The purpose of this work was to provide clarity about the nature of advocacy in nursing practice, with conclusions suggesting the significance of contextual features of the interrelationships of nurses' workplace cultures, learning experiences of the nurse, therapeutic and engaging relationships between nurses and their patients, continuing education and the enactment of advocacy.

Identification and illustration of nurse advocates' activities in ethically difficult care situations with terminally ill patients was the purpose of the qualitative study using a

hermeneutic phenomenological approach carried out by McSteen and Peden-McAlpine (2006). Three primary subplots were identified: 1) Acting as a guide during transitions at the end of life; 2) Acting as a liaison between the healthcare team and the family; and 3) Acting to support the meaning of the illness to the patient and the family. These authors viewed the emergent subplots as essential components of nursing advocacy, finding them to be present in combination with situational events and to be supported by available literature – especially Gadow's (1980) description of existential advocacy (McSteen & Peden-McAlpine, 2006).

In one of the first attempts to capture information regarding oncology nurses and advocacy, Gosselin-Acomb and colleagues (2007) surveyed 141 oncology nurses in North Carolina using a mailed semistructured questionnaire. This tool was developed to elicit information about how nurses advocate for patients' needs and the resources used to do so. Findings of this study indicate that nurses need methods to provide ongoing education and update on relevant advocacy issues and mentoring opportunities. Stated implications of this work include the need for research and education to enhance the role of oncology nurses as patient advocates (Gosselin-Acomb et al., 2007).

Limitations of Empirical Work

Three of the sixteen studies cited combined qualitative methods with various quantitative instruments that measured related concepts such as anxiety and depression, physiologic symptoms (Ambler et al., 1999), nurses' decision-making style (Sellin, 1995), and effects of demographic variables (Millette, 1993). The work of Gosselin-Acomba and colleagues (2007) employed a self-administered questionnaire to

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obtain demographic and frequency data. The remaining 13 studies employed qualitative methodologies, making generalization to other populations impossible. The majority of studies focused on narrowly defined specialty nurses (Ambler et al., 1999; Mallick, 1997) or nurses working with populations deemed to be particularly vulnerable, such as dying patients (Martin, 1998; McSteen & Peden-McAlpine, 2006) and other so-called "silent" patients. Sampling methods vary and sample sizes, even though consistent with qualitative method, have generally been quite small, ranging from 1 in a case study (Vlasses, 1997) to 222 (Millette, 1993): most studies had fewer than 20 participants. Only one study explored patient outcomes of the advocacy role (Ambler et al., 1999). Each study identified the significance of contextual issues, including health care delivery system variations among locations in which studies are carried out, again, adding to the difficulty of applicability of findings. Only four studies reported the educational preparation and credentialing of nurse participants (Foley et al., 2000, 2002, Gosselin-Acomb et al., 2007; Millette, 1993). McSteen and Peden-McAlpine collected demographic data on their nurse-informants, including years of experience in caring for dying patients. Seven of the 16 studies cited used U.S. nurse participants – although participants in the reports by Foley and colleagues (2000, 2002) were military nurses deployed in Eastern Europe at the time of data collection.

<center>Advocacy and Healing</center>

Curtin (1983) infers that the outcome of the nurse's role as patient advocate is the creation of an atmosphere in which human values, respect, and compassion are realized. This outcome is similar to those noted by Kritek and colleagues (1997a) in their seminal

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work on healing as a central nursing construct. Kritek says that nurses "attend to both subjective and objective meanings of healing and wholeness and engage in interactions with others where both meanings guide nursing responses" (1997b, p. 14). Similarly, Erickson and colleagues (1984, p. 49) define nursing as "the holistic helping of persons with their self-care activities… an interactive, interpersonal process that nurtures strengths to enable development, release, and channeling of resources for coping with one's circumstances and environment… (and the) goal is to achieve a state of perceived optimum health and contentment."

Vlasses (1997), in considering unaccounted-for aspects of nurse's work, revealed the work that, according to nurses, no one else sees – facilitating, making things happen, filling in gaps, and putting the self in the situation - that are consistent with theoretical and empirical descriptions of nurse advocacy. The problem, according to Vlasses, is that quite often the advocacy work of nurses is too familiar for words. Yet, Clark and Lang (1992) remind us that "if we cannot name it, we cannot control it, finance it, research it, teach it, or put it into public policy" (p. 109).

Advocacy is a complex concept, but one that is increasingly important for patients and significant for the evolution of nursing as a healing science. Foley and colleagues (2000) suggest that advocating is increasingly important in a dehumanizing, impersonal, and profit-driven health care system. Chafey and colleagues (1998) pose intriguing questions about changes in the nursing profession and consequent potential divergence of the advocacy role from that described in the professional literature and taught in baccalaureate nursing curricula. One of Snowball's (1996) subjects captured the essence

of the dilemmas imposed by our lack of clarity about advocacy, patients, nurses and nursing: "Advocacy is not profound in its enactment, but I think it possibly can be in its effect" (p. 72).

Modeling and Role-Modeling Nursing Theory as a Sensitizing Framework

Modeling and Role-Modeling: A Theory and Paradigm for Nursing, (Erickson et al., 1983) was first published in 1983. The client's model of the world is central to the theory, offering a way to holistically assess and approach health, wellness, and healing of persons who are receiving nursing care. Modeling and Role-Modeling (MRM) theory is inductively (from the authors' collective practice experiences), deductively (from empirical studies), and retroductively (from several well-established foundational theories) derived. Foundational theories in MRM include the works of Maslow (1968), Piaget (1969), Erikson (1963), Selye (1976), Lazarus (1966), Engel (1962), Seligman (1975), and others. For example, a nurse's assessments of the degree to which a patient's needs are met are defined by Maslow's theory (1968), psychosocial development is assessed using Erikson (1963) as a guide, and cognitive developmental assessment follows parameters identified by Piaget (1969).

MRM evolves from a philosophical approach, assuming that in some respects people are alike, while in others, people are different, and that these likenesses and differences can be linked. Eight explicit assumptions, derived from the thorough understanding of supporting foundational theories, underlie evolving MRM theory (Erickson et al., 1983; Erickson & Kinney, 1990; Kinney, 1990; Liehr & Smith, 1999):

1.   Basic need satisfaction is a prerequisite for developmental task resolution.

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2. Unmet basic needs interfere with growth processes.

3. Persons become attached to those objects that satisfy basic needs.

4. Secure attachment produces feelings of worthiness.

5. Feelings of worthiness result in a sense of futurity.

6. Real, threatened or perceived loss of the attachment object results in grief.

7. Individual's ability to contend with stressors is directly related to the ability to mobilize resources.

8. Individuals' ability to mobilize resources is directly related to their need deficits and assets.

Modeling, based on the work of Milton H. Erickson, is the process used to develop an understanding of the patient's world, as he or she perceives it (Zeig, 1982). Erickson contended that appreciation for the patient's model of the world is a prerequisite for providing holistic care. Role-Modeling involves the individualization of care based on the patient's model of the world and, according to Erickson and colleagues (1983) uses theoretical bases to plan and implement nursing interventions that facilitate the person's attaining, maintaining or promoting his or her own health. All interventions are based on five principles that relate to commonalities among humans:

1. Build trust.

2. Promote positive orientation.

3. Perceived control.

4. Promote strengths.

5. Set mutual goals that are health directed.

Nursing, person, health, and environment, the major components of MRM, relate to assumptions and philosophical beliefs about ways in which people are alike (holism, mind-body connections and basic needs), how they differ (genetic endowment, world views, adaptation, and self-care abilities), and finally, what it is that nurses do. These concepts are well-defined, are used and supported by other acknowledged entities such as the World Health Organization, and generate little or no controversy.

Erickson, Tomlin, and Swain (1983, p. 43-44) characterize nursing as a "process between the nurse and client… that is independent of the doctor-patient relationship." They add that nursing "occurs both independent of and in collaboration with a doctor". (p. 44). Ultimately, they define nursing in this way:

> *Nursing* is the holistic helping of persons with their self-care activities in relation
> to their health. This is an interactive, interpersonal process that nurtures strengths
> to enable development, release, and channeling of resources for coping with one's
> circumstances and environment. The goal is to achieve a state of perceived
> optimum health and contentment (p. 49).

Human beings, according to MRM, are holistic and possess interacting subsystems (biophysical, psychological, social, and cognitive) with inherent genetic bases and spiritual drive. Body, mind, emotion, and spirit are a total unit and act together to create holism, which implies that the whole is greater than the sum of the parts (Erickson et al., 1983, p. 45). MRM theory assumes an inherent human drive towards health, growth and development.

The definition of health used in MRM is similar to that used by the World Health Organization: "Health is a state of physical, mental, and social well-being, not merely the absence of disease or infirmity" (WHO, 1946). In addition, MRM recognizes health as a "state of dynamic equilibrium among the various subsystems" (Erickson et al., p. 46). Environment, as defined in MRM, is both internal and external, and includes stressors and resources for adapting to stressors. Persons may need assistance is recognizing and mobilizing adaptive environmental resources.

Additional concepts used in MRM to explain human nature include adaptation, self-care, and affiliated-individuation. Adaptive responses used in MRM follow the generally accepted theories of Engel (1962) and Selye (1976), implying that humans use stressors to move forward, that taxing one subsystem to cope may stress another, and that this process may result in physical illness. Health and well-being, according to the theory, depend on learning to cope by mobilizing resources. In MRM, self-care incorporates three elements: Self-care knowledge (the person knows what promotes or interferes with health), self-care resources (internal and external source of help to cope with stressors), and self-care action (development and use of knowledge and resources to promote optimum health.). The concept of affiliated-individuation, unique to MRM, maintains that persons have an instinctual need to be dependent on support systems and at the same time, remain independent from these systems (Erickson et al., 1983).

Rogers (1996) proposed *facilitative affiliation*, a model of nurse-client interactions, as a construct within MRM. Erikson and colleagues (1983) identified *facilitation* as a primary nursing role that they perceive as fundamentally what nurses do.

The nurse-client relationship is reflected in the word *affiliation,* for its meaning as the act of bringing into close association. Ultimately, *facilitative affiliation* is defined as "any nurse-client interaction in which the nurse assesses the client's needs based on that individual's self-care knowledge and perceived resources and creates individualized interventions based on those identified needs" (Rogers, 1996, p. 175).

Defining attributes of facilitative affiliation, according to Rogers (1996), are:

- Presence – physically being there and psychologically being with;

- Assessment of needs based on clients' self-care knowledge and perceived resources;

- Creative individualized interventions that build on clients' strengths, potential, and resources to address unmet needs;

- Normative disregard – rule-bending or breaking;

- Mutual trust;

- Nurturance – the nurse seeks understanding of and values client's model of the world, and use of interventions that facilitate the client's return to holistic health; and,

- Advocacy, in which clients are assisted by nurses to exercise their own self-determination.

Advocacy and Oncology Nursing

Gadow suggests "cancer patients are perhaps the most vulnerable of all those who seek professional care" (1983, p. 99), citing cancer patients' unique confrontation with a number of forces that suppress their autonomy. Likewise, Copp (1986) notes a continuum

of vulnerability in which people at risk for cancer diagnoses are "potentially vulnerable",

those with episodic or recurrent cancers may be "episodically vulnerable", and our elders,

with or without cancer, "inevitably vulnerable" (p. 258). Through loss of independence,

barriers to informed choices and decision-making, the absence or presence of that which

is needed, and the loss of individuality, people with cancer are at risk for damage to their

self-image and humanity (Copp, 1986). A cancer diagnosis can determine the quality of

an individual's life and diminish one's sense of personal control. Applying Gadow's

notion of existential advocacy, the nurse advocate's role is to help patients clarify and

understand their beliefs, values, and goals as they assess available cancer and symptom

management options. Clarifying one's values when making decisions that affect the

quality and continuation of one's life must be accomplished in the setting of cancer care,

where the language, terminology and the options themselves are unfamiliar and complex.

The Oncology Nursing Society (ONS) maintains a voluntary membership of over

35,000 nurses worldwide. It is considered the authority on oncology nursing practice,

research, education, and administration. Building on the American Nurses Association's

(ANA) foundational documents (ANA, 2003, 2004) and in collaboration with ANA, ONS

created *Outcome Standards for Cancer Nursing Practice* in 1979 and *Standards of

Oncology Nursing Practice* in 1987. Revisions to the latter document led to the crafting

of the *Statement on the Scope and Standards of Oncology Nursing Practice* (Brant,

1996), revised and published independently by the ONS in 2004 (Brant & Wickham,

2004).

According to the most recent *Statement on the Scope and Standards of Oncology Nursing Practice* (Brant & Wickham, 2004), the "primary goals of oncology nursing practice are to promote cancer prevention and early detection practices and to facilitate optimal individual and family functioning throughout the disease trajectory" (p. 7). The oncology nurse is directed to function as a "coordinator of patient care" in collaboration with other professional care providers and members of the health care team. As such, the oncology nurse "acts as a patient guide and advocate by assisting patients and families to seek information, ensuring informed consent regarding treatment decisions and promoting the maximal level of patient-desired independence" (p. 8).

The ONS Standards of Professional Performance promote the nursing process as the framework for care planning and delivery around 14 identified high-incident problem areas (Brant & Wickham, 2004). These Standards direct oncology nurses to develop ethically sound practice, to confront ethical challenges, use resources wisely, and assume leadership roles in health care. Guided by professional performance Standard V, oncology nurses are to use "ethical principles as a basis for decision making and patient advocacy" (p. 37), advocating for "patients and families in decision-making discussions" (p. 38). Additional expectations relevant to advocacy fall into Standard IX, "Leadership" – guiding oncology nurses to identify and advocate "for vulnerable, underserved populations" – exemplified as "rural elderly patients who do not speak English or use English as a second language, inner-city underserved individuals, single parents with limited or no social support" (p. 41). Like the ANA's *Nursing: Scope and Standards of Practice* (2004), the *Statement on the Scope and Standards of Oncology Nursing Practice*

(Brant & Wickham, 2004) fails to delineate "what, where, when, why, and how" oncology nurses serve as patient advocates.

The Statement on the Scope and Standards of Advanced Practice Nursing in Oncology (Jacobs, 2003) draws from the ANA's *Code of Ethics for Nurses With Interpretive Statements* (2001), directing oncology advanced practice nurses to "acknowledge a patient's right to self-determination, truthful disclosure, privacy, and confidentiality and must respect the patient's dignity and cultural beliefs" (Jacobs, p. 5). Oncology advanced practice nurses are envisioned to be in a "unique position to act as a patient advocate and facilitator in decision making regarding access to care and clinical trials, initiation, refusal or discontinuation of treatment, and follow-up care" (p. 5), and are expected to "advocate for ethical patient care" with "specific attention to access to care, comfort and pain management, and end-of-life decisions" (p. 5). Standards of professional performance for oncology advanced practice nurses are based on five core values: integrity, innovation, stewardship, advocacy, excellence, and inclusiveness (Jacobs, 2003). An expanded delineation of "advocacy" in the *Standards of Professional Performance* is offered:

> Oncology APNs advocate on behalf of people with cancer to ensure their quality of life and their access to exemplary care throughout the continuum of life. They advocate on behalf of the nursing profession and the oncology specialty to ensure respect and recognition, access to education, safe working environments, and fair reimbursement. Oncology APNs also serve as advocates for public policy, particularly in matters of health (Jacobs, p. 8).

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Standard V delineates ethical performance and measurement criteria, including ensuring that rights of patients, families, communities and nurses are respected and safeguarded, education and information is provided to patients and families to facilitate informed decision making, and encouragement to include patients, families, nurses and other colleagues in healthcare decisions (p. 19). There is slightly more clarity with regard to issues that warrant nurses' advocacy efforts in the ONS *Statement on the Scope and Standards of Advanced Practice Nursing in Oncology* document, but directions to fully address the questions "what, where, when, why, and how" remain unformulated.

The ANA and ONS documents emphasize patients' rights, particularly patients' right to informed consent, which is in turn, linked to patient self-determination. Nurses are expected to ensure that patients are informed and that consent is valid. Along with informed consent to undergo invasive procedures and participate in research, patients also have a right to informed refusal. Obtaining patients' informed consent has historically been the responsibility of the person performing the procedure, but it is nurses who often find that patients do not fully understand risks and benefits associated with treatment options that are presented to them (Grace & McLaughlin, 2005; Guido, 2006).

In the setting of cancer care and related issues leading to nurse advocacy, informed consent and patients' rights are only one aspect of patients' needs, expectations, and relevant outcomes. Patients' and families' comprehension of risks and benefits associated with recommended cancer management strategies throughout the cancer trajectory (including prevention, early detection, diagnostic workup, treatment options, symptom management, palliative options and end-of-life care, and ongoing follow-up

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after treatment ends) that are increasingly complicated is also increasingly a responsibility of nurses. Long-term sequelae of cancer and cancer treatment often come as surprises to those who survive after initial cancer treatment, but were uninformed about the consequences of various treatment modalities before treatment was initiated (Haylock et al., 2007). Yet, some 75% of survivors have health deficits that relate to their treatment, including chronic pain, dysfunction in major organ system, depression, and infertility (Aziz & Rowland, 2003). Survivors among racial and ethnic minority and other underserved populations have more post treatment symptoms than their white counterparts (CDC, 2004; Eversley, 2005; Freeman, 2004). Almost half of cancer survivors responding to a poll conducted by the Lance Armstrong Foundation in 2004 indicated that their non-medical needs were not met; 70% reported their physicians failed to offer guidance needed to anticipate and cope with these issues (Lance Armstrong Foundation, 2004).

In its report *Ensuring Quality Cancer Care*, the Institute of Medicine concluded: "Much of cancer treatment involves managing cancer symptoms, including pain and the side effects of cancer treatment" (Hewitt & Simone, 1999, p. 24). It follows that much of cancer care occurs within the scope and practice of oncology nursing, since it is primarily nurses, in collaboration with patients and family caregivers, who plan for, assess, and manage cancer and cancer treatment-related symptoms (Haylock, 2006; Brant & Wickham, 2004).

In a phenomenological study designed to study the essence of oncology nursing, informants identified three roles, each characterized by a set of activities: 1) maintaining

the values of the healthcare establishment, characterized by monitoring, acting on patients' behalf, protecting patients, and bringing patients into line; 2) participating in patients' experiences, characterized by being there for patients, being with dying patients, and in a sense, becoming part of patients' families; and 3) reconciling healthcare values and the experience of patients, characterized by teaching and telling the truth (Steeves et al., 1994).

Summary

This chapter provided an in-depth review of available literature relevant to advocacy as it relates to professional nursing. An historical context offered a perspective from which contemporary philosophical and theoretical discourse are established and reviewed in this chapter. The state of the science as it relates to empirical exploration of various aspects of nurse advocacy was described. The rationale for use of Modeling and Role-Modeling nursing theory (Erickson et al., 1983) as a sensitizing framework for this study was described. Finally, the concept of advocacy as it is reported and used in the context of oncology nursing practice and scope and standards of nursing practice documents issued by the Oncology Nursing Society were reviewed. This background information, concepts, issues, questions, and professional specialty practice guidelines are applied to devise appropriate methodology with which to proceed with this study which is described in Chapter Three.

CHAPTER THREE

RESEARCH DESIGN AND METHODS

This chapter presents the research design and methods used in this study. The study design and research questions are explained and rationale for the selection of grounded theory methodology is presented. Participant recruitment procedures, and collection, analysis, interpretation and synthesis of data consistent with this methodology are described. Considerations and processes to protect human subjects' rights and establishment and maintenance of scientific rigor during this qualitative study are explained.

Research Questions

The aim of this study is to create a new and theory-based understanding of oncology nurses' advocacy behaviors and actions. To achieve this aim, grounded theory methodology is used to address the following research questions:

1) How is advocacy described by nurses working in clinical practice settings?

2) What are the social and cognitive processes used by oncology nurses' when deciding to advocate?

3) How is advocacy operationalized by nurses?

4) What are the client-focused outcomes nurses describe as being influenced by their advocacy efforts?

Grounded Theory as Method

As it was originally conceived, grounded theory methodology was proposed by

Glaser and Strauss as a social research method for discovering theory based, or grounded,

in data accumulated in real world settings as opposed to artificially contrived research

settings (Glaser & Strauss, 1967; Walker & Myrick, 2006). Grounded theory as research

methodology is a qualitative form of field research used to discover and explore

phenomena in naturalistic settings. (Glaser & Strauss, 1966, 1967). Field studies offer

opportunities for in-depth examination of individuals and groups in the field - where

"individuals of interest live and experience life" (Speziale & Carpenter, 2006, p. 28) -

using systematically applied procedural steps to develop a theory of phenomena

grounded in data. Theory, in this context, refers to the identification of "plausible

relationships among concepts and sets of concepts" (Strauss & Corbin, 1998b, p. 168).

Fundamental and unique elements of grounded theory methodology are

theoretical sampling of different groups, maximizing the potential of similarities and

differences of information to emerge, and the constant comparison of existing data with

emerging categories. Both theoretical sampling and constant comparison are linked to the

theoretical sensitivity – professional knowledge, research and personal experiences – that

the researcher brings to the inquiry (Strauss & Corbin, 1998b). Functional components of

grounded theory method are: 1) collection of empirical data; 2) concept formation; 3)

concept development; 4) concept modification and integration; and 5) report production.

Procedural steps occur simultaneously. Unlike quantitative research, grounded theory

does not begin with an existing theory. Instead, provisional hypotheses are formed during

initial data collection, verification occurs through additional data collection and analysis, and theory is derived deductively from general principles (Carpenter, 2006; McCann & Clark, 2003a).

Grounded theory is valuable in the study of interpersonal processes within human interactions, including interpersonal phenomena important in professional nursing (Maijala et al., 2003). The method continues to evolve and is extensively applied, with grounded theorists making important contributions to the development of nursing knowledge. Grounded theory research can contribute to development of middle range theory by offering explanations of social processes among people living through health-related situations. Attention is focused on the complexities of the individuals undergoing change, the influence of social interactions on outcomes, critical junctures affecting adaptation, and the influence of social environments on human experiences (Benoliel, 1996; Speziale & Carpenter, 2006). Of particular importance to the current study, grounded theory methodology allows the integration of the contextual influences of interactions occurring, in this instance, between nurses and patients or populations. Benoliel (1996) contends that findings from grounded theory research can serve as grounds for social interventions and the modification or elimination of obstacles to effective nursing care. This methodology offers opportunities to enhance understanding of the construct of advocacy and guide subsequent action, and is particularly useful when a topic is largely unexplored (McCann & Clark, 2003a; Smith & Biley, 1997). Therefore, grounded theory is a good fit for this qualitative study (Baldwin, 2003; Benoliel, 1996; Grace, 2001; Hanks, 2005; McCann & Clark, 2003a).

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Setting

Data for this study were collected using semi-structured and audio-recorded interviews of nurse participants who live and work in the United States. Interviews were conducted in person and via telephone, with participants determining the time, place, and method (in person or telephone) of the interview. The initial five participants were interviewed during a survivorship retreat attended by adult female cancer survivors and nurses and drawn from oncology private practice settings throughout the United States. Additional in-person interviews were conducted during an annual Congress of the Oncology Nursing Society, with the remaining interviews conducted via telephone.

The Sampling Model and the Sample

Theoretical Sampling and Recruitment Procedures

Theoretical sampling, described by Glaser and Strauss (1967) as "a process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes date" (Glaser & Strauss, p. 45), was used in this grounded theory study. Theoretical sampling is purposeful, in that potential informants are individuals who have experience with the phenomena under study and can provide full and rich descriptions of the phenomena and human interactions in the setting can be elicited and analyzed.

Theoretical sampling requires inclusion of many sites and maximum variation in participants' perspectives in order to generate similarities and contrasts that contribute to emerging theory (Dey, 1999). Individuals eligible for participation in this study were registered nurses (R.N.) of either gender, although no males volunteered. Participants were recruited from among some 35,000 Oncology Nursing Society (ONS) members

throughout the United States. This population of nurses was selected because voluntary full membership (as opposed to student and associate membership categories) in the Oncology Nursing Society (ONS) was assumed to be indicative of participants' acknowledgment of the scope of oncology nursing practice and active registered nurse (R.N.) licensure. Participants were engaged in direct care of individuals (patients, family members, and caregivers) affected by cancer in a U.S. health care setting at the time of the study. Maximum variation sampling was achieved by enrolling consenting volunteers with geographic, age, ethnic, and racial diversity to the extent possible. Eligibility criteria were:

1. Registered nurse (R.N.) of either gender;

2. Full membership in the Oncology Nursing Society;

3. Engaged in direct care of individuals affected by cancer in a U.S. health care setting at the time of the study;

4. Fluent in written and spoken English;

5. Self-identification or recognition by colleagues as an advocate; and,

6. Has practiced as an oncology nurse for a minimum of the previous five years.

Recruitment procedures were initiated with letters of introduction (Appendix A) and/or a recruitment flier posted at gatherings of oncology nurses (Appendix B) describing the aim of the study, the data collection process, and a request for participation. Both included instructions on how to contact me so that those interested in learning more about the study and possible participation talked directly to me.

Ultimately, the sample consisted of 19 female registered nurses. Informed consent (Appendix C) was signed and each participant was provided a copy of their signed informed consent form prior to initiation of data collection procedures.

Sampling and Sample

The study sample was selected to reflect the demographic variability, range of experience, and diverse perspectives of American oncology nurses in cancer care settings available to patients and families. This selection process was necessary given that there is no universally agreed-upon definition of nursing advocacy that could delineate selection criteria. In essence, those nurses volunteering to participate were self-selected as exemplary nurse advocates or identified by colleagues who recognized their expertise in nurse advocacy. The first five informants were recruited from among oncology nurses attending a three-day retreat for women cancer survivors and oncology nurses. These informants had been identified as exemplary nurse advocates by nurse managers affiliated with a nationwide oncology practice management company. During the retreat, the IRB-approved recruitment flier was posted in a common area and I was allowed to offer a verbal invitation during a plenary session where most nurse attendees were present. Five nurses volunteered to participate, signed consent forms were obtained, and interviews were conducted at the retreat setting.

Three informants responded to the IRB-approved recruitment letter (Appendix A) extended to participants in a nursing continuing education course focusing on oncology nursing advocacy offered in the San Francisco Bay Area. These nurses agreed to participate after telephone conversations with me during which the study aim and

methods were more fully described. Participants received informed consent forms as attachments to electronic mail, and returned signed consent forms to me using facsimile technology. Remaining participants were recruited after referral by oncology nursing colleagues or self-referrals after receiving personalized recruitment letters. Sampling in this study continued until no new themes emerged and categories reached theoretical saturation.

The all-female sample of 19 ranged in age from 37 to 61. Mean age was 49; median 50 years old. One participant self-identified as Hispanic and one as Chinese: the remainder of the participant sample was Caucasian. Two participants indicated they had an Associate Degree in Nursing (ADN), four (21%) held Bachelor of Science in Nursing (BSN) degrees, one held a nursing diploma with a Bachelor of Science degree, eleven (58%) had masters degrees, and one had a Doctor of Philosophy (PhD) in nursing. Seventeen (89%) of the participants held certification in oncology nursing granted by the Oncology Nursing Certification Corporation (ONCC): of these, six (32%) held advanced practice certification. One advance practice nurse held state-granted clinical nurse specialist certification, and one had advanced practice certification granted by the American Nurses Credentialing Center. The number of years in practice ranged from nine to 38: mean and median years in practice: 23 and 24 respectively. The majority (74%; N=14) practiced in urban settings; four practiced in suburban settings and one practiced in a small town. Six participants were staff nurses, six held management positions that included direct care responsibilities, five were nurse practitioners, and three were clinical nurse specialists. Two participants worked in radiation oncology settings; the remainder

of the sample worked in medical oncology settings: physician-based practices, acute care

hospitals, and ambulatory clinics. Table 3.1 provides a brief demographic overview of the

sample and complete sample demographics are presented in Appendix E.

<div align="center">Data Generation</div>

<div align="center">*Interviews*</div>

Semi-structured interviews, consistent with grounded theory, offered the

flexibility required for constant comparative analysis and allowed the direction of

interviews to be driven by emerging theory (Kvale, 1996). As Denzin (2001) suggests,

use of the interview guide (Appendix G) assured that all participants were given the

opportunity to respond to the same or similar questions, yet allowed me to alter phrasing

and the order in which questions were posed to fit the context and direction of individual

participants' responses. Each interview was audio-recorded and transcribed verbatim by

me. I verified transcriptional accuracy by reading and comparing the transcript to the

original recording. Participants' names were masked in the data to protect their

anonymity.

<div align="center">*Field Notes and Memos*</div>

Additional sources of data included the researcher's journal, field and

methodological notes. A Contact Summary Sheet as suggested by Miles and Huberman

(1994, p. 53) was used for recording and summarization of field notes. Contact Summary

Sheets completed after each interview provided a method for summarizing information,

main issues and themes that emerged during the interview, and to note additional

Table 3.1. Demographic Overview of Participants.

Age	Ethnicity	Years as RN	Basic RN Preparation	Highest Degree	Work Setting
50	Cau	20	MSN	MSN	TH -ACmo
50	Cau	13	BSN	BSN	TH -ACmo
53	Cau	32	ADN	MPH	SC
37	Cau	15	ADN	AND	MO
50	Cau	30	ADN	PhD	PO
45	Cau	24	Dip	MS	PO
49	Cau	29	Dip	MSN	CH
61	Cau	36	BSN	MN	RT
58	Cau	38	Dip	BS	RT
58	Hisp	19	ADN	MSN	CH
50	Cau	10	AA	AA+	CH
51	Cau	30	BSN	BSN	TH(SC)
38	Cau	15	BSN	MSN	PO
46	Cau	24	BSN	MSN+	PO
41	Cau	9	ADN	BSN	CH
50	Cau	25	BSN	BSN	HA
57	Cau	37	Dip	MN+	TH -ACmo
45	Chin	23	BSN	MS	CH
49	Cau	27	BSN	MSN+	TH -ACmo

Facility legend:

MO = Medical oncology hospital unit   TH = Tertiary Hospital
CH = Community Hospital   SC = Specialty clinic
PO = Physician office   RT = Radiation Therapy
ACmo = Ambulatory medical oncology   + = current student

information and ideas that arose during interview processes. Samples of completed

Contact Summary Sheets are included as Appendix G. My perspectives on existential and

outward events that occurred during my contact with participants were recorded in field

notes. My field notes and summary sheets allowed me to determine the usefulness of

target questions I had posed during interviews and to note and pursue emerging topics or

concepts during subsequent interviews.

Protection of Human Subjects

Approval to conduct this study was obtained from the University of Texas

Medical Branch in Galveston, Texas Institutional Review Board (IRB) on November 29,

2004 (Appendix D). Approved Recruitment letter of invitation (Appendix A), recruitment

flier (Appendix B), Subject Consent Form (Appendix C), and Interview Guide (Appendix

G) are in the appendices noted in parentheses.

Data Collection Procedures

Demographic Data

Demographic data collected from each participant included age, gender, race and

ethnicity, number of years as a registered nurse, the position or title held currently and the

number of years in that position, basic nursing education and highest degree held,

certification and credentialing agency, city of residence, and the type of facility in which

participants work. Complete participant demographic data are presented in Appendix E.

Interviews

Semi-structured individual interviews were conducted via telephone or in person

in locations of the participants' choosing. Selected settings included the aforementioned

retreat and conference settings, work and home settings in which confidentiality and privacy were assured. The interview guide, consistent with the intent of the research questions (Appendix F), was designed to elicit participants' personal perspectives on the construct of advocacy in their clinical nursing practice experiences. Each participant was invited to ask questions about the intent of the investigation and the interview process.

Grand Tour Question

A grand tour question blends research questions with study purpose. All interviews were initiated by the researcher asking the grand tour question crafted as an open ended question allowing participants to set the direction of the interview (Cresswell, 1994; McCaslin & Scott, 2003; Siegle, 2007). In this study, the grand tour question posed to participants was: "If you could tell the oncology nursing world what *advocacy* is, what would you say?" Subsequent sub-questions or prompts, noted in the Interview Guide (Appendix F), were crafted to follow leads provided by participants. Participants were interviewed once with interview sessions lasting from 45 to 90 minutes. At the conclusion of each interview, participants were invited to convey additional thoughts or issues about advocacy, and were also encouraged to contact me should they want to discuss these topics further. No participants contacted me to request additional clarification or discussion and there were no second interviews.

Data Analysis

Data analysis procedures used in this investigation are consistent with those suggested by Strauss and Corbin (1998) and included open coding, axial coding, and

selective coding. Through the process of constant comparison, informants' narratives were compared from one to another as described below.

Data collected during participants' semi-structured interviews is the primary source of data for this study, with additional data contributed by my memos and field notes. Analysis incorporated constant comparative analysis of verbatim interview transcripts and ongoing theoretical sampling, coding and categorizing interview data, field notes and memos. Throughout the data collection process, data were examined and informed the focus of subsequent interviews. I had initially expected that theoretical saturation, the point in coding when no new information is seen in the data (Strauss & Corbin, 1998), would occur after approximately 30 participants. Saturation became apparent following analysis of 14 narrative transcripts. An additional five interviews were conducted to assure saturation.

Constant Comparison Method

The data analysis process referred to as the constant comparative method is the systematic approach to analyzing data in grounded theory studies (Glaser & Strauss, 1967; Strauss & Corbin, 1998) in both Glasserian and Strausserian coding procedures (Walker & Myrick, 2006). Constant comparison, a main premise of grounded theory methodology, is a cyclical approach to data analysis that requires both inductive and deductive thinking (McCann & Clark, 2003b). In this study, coding processes were initiated with early data collection and continued throughout ongoing collection, organization and collapse of the data, categorization of concepts, and identification of theoretical constructs of social processes as they emerged.

Coding Techniques

Strauss and Corbin (1998a) define coding as "the analytic processes through which data are fractured, conceptualized, and integrated to form theory" (p. 3). Open coding, the first of three coding phases, is the "analytic process through which concepts are identified and their properties and dimensions are discovered in the data" (Strauss & Corbin, 1998a, p. 101). Identification of properties and related dimensions is a core task.

In axial coding, fractured data are reassembled to connect categories with subcategories, focusing on three aspects of the phenomenon under study: 1) conditions or situations in which the phenomenon occurs; 2) actions or intentions of individuals in response to what is happening; and 3) consequences of action taken or inaction (Strauss & Corbin, 1998a). During axial coding, the analyst pursues answers to the questions why, where, when, how, and with what consequences, and in the process, uncovers relationships among categories. Answers to these questions help to contextualize a phenomenon, relating structure to process, capturing the dynamic nature typical of real life phenomena.

Selective coding, the third coding phase, is defined as "the process of integrating and refining the theory" (Strauss & Corbin, 1998a, p. 143). Integration involves the analyst's decision of identifying and naming a central or core category that represents the main theme of the research. Theory is constructed by the analyst, after data are reduced from cases into concepts representative of many voices in the sample, and sets of relational statements that explain what is happening.

Coding Operations

Early data analysis was initiated by listening to and transcribing each audio recorded interview myself. I was sensitized to ideas and themes, referred to as "theoretical sensitivity" by Glaser and Strauss (1967, p. 46-47), by listening to audio-taped interviews first, and throughout the transcription process. Verification of accuracy was assured by, again, reading each interview transcript while listening to the audio-tape. Verbatim transcripts were sent via electronic mail back to participants to allow them to confirm accuracy: there were no questions relating to transcript accuracy. It has been suggested that this early phase of analysis allows the researcher to enter the participants' frame of reference (Burnard, 1991). These early processes allowed for the initiation of open coding, including identification of frequently used words and phrases, as well as recognition of possible themes and concepts in the data. Microsoft Word software applications were used to facilitate organizing, sorting, storing, and retrieving study data.

Open Coding

The aim of open coding is to "discover, name, and categorize phenomena according to their properties and dimensions" (Strauss & Corbin, 1998a, p. 206). To accomplish the discovery process, each word, line or paragraph in verbatim interview transcripts was examined for reflections of participants' perceived meaning of processes, behaviors and experiences associated with advocacy in their oncology nursing roles. Codes devised from participants' actual words or phrases were written in transcript margins. Transcript sections with coded events, happenings, acts and actions/interactions were manually cut from the transcript and pasted onto large (flip chart size) pages

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according to categories suggested by the original research questions, with the intent of answering the question "What is going on?" in the data (Strauss & Corbin, 1998a, p. 114). As additional interviews were conducted, emerging codes were constantly compared to existing data and codes. The open coding process yielded 30 codes (Appendix H: Codebook 1) and four categories that were consistent with the four stated research questions: Descriptions of advocacy; Nurses' social and cognitive processes; Operationalization of advocacy; and Client-focused outcomes.

Simultaneous operations of data collection and open coding maintained an analytic process that was open to additional possibilities that could emerge as a result of theoretical (Glaser & Strauss, 1967) and purposeful (Lincoln & Guba, 1985) sampling and maximized opportunities for discovery (Strauss & Corbin, 1998b). For example, in Codebook 1, data examples of advocacy specific to cancer care were coded as "Ramifications specific to cancer care" (A5), highlighting the complexities of cancer care, the uniqueness of the disease process, patients' illness severity, patients' informational needs and the significance of patients' decision-making. In Codebook 2, these data examples merged with additional data and were coded as the "Meaning" of advocacy to the nurse, and references to thought processes and procedures or were coded as "Ways of Knowing".

Axial Coding

Strauss and Corbin define *axial coding* as "the process of relating categories to their subcategories, termed *axial* because coding occurs around the axis of a category,

linking categories at the level of properties and dimensions" (1998a, p. 123). Basic tasks occurring throughout axial coding are:

1) Identifying properties and dimensions of categories that stand for phenomena;

2) Identification of conditions, actions and interactions, and consequences of a phenomenon;

3) Relating categories to subcategories through statements denoting relationships; and,

4) Searching for cues in the data that imply relationships of major categories. (Strauss & Corbin, 1998a, p. 126).

Axial coding processes facilitated my search for answers to the questions of why, where, when, how and with what results. Answers revealed relationships among the categories, contributing to the process of contextualizing the phenomenon of advocacy and relating structure with process (Strauss & Corbin, 1998a). Codebook 2 (Appendix I) reflects outcomes of the axial coding process employed in this study. Conceptual descriptions captured in narratives and included in Codebook 1 were merged to form new categories in Codebook 2. An example of this process is captured by examining Codebooks 1 and 2. "Description of Advocacy" in Codebook 1 is compared with additional data, and emerges as the "Meaning of advocacy to oncology nurses" in Codebook 2. Similarly, data from interview questions crafted to capture social and cognitive processes depicted in Codebook 1 were merged with additional data to comprise nurses' thought processes detailed in Codebook 2. Participants' descriptions relating to their own unique operationalization of the advocacy component of their roles

in Codebook 1 were expanded and given more depth in the Codebook 2 and coded as "nurse behaviors consistent with advocacy". Finally, Client-Focused Outcomes listed in Codebook 1 were expanded to include Outcomes and Value of nurses' advocacy efforts to clients, delivery systems, and the overall health care system in Codebook 2. More detailed descriptions of these analytic processes are presented in Chapter Four.

Selective Coding

The final phase of data analysis, *selective coding*, is the "process of integrating and refining categories" (Strauss & Corbin, 1998a, p. 143) so that they are interrelated in a theoretical scheme (Strauss & Corbin, 1998a). Identification of the core or central category, relating it to other categories, validating relationships, and filling in categories that warrant additional refinement and development are outcomes of selective coding (Strauss & Corbin, 1998a). The central category is the "central phenomenon around which all other categories are integrated" (Strauss & Corbin, 1998a, p. 146). Ultimately, the central category is an abstraction that consists of all products of analysis condensed into a few words that "explain what this research is all about" (Strauss & Corbin, 1998a, p. 146). Strauss and Corbin offer the following criteria for selection of a core category (1998a, p. 147):

1) It is central – all other categories relate to it;

2) It appears frequently in the data;

3) It is logical and consistent, and is not forced;

4) The phrase is sufficiently abstract and can be used to do research in other substantive areas;

5) As it is refined and integrated with the other concepts or categories derived from the data, it grows in depth and explanatory power; and,

6) It can explain variation and the main point made by the data.

All but one informant included "being a voice for" or "giving voice to" individual patients' needs. How they perceived this "voice" as being operationalized and how it affects outcomes became the five thematic concepts identified through Selective Coding and demonstrated in the Final Codebook (Appendix J) - "The meaning of advocacy", "Ways of being", "Ways of knowing", "Ways of doing", and "Outcomes and Value of Nurses' Advocacy". The near universal mention of "voice" and the relationship of all other categories to it suggest and support identification of "a voice for the vulnerable" as the core category in this study.

Scientific Rigor

While no consensus on quality criteria in the qualitative inquiry paradigm has been achieved, researchers do have methods to assure rigor (Bradbury-Jones, 2007; Davies & Dodd, 2002; Lomborg & Kirkevold, 2003; Tobin & Bagley, 2004). Researchers using methods to arrive at grounded theory are obliged to identify and make provisions for achievement of methodological rigor throughout their studies, thereby ensuring trustworthiness of outcomes. In this study, rigor was maintained using the criteria suggested by Lincoln and Guba (1989, p. 247) of credibility, transferability, dependability, and confirmability.

Credibility refers to the fit between experiences of study participants and a researcher's representation of them (Bradbury-Jones, 2007). Such representation is

determined to be credible through several mechanisms including: persistent observations in the data, peer review and agreement of findings, availability of an audit trail that serves to track decisions made during the research process and member checks (Tobin & Begley, 2004). In this study, provisions for achievement of credibility included:

- Two methods of data collection – interviews and field notes – were employed to assure credibility of data;

- Theoretical or purposeful sampling was employed to achieve maximum variation and representative credibility. After the initial interviews, subsequent participants were selected after earlier participants' transcripts had been analyzed with the intent of extending, testing, and filling in information. Considerations for participant selection included reputational and personal indications of consistent advocacy behaviors (Lincoln & Guba, 1985);

- Throughout the research process, I had the support and expertise of my doctoral committee chair and members in devising and implementing rigorous methods of data collection and analysis, contributing peer review to credibility criteria. Selected committee members brought complementary interests and expertise in the qualitative paradigm and grounded theory methodology, health care ethics, the construct of advocacy, nursing history and theory, and a holistic approach to providing care to individuals facing cancer. More than one researcher – the primary investigator and two dissertation committee members - participated in data analysis. Additionally, data analysis was confirmed by an outside researcher;

- The constant comparative data analysis methodology employed verified content step by step throughout the research process, with linkages systematically constructed, which, according to Morse (1998) supports the resulting theory. A verifiable audit trail using the "Contact Summary" forms (Appendix G) and researcher's memos were used to document this process; and,

- Member check: Participant inclusion criteria, including oncology nursing experience and their acknowledged advocacy behaviors minimizes concerns of divergent interests, commitments and goals between the researcher and participants that have been expressed by Sandelowski (1993). At the conclusion of data analysis, five of the nineteen participants (27%) were invited to review identified themes, codes, and findings identified in the Final Codebook and to offer feedback to verify the true-to-life and meaningful portraits of advocacy among oncology nurses. Responses from each of these five participants indicated support for the reported findings.

Transferability, as used by Lincoln and Guba (1989), the generalizability criterion in naturalistic inquiry (Tobin & Begley, 2004), is a function of the similarity between "fittingness" – the level of congruence between the context of the study and reality. It relates to how well a working hypotheses derived from one context is applicable in another. The researcher must provide description of the context of an inquiry to offer subsequent users information sufficient to judge fittingness – referred to as a "thick description" (Lincoln & Guba, 1989, p. 125). Thick descriptions specify everything a reader needs to know to understand findings. In this study, transferability considerations

include specific demographic inclusion and exclusion criteria, including work setting, oncology nursing experience, formal nursing education, informal experiential data, and identification of credentials reflective of the general oncology nursing population in the United States.

Dependability is achieved through an auditing process that is clearly documented, and reflects logical and traceable data collection and data analysis processes (Tobin & Begley, 2004). Throughout this study, Contact Summary Sheets, researcher memos, and a research journal provide a critical account of the research process.

Confirmability establishes that data and interpretations made during the analytic process are not imagined, but indeed, are clearly derived from data (Tobin & Begley, 2004). The audit trail provides evidence of confirmability.

Summary

This chapter provided an overview of the procedures, research design and grounded theory methodology used in this study of advocacy among oncology nurses. The sample population of nineteen oncology nurses was described as was the method used to secure participants. Procedures used to maintain and demonstrate rigor including credibility, transferability, dependability and confirmability, were described. The core or central concept that emerged from the data, "The voice for the vulnerable" – was demonstrated to meet Strauss and Corbin's (1998a) criteria for this crucial element of grounded theory, and ultimately describe what this research is about. A full description of the results and the grounded theory that emerged from this investigation are provided in Chapter Four.

CHAPTER FOUR

FINDINGS

Introduction

Analysis and interpretation of data collected in this grounded theory study are presented in this chapter. The Modeling and Role-Modeling (MRM) nursing theory served as a sensitizing framework for this study and provided a context for analysis and interpretation.

Within the natural setting and context of oncology nurse participants' direct and indirect patient care responsibilities, MRM nursing theory contributed to my understanding of these nurses' holistic approach to patients in which biophysical, psychosocial, and spiritual needs are assessed and considered. Guided by principles of MRM theory, we can integrate oncology nurses' belief that their patients are "holistic, multisystem beings" (Erikson et al., 1983, p. 55) who are affected by relationships between mind and body into a grounded theory of the advocacy component of oncology nursing practice.

Prelude to Central Findings

The core variable, *voice for the vulnerable*, emerged from the analysis and interpretation of this sample of oncology nurses' articulated thoughts about the advocacy component of their varied roles in contemporary oncology practice settings. Sections in this chapter identify and reveal themes in the data in the context of the research questions.

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The resulting grounded theory provides contextual and theoretical support for the core variable.

The notion of the nurse *being a voice for* or *giving voice to* individual patients' needs was clearly articulated by all but one participant throughout the interviews, often occurring first or at least early during interviews in response to the grand tour question – *If you could tell the oncology nursing world what advocacy is, what would you say?*

Giving Voice to Patients' Needs

The majority of sample participants were clear in their shared notion of advocacy as "giving voice" to the biophysical, psychosocial, and spiritual needs of their patients, patients' family members and significant others. The core concept presented itself at the very beginning of data collection, was strengthened as constant comparative data analysis progressed, and was noted over and over again throughout subsequent interviews. The following five interview excerpts provide descriptions of this concept.

Ms. M. (#01), a 38-year old transplant coordinator, has been a registered nurse for 15 years. She is an Advanced Oncology Certified Nurse (AOCN®), practicing in a multi-physician oncology office. In the first interview conducted as part of this study, Ms. M. described advocacy this way:

> When I was in nursing school, I remember that being one of those little rules – you know – rules of the nurse – it was totally in there – advocate – that's what they told you from the beginning. *You needed to be their voice when they did not want to have a voice – or they were afraid to have one.* (#01: 563-569)

In the second interview conducted in this study, Ms. P. (#02), a 37-year old staff nurse, Oncology Certified Nurse (OCN®) and student in an ADN to MSN program, who works in a free standing cancer center, responded in this way to the grand tour question:

I would say [advocacy is] *assisting the patients in finding their voice*, you know, so that their voice is heard in the bigger picture… their voice is heard by their physician, their voice is heard by legislators… (#02: 12-15)

Ms. C., OCN, (#04), with a Masters in Public Health degree and 32 years experience in the field, is now a breast care specialist. She also referred to "giving voice" early in the interview process:

I think *advocacy is really giving a voice to people,* empowering their own voice, or speaking for them, when they are unable to. Often times in nursing… in oncology, there're often times patients are too ill and *you have to be the voice for them,* and hope they can recover to the point where they can indeed become self-advocates… (#04: 12-19)

Ms. J. (#05) is a doctorally-prepared oncology nurse practitioner with over 30 years of oncology experience who currently works in an office-based medical oncology setting. She acknowledged the inclusion of advocacy groups and community groups as clients in her own practice, while still referring to being a voice for patients:

It's a skill that nurses bring to the table, to empower the patient so that they can go out and become their own advocate and help others as well. So, I think it starts there. But I think oncology nurses also have to take a stand in other scenarios, like in the community and also, not just in advocate groups but *in those places*

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where there's not a voice for patients and many times we find ourselves in that particular setting, and *we have to speak for patients*. (#05: 20-28)

Ms. K. (#09) is a nurse clinician in a comprehensive cancer center ambulatory head and neck service. She has been in her current role for 11 years, but has been an oncology nurse for over 30 years. She says "I love those patients – I absolutely love them, and I know I'm going to stay here until I retire." To her, advocacy is:

> …being a spokesperson for the patient. The patient, through no choice of theirs, enters a world that they are completely unfamiliar with. It's really, in a way, *it's being a spokesperson for them, it's watching them, it's helping guide them through, and supporting them through it;* offering your assistance if they need it. To me, that would be my role, or any nurse's role, as far as I can see it. (#09: 100-105)

<div align="center">

Vulnerabilities of People Affected by Cancer

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The concepts of vulnerability, people made vulnerable as a result of cancer, and nurses as protectors, though not labeled as such, appearing in several participants' narratives as is seen in the following incidents of data:

> That's what an advocate does – they kind of take the side of who they think is the vulnerable person – the person who needs something. (#11:534-538)
> In the oncology world, there are often times patients are too ill and you have to be the voice for them. (#04:16-17)

We are the people seeing those patients, or talking to those patients more than anybody else. We assess their needs more than anybody else. And if we don't let them know that they have a voice, they suffer needlessly. (#02:530-533) If you feel that something is being done inappropriately, or the team is not taking something into account that is affecting your patient, you can go directly to the attending and bring it to his or her attention so that we can rectify the situation. (#03: 17-20) …They are entering a whole new world that is totally alien to them and they don't even know what to ask; they don't know what to expect. (#03: 313-315)

These excerpts are representative of the meaning of advocacy to a majority of study participants. Continued analyses revealed similarities in data which were then grouped by like meaning, eventually providing evidence for creation of data clusters reflecting the contexts of advocacy. These data clusters collapsed into more abstract categories, representing larger meaningful constructs that capture and describe comparable phenomena described by study participants. Five focal content areas that support recognition of the core variable emerged and will be discussed later in this chapter.

<div align="center">Central Findings Organized by Research Questions</div>

Constant comparison and abstraction of data provided answers to the research questions posed in this study, and eventually, to the emergence of five central thematic concepts useful to development of the grounded theory. Findings that provide a

conceptual portrait of advocacy in oncology nursing are organized by the research

questions, presented in the following section, and summarized in Table 4.1.

Research Question 1

How is advocacy described by oncology nurses working in clinical practice settings?

Although instances of data supporting "giving voice" as a thematic concept

appear frequently, additional data provide evidence of the complexity of the concept. The

numerous ways in which advocacy is described by informants in this small sample, its

meaning in the context of their work, and the backdrop of diverse personal and

professional values reflect the historic difficulty of arriving at a universally-accepted

definition of advocacy as it relates to professional nursing. Four thematic concepts

relating to the first research question emerged from analytic processes: supporting

instances of data are presented here.

Thematic Concept One: Giving Voice to Patients' Needs

Study participants were nearly unanimous in their descriptions of advocacy as

being a voice for or giving voice to patients' needs. Narratives provided evidence of

nurses' perceptions that people with cancer often lack means and skills to fully

comprehend information provided and effectively communicate their wishes and needs to

family and professional caregivers. In these circumstances, outcomes can be contrary to

Table 4.1. Summary of Findings

Meaning of Advocacy	Ways of Being	Ways of Knowing	Ways of Doing	Value of Nurses' Advocacy
Voice for the patient/Population • Speaking on behalf of patient • Many forms: to family, physician, policy-makers • Standing up for patients' rights • Taking the side of the person who needs something • Necessary or patients suffer needlessly • Patients lack means and skills to understand information • Patients lack communication skills **Component of ethical nursing practice** • It's part of our job • It's our duty • It's our responsibility	**Expertise, knowledge, wisdom gained through education and practice experience** • Novice to expert • Self-confidence • Comfort with difficult issues • Competency in oncology nursing (skills and knowledge) • Innate ability to assess patients' needs • Understand inter-connectedness of patients' needs **Nurses' personal values** • Caring • Empathetic • It's not about me: it's about what patients need • Holistic nursing philosophy	**Recognition of vulnerability of cancer patients** • Taking the side of who they think is vulnerable • The person who needs something • Something is being done inappropriately • Patients are too ill to advocate for themselves • People are entering an alien world **Knowing the population** • I ask them • Compare needs with knowledge of disease process and treatment • Ability to predict	**Establish and nourish the nurse-patient relationship** • Being present • Expertise fosters patients' trust • Talk about what is going on • Demonstrate caring **Informing, educating, communicating** • Patients' decision-making based on accurate knowledge and supporting patients' decisions • Step in when patients don't understand risks and benefits of treatment options **Navigating, coaching, guiding** • Match needs and limitations to available resources • Facilitate second opinions	**To health care and delivery system** • Health policy • Delivery system • Patient satisfaction • Cost-effectiveness • Using system effectively • Impact on incidence of adverse events **To individual patients and clients** • Informed decision-making • Empower patients to live life as fully as possible • Nurse is teacher and guide • Patients' are able to access resources • Patient satisfaction • Optimal symptom control • Getting the treatment they need

Table 4.1. Summary of Findings (cont.)

Meaning of Advocacy	Ways of Being	Ways of Knowing	Ways of Doing	Value of Nurses' Advocacy
Empowerment • Empower patients • Empower colleagues • Patient self-advocacy	• Spiritual and moral investment • Spiritual and ethical responsibility to patients • My school of nursing shaped the "nursing me" • Self-awareness of beliefs • Conscientious thoughtfulness **The practice environment** • Supports nurses' advocacy efforts • Promotes nurse autonomy • Helping nurses take care of themselves and each other • Collegial respect • Impact of patient load • Nurse manager as supportive champion • Allies in caring • Ability to make a difference	**Modeling the patient's world** • Empathy • Listening • Good history and physical assessment • Dealing with patients as I would want to be	• Use and manipulate the system to get best outcomes for patients/clients	**To nurses and nursing** • Work role satisfaction • Making a difference in the lives of patients, families, survivors • Valuing and being valued • Fulfillment of reasons to become a nurse; fulfilling my passion • Meaningful to see patients go on with their lives • It's hard; wears you down when nothing is followed through • Feeling blessed and honored to have been let in • Ability to create something that's going to live on

Table 4.1. Summary of Findings (cont.)

Meaning of Advocacy	Ways of Being	Ways of Knowing	Ways of Doing	Value of Nurses' Advocacy
	• Feeling cared for and cared about • Nurse owns her position **Professional Commitment** • Use of ONS Standards and Guidelines • ONS involvement • Certification • It's not a job; it's a calling • It's a ministry • A profession, not a job • It's my persona • Affinity toward cancer patients			

patients' wishes, thereby diminishing attainment of desired therapeutic goals and patients' self-determination.

Informant Ms. C. (#04), a 53 year-old certified oncology nurse with an advanced degree in public health, 32 years of oncology nursing experience, now working as a breast cancer nurse navigator, described the nurse-patient partnership of advocacy in this way:

> It's being able to help people, either singing for them, speaking for them and with them, or helping them identify what they need and helping them be able to advocate for themselves. (#04:744-747)

Ms. S. (#06) is an oncology nurse practitioner with 24 years of nursing experience currently working in a physician office setting. In this excerpt, she articulated the prevalent view that nurses often are placed in positions of advocating for patients' rights to optimal therapy and symptom management:

> To me, advocacy is standing up for the patients' rights. If you feel as though the patient is not getting the treatment they need, then standing up and being the voice for that patient. If the patient is having symptoms, and the symptoms are not being controlled, then you are the advocate to go forward for the patient, and stand up for their need to get their symptoms under control or to get adequate treatment. (#06:11-17)

The majority of participants' descriptions directly state or indirectly imply their rationale for pursuing advocacy efforts and the meaning of advocacy to them, contributing to the emergence of three additional thematic concepts.

Thematic Concept Two: Advocacy as Nurses' Ethical and Moral Duty

A few nurse informants referenced state nurse practice acts' stipulation of advocacy as a duty and responsibility of professional nurses, while several also described advocacy as being derived from, at least partly, their personal ethical and moral development.

Ms. M. (#01) is 38 years old, has been a nurse for 15 years, and in her present oncology role for the past eight years. Her comments in this excerpt relate to nurses' reasons to advocate:

> I do feel that 50 percent of our willingness to advocate is how you feel about yourself. To help patients and your commitment to nursing… you know, there's always the reason that you went into nursing. (#01:604-607)

She has a broad perspective of advocacy that she believes was instilled by her basic nursing education:

> I've only been a nurse for 15 years. But when I was in school, I remember that as being one of those little rules – you know, we learned about the rules of the nurse – it was totally in there – advocate – that's what they told you from the beginning. You needed to be their voice when they did want to have a voice, or they were afraid to have one. (#01: 423-428)

Ms. P. (#02), working per diem in a physician practice setting while working towards a master's degree, has accepted a volunteer appointment to represent the Oncology Nursing Society (ONS) in policy-related discussions with state legislators and articulates advocacy as a duty that extends beyond one-on-one nurse-patient interactions:

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I think of it as a duty… it's our duty to be patients' advocates… I mean,

it's in the nurse practice act, that you should advocate for your patients. It IS your

responsibility as a nurse to make sure that you are advocating for your patients…

and it should go hand in hand with what we do.(#02:164-178)

I talked to the nurses at our local ONS chapter meeting and encouraged

them… 'you need to write your legislator about this.' I think just giving the

information, letting colleagues know about the importance of weighing in and

what that means, that just their voice is usually counted for more than just their

voice. And decisions are being made, and I let them know that if they don't help

make the decisions, that decisions are being made for them. It's just an extension

of it… I mean, you can advocate for your patient in different ways. (#02:384-400)

Ms. L. (#07) is an oncology nurse-practitioner at a comprehensive cancer center,

currently enrolled in a doctoral program. While talking about frustrations and

satisfactions in her role, she expressed her belief in a moral and spiritual commitment to

her work:

I have a lot of satisfaction in my role – a lot of satisfaction. I have

frustrations relating to procedural issues. And every time I get frustrated, and say,

'OK, I'm hanging this, and I'm doing something else, with the volume and

amount of work we've got to do and everything. It just takes one patient comment

or event to center me again. I'm sure I clearly got my roots from my parents and

how I was raised and all that, but I also went to a Catholic undergrad program,

and I really think that's where I got my roots of how I care for patients. Because I

feel I have a real spiritual and moral investment in all of this. And I think it

comes from my faith and it comes from who I am too. (#07:321-335)

I do know there are an awful lot of oncology nurses that have this inner

sense of "it's about them" – meaning, it's their spiritual… I don't know. I

probably first identified it when I went back to [my school of nursing] for my 15

year reunion and I realized that they had shaped the "me" – and no, they didn't

shape me because I know that my parents shaped me, but they shaped the

"nursing me". I really do think that having the Catholic education, that they

shaped my spiritual and ethical responsibility to a patient. (#07:371-380)

Ms. G. (#19) is an oncology nurse practitioner in a comprehensive cancer center,

currently enrolled in a doctoral program. In a narrative relating to why one nurse accepts

the *status quo* and another chooses to advocate for something different, said:

I think it's an intrinsic value. I mean, it's something that's within them. And I

suppose there might be a learned component to it after a while in different work

settings, as a nurse, different cultures, where you were educated or where you

began to practice. But, I think it starts with the individual. (#19:374-379)

Thematic Concept Three: Empowerment and Enhanced Self-Advocacy Skills

Ms. P. (#02) described nurses' roles in fostering self-care and self-advocacy

skills:

Advocacy is assisting the patients in finding their voice, so that their voice

is heard in the bigger picture… their voice is heard by their physician, their voice

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is heard by legislators… so that they can… it's not to do it for them, it's to help them so they can help themselves. (#02:12-16)

I have a friend who's being treated at one of our clinics, a clinic that I don't work at. She was having some issues with nausea and kind of thought that she had to live with it. And I said "No, no no.. you need to go back and you need to ask for this and this. She called me and said "I told the nurse that I wanted this and she said 'well, we don't usually order that.'" And I said "No, no, no"… and I felt awful, I felt awful because it was a colleague of mine, first. And I felt awful because I know that there's probably hundreds of other patients out there that get the same "No, this is what we do" or "No, we don't think anything will help." It's bothersome to me that these situations happen and motivating to me to continue doing what I'm doing because I want patients to find their voice; I want them to be able to NOT take NO for an answer… not necessarily "no", but not take the standard answer, and to push a little bit more if they have to. (#02:401-418)

Ms. D. (#03) is a staff nurse unit leader on an in-patient unit of a comprehensive cancer center and is deeply involved in national-level cancer advocacy efforts. She expressed the importance of advocacy relating to empowerment of patients and colleagues.

I think there're two pieces to the advocacy component. There is the piece where you're working with individual patients and it's your job to advocate for that patient within the broader perspective of the health care team. … Then,

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there's the broader level of advocacy which is on a national level to advocate for

quality cancer are for all people diagnosed with cancer. (#03:11-14; 21-23)

To me, advocacy means to stand up for what you think is right, try to

make a difference, and to teach other people and empower them to make a

difference. (#03:605-607)

Participants often referred to the cancer trajectory, discussing needs that occur in

all phases of cancer, ranging from prevention and early detection, to presentation and

selection of treatment options, physiologic and psychosocial needs that occur during

active treatment and follow-up, and those that are often present for people dealing with

end-of-life issues. Still, the majority of participants recognized that despite the nature of

identified needs, measures to address those needs consistently relate to patients/clients

interests with regard to informed decision-making, empowerment, and self-advocacy.

Ms. V. (#14), a clinical nurse specialist in a community hospital, described her work in

various phases of the cancer trajectory:

One of the key things I do is advocacy in the area of early detection, and

even prevention. It's trying to help people be responsible for their own health

care. Understanding the screenings that need to be done. And, if the physician

doesn't say "You're 50 years old now, this is something we need to do" – You

want them to learn to say: "I'm 50 years old, this is something I've heard about,

can we talk about it?" So, it's advocating for patients to be their own advocates

for their health care in the areas of cancer prevention and early detection. (#14:

102-111)

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If a patient is kind of confused about treatment recommendations at the time of diagnosis, and they're not quite sure what the next step is: they're confused because they've had different friends or family give them recommendations that may conflict or are confusing, or they may visit a couple of different physicians and the recommendations don't quite jive with one another. I feel that the advocacy that I do in that area is one of supporting them in their efforts to try to make that decision, to try to help them navigate the system. Not that I provide the answers of what they should do, but to make sure that they know what questions to ask, that they understand better the information that they have been given. (#14:58-71)

Maybe because it's the area that I tend to work in most is during recurrent disease… if we're having to look at changes, when you reframe their hope, when it's changes in their goals. It's helping them make decisions as far as end of life. It's supporting them in that, that's that advocate role, making sure that they know you're gonna be there no matter what… helping them through some of the difficult issues. (#14: 92-98)

Thematic Concept Four: Practice and Policy Implications

Twelve of 19 participants in the sample referred to policy and political implications of advocacy as being integral to their professional practice and their chosen profession. Instances of data that allude to practice and health policy are revealed here:

Ms. V. (#14) is an oncology clinical nurse specialist in a community hospital. She connected "being the patients' voice" to her efforts in practice and policy levels:

That 'speaking on their behalf' can take many different forms. It may be speaking on their behalf to a family member who doesn't understand what's going on or understand their feelings. It may be speaking on their behalf, you know, with their physician. It may be beyond that, when you think of the global community of cancer patients and working as a political advocate, so to speak, in trying to get something changed. (#14: 44-50)

And if you go to the next realm of advocacy, which is to me, the political arena, and that's where you speak on behalf of them. We've been trying for four or five years now to get colorectal screening covered, mandated, for insurance companies and that's a huge issue. You do things at the state level, recognizing that you know that this is going to provide benefit, but you are in fact, speaking for individuals who may at some point be diagnosed or are at risk.(#14:111-124)

The office practice environment where Ms. M. (#01) works as a transplant coordinator presents many policy-related challenges that must be confronted. She explained:

When we first started the bone marrow transplant unit at the University, our physicians would go up to the state capitol to help people who were on our Medicaid plan to get their transplants covered. That's the level sometimes you have to go to for your patients because sometimes the system doesn't catch up with the science. And you have to be an advocate, like being right there on that front line to explain that … I don't know… I just always got a feeling that when you were doing that, people had a perception you were just being alarmist, that

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"Oh, if you're not covered, they should just accept that". And, we shouldn't. If

you have a culture of that, it makes it so much easier – that you are doing more

than just one patient at a time. You're sort of looking at the needs of the future.

(#01: 293-312)

Research Question 2

What are the social and cognitive processes used by oncology nurses when deciding to

advocate?

Data derived from exploration of this research question are indicative of the

interplay of social and cognitive processes participants often describe as important to

considering, planning, and doing advocacy. Instances of data reveal a fluidity in which an

individual nurse's traits, her experience and knowledge coalesce to inform and motivate

the nurse to advocate, and are in a constant state of feedback throughout the nurse-patient

relationship. Most informants' shared an holistic philosophy of nursing. Data suggest that

oncology nurses who are successful advocates possess common inherent traits, or *Ways*

of Being, from which emerged five conceptual themes: 1) Holistic nursing philosophy; 2)

Expertise, knowledge and wisdom gained through education and practice experience; 3)

Personal values; 4) Practice environment supportive of nurse advocacy; and, 5)

Professional commitment.

Thematic Concept One: Holistic Nursing Philosophy

During her interview, Ms. W. (#08) was asked how she goes about determining

what advocacy needs a new patient might have. She articulated the breadth of

information she elicits from patients, and provided a compelling example from her practice.

> Usually through the educational process, especially if it's a brand new patient with a new diagnosis, that, as we are talking about the treatment options, I also try to get information about the family, whether they have a support system, whether they have small children, trying to get some feedback about the marriage or relationship, relationships with friends, other relationships like church people, or to try and get them lined up with support pretty early on. (#08:87-95)

> About two years ago, we had a lymphoma patient who had small children, and was chronically overwhelmed by her diagnosis. Her best friend had died of the exact same lymphoma, and her family had gone through all of that, so it was very traumatic for her kids. And then, her family had come from far away to try and support her. So, she let us know who was going to have a hard time and who wasn't, what she'd been through. And once again, we immediately brought the social worker in, who was wonderful in helping the kids, with different ages and support groups and so forth. So, we really did treat the entire family – it wasn't just the patient needs… we can help get support or education, to free up their own energy to deal with what they've got on their own plate. (#08:103-118)

Ms. M. (#01), transplant coordinator in an office setting, acknowledged her holistic approach to assessing patients' needs.

> I think our role is to assess what the patients' needs are and then we have to figure out how to get that information to whoever needs to know in order to assist

them with caring for themselves. We take whatever the patient's situation is, and

we advocate for what they need to accomplish their wellness. And, whether that's

advocating to the physician about a treatment change or supportive care change,

or helping them advocate with their family what their wishes are… whether it's

advocating for their own needs and how they want their treatment to be. So, I

really see our role as figuring out what they need us to help them advocate for.

And that's where we have to multi-task all the time… you know, is it a

psychosocial need, does it relate to a symptom, or is it a basic need, where they

might need help with transportation, or food, you know, what are their needs, and

we have to look at all of those needs and help them meet them in order for them

to be successful for whatever we're treating. (#01:13-30)

Thematic Concept Two: Expertise, Knowledge, and Wisdom Gained Through Education
and Practice Experience

Thematic concept two is derived from instances of data in which participants

acknowledged the evolution of their levels of confidence and expertise, often referencing

Benner's "Novice to Expert" work (Benner, 1984), and learning and wisdom gained from

personal and professional experience and maturity. Knowing the patient population has to

do with nurses' abilities to anticipate patients' needs, and to create individualized plans

with patients based on experience with other patients and knowledge of therapeutic

interventions. The following excerpts are instances of data in which informants identified

social and cognitive processes they perceive as inherent in nurse advocacy.

Data extracted from Ms. M.'s (#01) interview, the first interview of the data

collection process, reveals the perceived significance of nurses' increasing levels of

expertise, confidence, and wisdom:

> I think our role in being experts in what we are doing develops trust with
> the patient. If they are confident that we, when we are doing such technical things
> to them, giving them agents that are potentially very harmful for them,
> understanding how they work and what it's going to do to them. Taking our
> knowledge of working with other patients that have been through similar
> experiences to help them. (#01:213-219)

> When you're a younger nurse, you're so focused on not hurting people!
> (laughs) You know, just doing the right thing, and getting your meds done on
> time, and knowing everything about every med you give, and I think, once you
> get more comfortable with that, I think you can… it's that novice to expert thing.
> I really think it's that, and some people just get there faster than others. (#01:473-
> 479)

Ms. E. (#10) is a 58 year-old master's prepared nurse, who entered nursing as a

second career 19 years ago. She is also a cancer survivor.

> Just having a different life experience helped. Because, when I became a nurse, I
> was grown up. You know, I had already had a career. I had worked with people,
> I'd been in the world, and I'd worked with all kinds of different people. So, when
> I went into nursing, it was kind of the same thing, you know, you're dealing with
> the same kinds of things but just in a different setting. (#10:462-468)

Ms. S. (#06), an oncology nurse practitioner, equated her 24 years of nursing experience with an innate ability to accurately and efficiently assess patients' needs:

I guess being in oncology as long as I have been, you just have this innate ability to see when the patient is absolutely lost and they don't know which direction to go or they look at you and say 'What would you do?' (#06:38-41)

An additional excerpt from Ms. S. reveals the critical nature of the nurse advocate's oncology knowledge base and self-confidence:

I think those who are lost in the system are the ones that don't know what kind of questions to ask. The ones that just take for granted that this is what you should do. For instance, a patient not too long ago was diagnosed with Stage IIB breast cancer, she was premenopausal, she had no nodes involved, underwent a mastectomy, and she was given the option of being placed on an aromatase inhibitor. Well, I could tell that she didn't really have all the information that she needed. And she was lost. You know, do you go with exactly what the oncologist is telling you? Or, do you keep searching for another answer. And I encouraged her to get a second opinion. And even though that made a little um, not animosity, but a little bit of tension with the oncologist and I, I just felt like the patient needed chemotherapy, she needed systemic therapy just because of the risk down the road. She did go for a second opinion and the second oncologist agreed that she needed some type of systemic therapy. She came back to our center and was treated with four cycles of chemotherapy and the oncologist was OK with all of that. (#06:121-140)

Thematic Concept Three: Personal Values

Several participants articulated the significance of the personal values that they bring to their professional roles and the influence of these values with regard to advocacy. While participants often acknowledged that personal values influenced the likelihood of nurses advocating for patients' needs, they were also clear about nurses' need to understand and put personal beliefs aside in favor of patients' wishes and needs. Ms. C. (#04) said:

> My goal is just to make sure the patient truly makes decisions based on information… to me, that's advocacy. And then, supporting the patient, whether I agree with it or not is not the issue. It's what the patient feels like they want to do. Having said that, it's just determining that the patient does in fact, have all of the knowledge that they need to make an informed decision. (#04: 461-471)

Clinical nurse specialist Ms. V. (#14) acknowledged that separating her personal biases can be difficult, but is nevertheless, an important aspect of advocacy.

> It's always difficult too, as an advocate, to try not to get any of your own biases in there, especially with physicians. I would say, probably… if the patient was going to go to a surgeon that I felt was not good at all, I would probably say something because I know her. Or, to say, 'you know, maybe you might want to consider getting a second opinion' – and that's usually how I will try to put something kindly some days. (#14:215-222)

Ms. U. (#16), nurse practitioner, talked about the importance of remaining open and non-judgmental when considering patients' needs.

I'm always open. I never think I've heard it all. I try not to judge people. I think, when we try to keep our culture and our religions, and everything, our beliefs, up front, you're blinded to being open to what we can really do for patients. So, I think being open and non-judgmental, and listening. (#16:342-347)

The concept of paternalism is an oft-cited concern among nurse leaders and a source of controversy among those considering nurses as advocates. Contrary to expressed concerns, nearly all nurse participants in this study articulated the degree to which they take precautions to avoid paternalistic approaches to care planning and care giving. Ms. C. (#04) talked about the importance of determining needs with patients.

You can't work on the patients' needs or behalf really, unless you determine from them what they feel that they need. My bias is that, even if it's the most off the wall thing – what is it that is important to them? In Montana, it may be 'who's gonna take care of their farm?' Now, that's not necessarily a nursing need, but I don't think you can peel through those layers until you can figure out what the patient perceives their needs to be. In my experience, if you don't meet that, you don't get very far, because that's obviously what's in the way of their healing. And, it's their life. (#04:74-83)

Ms. W. (#08) is a staff nurse with an Associate nursing degree, who currently works at a community hospital. Early in her interview, she brought up the notion that hospitalized patients might reveal different needs at different times, but related the overall importance of patients' perspectives. She says:

Talking with a patient will open up very different aspects of their cancer struggle. Night shift, they don't sleep, because they are afraid of dying, so you tend to get more of that information than day shift where you tend to get more – basic, you are prepping them for treatment. But our patients are pretty open. They want to be knowledgeable, they want to be informed, and they really want to be part of the decision-making process. So, it's really important to start talking with them about what's important to them in general, and what's important to them in this battle, and then what parts of their self do they want honored? What religion is important, spiritual aspects, and just try to support them in whatever ways we can. (#08:3-14)

Other aspects of nurses' value systems, including what informants often referred to as their basic personalities, were frequently mentioned as factors in their willingness to advocate. Oncology nurse practitioner Ms. S. (#06) described the role her personality plays in her practice:

I think that's my personality. I'm not one to sit back if I feel like things aren't going like I think they should be going. I'm pretty good about the usual… 'I was wondering if we should try', or, 'the last time I looked at the literature, I saw that they were doing this, what do you think about that?' … trying to make it more the physician's idea than my idea since they are ultimately going to be carrying out the plan. (#06:145-152)

Similarly, Ms. J. (#05), alluded to her personality as a significant aspect of her advocacy efforts:

I think you just have to pick your battles. I think I'm one of those people who likes to take the battles that nobody else is fighting. (#05:94-96)

Ms. A. (#12), a 50 year-old BSN-prepared and oncology certified nurse, has 25 years experience in oncology nursing and has been in her current role as the bone marrow transplant coordinator in a hospital-based ambulatory medical oncology program for ten years. She referred to the evolution of the nurse as an advocate and subsequent changes in focus.

I think when you're younger in your career, it's about making patients dependent on you. But as you mature in your role, it's more about empowering patients and their families to live life as fully as possible with a diagnosis of cancer. (#12:22-25).

Without realizing it, you're making patients more dependent on you. The nurse will take care of that; the nurse will do that; My nurse does it that way. And you very quickly realize that that's not helpful to the patient because if you're not there, then it's very uncomfortable for the patient, very anxiety-producing for the patient. As you mature in your career, I think you act more as a resource in addition to mentoring other nurses and not making the patient and family dependent on just one person – that they realize that there are multiple resources there for them at all times. And I think that's critical. (#12:133-142)

Ms. E. (#10) who came to nursing as a second career, talked about the philosophy that defines her nursing persona:

I just have a different philosophy and I have my own spiritual philosophy, and it's just different. I have a deep faith. And I have a good relationship with God, you know, my God. And I feel that my job as an oncology nurse, and always have felt that way, is a ministry, more than a job. So that, whatever I do with patients, I'm ministering to them. I'm not invoking my religion on them, or my beliefs in God, I don't do any of that. But I feel that what I do with patients is a ministry. So, to help them and to make them feel better and to get them to a point where they are comfortable either with the disease, the dying process, or even with getting well, you know, not taking away their hope. So, I've always felt that my job as an oncology nurse is a ministry. So, that's my faith philosophy. (#10:232-249)

Fifty-one year old Ms. K. (#09) has been a nurse for 30 years and in her current role in an ambulatory head and neck surgical service at a comprehensive cancer center for the past 11 years. She emphasized the importance of the knowledge she has gained during her lengthy nursing experience, her commitment to this patient population, and her confidence and competence.

> I've learned so much from these patients – even though I consider myself an old head and neck nurse – I've been in there for 30 years: I grew up on head and neck. I've learned a lot from just hearing what those patients have to go through. (#09:55-59)

> I've been doing this long enough, I know what I'm talking about. So, I usually will be teaching and guiding patients before they ever see a physician. (#09:80-82)

I automatically have compassion for these people because I see how

distraught they are, how, with the diagnosis of cancer, I think it's when people

initially see their own mortality. (#09:122-125)

Ms. V. (#14), currently an oncology clinical nurse specialist, is 49 years old and

has been a nurse for 29 years. She emphasized the importance of nurses' self-awareness:

One of the things you have to do is be very aware of what your beliefs are, what

your feelings are, especially, like for instance, when you're dealing with end-of-

life issues – is that you know where you are so that then you can set that aside

and make sure that what you do is listen to where they are and try to be with them

at that time, and realize that it isn't about you … you are not there for you, you

are there for them, to support them and provide guidance if that's what's needed.

I think it takes experience; I think it takes conscientious thoughtfulness to do it.

(#14:273-282)

Thematic Concept Four: Practice Environment

Many study participants described practice settings, management, collegial

relationships, and patient populations that served to promote or facilitate their advocacy

efforts as well as circumstances that limited the advocacy-related outcomes they could

achieve.

Ms. M. (#01) compared office practice to hospital-based settings.

In some ways, it's a lot more challenging to advocate [in the office setting]

because in the hospital, or the acute care setting, you have more one-on-one time.

You might, even though you're overwhelmed with seven patients, you only have

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seven patients… whereas in the community setting, you might be responsible for twenty patients that day. So, I think it kind of just becomes more challenging because you have more of a patient load that you have to do all that assessing and you have to try to do all that assessing and then, try to help set them up or help them achieve whatever the need to achieve. (#01:52-60)

Ms. W. (#08) was adamant about the impact of nurse managers, facility administrators, and personnel dynamics on staff members' effectiveness as advocates.

I find it really interesting, the dynamics of all these women working together. Our direct charge nurse is very supportive – until you are able to demonstrate any knowledge base that's beyond her, and she feels threatened. So, you learn pretty quickly who your allies are. Our social worker is uniquely gifted and is incredible working with patients. So's our pastoral support – he's very very creative. And as far as upper management, we've recently had a shift. Our nurse manager recently left the floor. She was an incredible force that was firmly rooted in a holistic approach and supported staff in accomplishing that. We no longer have that. So, at this particular juncture, I would probably rely on the social worker and my case manager and be as creative as possible, and would involve management as little as possible. (#08:25-39)

In an effort to accommodate her young family, Ms. K. (#09) changed jobs, moving from an oncology role to an emergency department closer to her home. She compared that environment to her current setting in a cancer center:

I could definitely see the difference in my behaviors here as compared to working in the emergency room. Basically, my husband said I had had a personality transplant. Some of the verbal abuse that I received, I was so unused to – it was so foreign to me, having started in a place like this. I have to say that during my years in the ER, I lost faith in people. I stopped believing in people. I actually disliked people. And, I can remember being in triage – I think I had a chip on my shoulder. I think it's the years of stress – I guess it was burnout. I was there for six years, and I think the last three years were terrible. And I remember thinking to myself, I have to go back to a place where people are nice… (#09:110-121)

Ms. D. (#03) linked workplace, patient satisfaction issues, and advocacy.

I've heard a lot of nurses say for years, when we were having ten patients apiece… 'Why do I do this night after night after night? This is crazy… I could go somewhere else and make more money, and work, you know, get a lunch break, be able to go to the bathroom on my shift.' And they would leave – either go to another hospital or they would leave bedside nursing and go work for a pharmaceutical company or something. And it's a tough sell to convince people that they can make a difference: you have to have some little measures of success to prove to them that, ya, you take little baby steps, but with each one, you get further along the path. (#03:159-169)

In many places, management doesn't listen to the nurses; they don't really care. And the nurses feel that they're not cared for or cared about. They feel like they are a line item on the budget, nothing more. And those nurses are not happy

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nurses. And they're not gonna stay for a long period of time. And if you come to

work with a chip on your shoulder and you walk into a patient's room, they are

gonna sense the chip on your shoulder. They feel like a burden. They don't want

to put the call light on; they don't want to bother you. And they may not put the

call light on when they need to. And that's not right – that's not what they are

there for. (#03:189-199)

Ms. E. highlighted a work environment that supports nurse advocacy:

I think it's really involving all the key players, involving the nurses in

what goes on in the unit, involving them in the good and the bad, having them

support each other, having them be supported by other people. So, for example,

we had a chaplain who did lots of programs for the staff. Now, it wasn't a God

thing, it was a spiritual thing. One time, we had a blessing of their hands. And we

did, when we had a patient who died, who's been a long-time patient, we'd have a

memorial service just for the staff. … Everybody doesn't have to be, to have the

same philosophy, but helping them take care of themselves, and taking care of

each other, really helped, really helped to bring them together. (#10:357-376)

I know for myself as an oncology nurse, and I think one of the reasons, the

hours that you put in, and the time that you put in, and the emotional energy that

you put into taking care of patients, why I don't get burned out is, I guess, it's just

because I just know that I'm making a difference. (#10:383-389)

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Thematic Concept Five: Professional Commitment

Many of the traits that study participants shared relate to their personal commitment to nursing, and more specifically, to the oncology nursing specialty. Commitment was articulated in a number of ways; active involvement in the Oncology Nursing Society; adherence to professional practice standards; nurse-led contributions to local community efforts; personal values associated with ongoing education and credentialing; and mentoring of and support for the next generation of nurses.

Ms. C. (#04) started working with cancer patients as a 15-year-old Candy Striper at an academic cancer center, and has continued to work with cancer patients throughout her career. She talked about her view of herself as a nurse, and nursing as her calling:

> I remember sneaking animals into patients' rooms, and I wasn't a kind of the typical nurse, in the sense that it was never a job to me. I think it's always been a calling to me. And I think that I look at nurses today, and I don't think that many of them look at it that way. I think they look at it as a job. (#04:237-244)

Similarly, Ms. L. (#07), a 49 year-old oncology nurse practitioner in a comprehensive cancer center, is currently pursuing a PhD in nursing, talked about differentiating a job and the nursing profession:

> I have never approached my job, ever, in just 'this is where I go to work and I come home and I leave.' I have always approached it as a profession, and not as a job. I've always viewed, even in my earlier years, maybe I didn't identify it, but retrospectively, I always viewed this as my profession – it wasn't just my job. … Nursing to me has been, it's my persona. (#07:338-347)

Ms. E. (#10) had functioned as a nurse-manager in a non-oncology setting, and talked about the differences between oncology and non-oncology nurses.

Oncology nurses are different, you know, there's a different affinity towards cancer patients. … What I noted was that nurses were more aggressive and more assertive with the physicians with our cancer patients. There's an emotional difference. I saw that nurses on the [other specialty] floor got burned out faster than the oncology nurses. And part of it was because the oncology nurses were really involved with the patients, they were involved with the families … With oncology nurses, they had a standard to fall back on. So, ONS provided that standard for us, and the guidelines. I used those standards and guidelines to educate the nurses and to help them understand what patients needed. (#10:58-62, 76-81, 102-108)

Ms. L. (#15), 50 years old and a second-career nurse, is a master's-prepared case manager for head and neck and breast cancer patients in a free-standing cancer center. She included ongoing education and professional involvement among her advocacy efforts:

I pick my battles. I pick my battles with a particular patient. And then, I pick my battles with my colleagues, and then, I pick my battles with the institution. …With my colleagues, … I'm high on education and certification. I would say, percentage wise, maybe 20% of the cancer nurses in our practice agree with me on this, so it's definitely an uphill battle, and I try to pick times to work one on

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one with new fresh nurses that might be motivated to write an abstract or be

certified or things like that. (#15:112-117)

Research Question 3

How is advocacy operationalized by nurses?

How each nurse participant operationalizes advocacy is contextual – affected by

numerous variables and antecedents that the nurse must include in her considerations. As

a group, study participants identified several basic assumptions that provide the backdrop

for advocacy efforts. The first assumption is: People with cancer are inherently

vulnerable – including potential and actual vulnerabilities arising from the physical

effects of the disease process and treatment-related sequelae, lack of information,

inability to comprehend information presented to them, lack of or limited access to

oncology experts and state-of-the-art technologies, lack of fiscal resources, and lack of

physical and psychosocial support. Findings in this study suggest that operationalization

involves a set of dynamic processes that include nurses' *Ways of Knowing* what patients'

needs are and nurses' unique methods of carrying out – *Ways of Doing* - acts of

advocacy. Five thematic concepts emerged from data relevant to this research question:

(1) *Inherent patient vulnerabilities;* (2) *Modeling patients' worlds;* (3) *The Nurse-Patient*

Relationship; (4) *Informing, Educating, Communicating;* and (5) *Navigating, Guiding,*

and Coaching. Excerpts providing instances of data supporting thematic concepts

germane to ways in which advocacy is carried out are presented here.

Thematic Concept One: Inherent Patient Vulnerabilities

Ms. D. (#03) referred to the cancer care world as "alien" – and her role in guiding patients through the system.

It's more than just asking the patient what their needs are. It has to be because they are entering a whole new world that is totally alien to them, and they don't even know what to ask, they don't know what to expect. And you've been around the block with other patients, and you know what's coming up for them. And, if you can help them navigate that path, that's part of your job, to advocate for them and make sure that their needs are met. (#03:312-318)

Ms. K. (#09) echoes the alien nature of the cancer care world:

The patient, through no choice of their, enters a world that they are completely unfamiliar with. (#09:101-102)

Ms. C. (#04) mentioned many of the inherent vulnerabilities in the cancer patient population and potential conflicting expectations of cancer care providers in this excerpt.

I think the saddest thing that could happen to somebody is that they look back and think – "Oh – I should have…", "I could have,"… "If I would have…" Because I also believe that the first stab at treatment, your first treatment is the best shot at getting control of the cancer. (#04:220-226)

I think now we put so much pressure on patients to seek their information. We say to patients, "It's your decision." But, you know we are putting patients in these decision-making situations when people are not at their best. I mean, we are not dealing with whether they are choosing between geraniums and roses. They

are choosing between clinical trials with huge ramifications, or drug therapies that

their insurance may not cover, or lots of things. (#04:435-444)

Ms. L. (#07) acknowledged the uniqueness of the oncology patient population in

this excerpt:

I think the overlay that comes with the oncology patient is the psychological

overlay. I think some of the psychological things that come with [all patients]

could be similar, but I think most people aren't facing death in a lot of other

entities, and I think that's where they're different. (#07:604-606, 617-620)

Ms. K. (#09) described how she turns moments of vulnerability into teachable

moments:

I won't give up on the first "no". I had a man the other day who came in, he had a

major chip on his shoulder. I could see past that, it didn't really faze me. When I

went through his whole history, and he told me that he smokes a pack of day for

45 years, and he's still smoking. I said, you know, it's really important… I went

through how tobacco is related not just to head and neck, you know, I went

through the whole spiel, and I said that "you said you didn't want a referral." I

said that it's very easy for me to do it, I gave him the smoking cessation

pamphlet, and FINALLY, as I'm finishing, we touched on it again, and he said

"alright." The doctor gave him some good news, so I guess he was feeling in a

better frame of mind, he looked at me and said "Although when I came in, I know

I didn't come in in a very good mood, but I'm thankful for your help. And,

because I'm in a role that I really, really enjoy, and I really, really take it

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seriously that I'm at a pivotal point in some of these people' lives, that I can make

a difference. (#09:168-193)

Thematic Concept Two: Modeling Patients' Worlds

The concept *modeling the patients' world*, from the Modeling and Role-Modeling

(MRM) theory, refers to "the way an individual perceives life, events, people, and

situations, the way an individual communicates, thinks, feels, acts, and reacts" (Erickson

et al., 1983, p. 84) – all factors that comprise each person's model of his or her world. In

the context of MRM, appreciation of each person's world model is a prerequisite for

providing holistic care. Without referring directly to MRM, informants in this study

nevertheless made frequent reference to what can be interpreted as modeling the patient's

world.

For example, nurse practitioner Ms. S. (#06) described how she identifies

patients' needs in this excerpt:

When they initially present, I just gather a history from them: what their

educational background is, what their support systems are, how many questions

they ask, how much involved they want to be, what their medical history is. I

think just doing that initial history will give you a lot of information about what

your patient's gonna need down the road. I start with their chief complaint, and

what we know is the problem, and then I go from there. You know, what their

family history is, what their social history is, where do they live, what kind of

work do they do. Children, support systems, surgical history. (#06:97-111)

Ms. G. (#19), a nurse practitioner in a comprehensive cancer center, indicated that there may be a predictive element associated with modeling that can be useful in identifying and addressing patients' needs.

I don't mean to sound elitist, but what I've done over time is, I mean, some of these things just become sort of second hand or sort of an intuitive process that you go through. If someone says they don't have a stable home situation, and then you start to predict, well how are you going to be able to get here, and how are you going to manage if you get sick at home during the night. Those things then just sort of come to mind. So, it's sort of an intuitive process that jumps off of key indicators or red flags that people will say. (#19:103-114)

Ms. M. (#01) related the way modeling the patient's world can be instructive in the assessment, care planning and delivery processes:

I really feel that if you do a good physical assessment, and you develop that relationship of trust, that the needs will come out. Because they are so inter-connected – I mean, 'Why aren't you staying hydrated?' You know: 'Is it because you were so busy with the children, trying to still maintain the role of a mother, or, that you're not being able to keep up with the fluids?' That's how I always see things – as being inter-connected in that way, is really talking to them about what's going on with them, in order to be successful to get through their treatment, and then, what's inhibiting the person from being able to do those things. (#01:149-158)

Thematic Concept Three: The Nurse-Patient Relationship

Study participants often identified nurse-patient relationships as central to their abilities to know and advocate for patients most effectively. Some also spoke to time factors associated with various work environments. Although a long-term association might be thought necessary to developing a solid nurse-patient relationship, participants often contradicted this, instead, acknowledging the importance of starting off on the right foot with patients with initial demonstrations of trustworthiness, expertise, and competency.

> I think one of the most important things we can do as nurses is to be present with the patient when we are caring for them. I know that's what I look for in a caregiver: I want the person to look at me and talk to me and listen. …Taking our knowledge of working with other patients that have been through similar experiences to help them. I think it's being present and letting them know that you understand what you're doing, and that you are confident in what you're doing. … It's not like going in and getting your flu shot and not seeing the person for another eight months. You are going to be with each other every day, from month to month, a lot of times. So, I think that's a key. I feel that a lot of trust comes from your expertise in what you do. And then, I think the other part comes from being a present and caring person. And those two things have to be there to really have the trust. (#01:209-235)

Once patients realize that you are trying to work for them and are able to

get through this decision, and whatever treatments they decide, THEY just tend to

open up and ask for support themselves. They trust. (#08: 95-100)

Thematic Concept Four: Informing, Educating, Communicating

Patient, family and public education are among the responsibilities of oncology

nurses recognized in the ONS *Standards of Oncology Education: Patient/Significant*

Other and Public (Blecher, 2004). Over time, patient and family education have moved

from the relatively straightforward notion of providing enough information to allow

patients to give informed consent for invasive procedures and to participate in clinical

research, to more inclusive educational goals that involve nurses imparting information in

all phases of cancer care to promote optimal patient well-being, patient/family self-care,

health promotion, informed consent and informed decision-making (Blecher).

Information-seeking, negotiating, decision-making, communication, problem-solving,

and self-advocacy skills training are considered critical tasks for persons affected by

cancer to employ in recovery and healing processes (Clark & Stovall, 1996). Several

study participants revealed numerous ways and purposes associated with helping patients,

families, the general public, and health care colleagues to get and share information.

Ms. M. (#01) mentioned professional information-sharing as a responsibility:

When you see commonalities in responses from patients, that's something that

needs to be studied, or put in your materials if you're responsible for education

materials. There's a certain degree of responsibility to get the word out. Whether

it is through research, or it is through materials about your own practice, program,

or that chemotherapy. If it's a certain drug, you have a responsibility, if you start seeing something, and then, you start treating in a certain way and you are successful, I think you have a responsibility to get that information to other nurses around the country. (#01:454-464)

ONS figured prominently in the professional lives of most study participants, particularly in relationship to ongoing educational opportunities, local, regional and national collegial networking, and participation in creation of and access to national standards and guidelines of oncology nursing.

An aspect of professional advocacy [is that] you're maintaining your knowledge base going to your local ONS, going to National ONS, going to meetings and conferences in your area of expertise so that you are really up on the information, so that the patient population has access to that. (#11:318-323)

In her work in ambulatory cancer centers, Ms. P. (#02) described ways of helping patients communicate more effectively with physicians, reflecting concerns of a majority of study participants:

I see it on a daily basis in that, [patients] felt rushed through their physicians' appointments, they don't feel like the doctor's answering their questions completely, so I usually try to help give them the tools that they need in order to be heard by their physicians. I tell them to go in with a written list of questions and tell them 'I want those questions answered before I leave,' you know, keep the doctor on subject if they try to blow them off when they ask a particular question. (#02:18-26)

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Ms. D. (#03) referred to issues of knowledgeable decision-making versus informed consent:

Another issue for me is fertility. I'll go in to start a first time chemo on somebody, typically, a young guy – a Ewing's guy – his first chemo. And I said, 'Has anybody talked to you about sperm banking?' 'No.' 'Do you know what sperm banking is?' 'No.' So, I go back to the docs and say – 'You know, you didn't get informed consent for this chemo.' And they're like, 'What do you mean?' And I said, 'Well, you didn't tell him about all of the side effects. He's getting high dose ifosfamide, you might want to ask him if he wants to sperm bank.' And they are like, 'Oh, O.K.' If you don't step up to the plate and say, 'This is an important issue' - after you give the first chemo, it's too late. (#03:258-272)

In a related situation, Ms. D. was again concerned about informed consent and fertility issues, this time with an emotionally distraught young woman:

One of our leukemia patients – and I'm a little bit leery about leukemics because time is a factor – her white count was about 50,000. She was pregnant when she was diagnosed and they made her have an abortion. She cried from the minute she arrived on the unit non-stop. And her husband was very stressed out, and I said… 'Well, has anybody talked to you about options for preserving your fertility before you start treatment?' So, she said 'No.' And I said 'Well, we have a reproductive endocrinology department here and we can get somebody to come to talk to you.' And we got somebody to come to talk to her and they decided she

could delay her treatment for a couple of weeks, and keep a close eye on her with daily blood counts. She harvested some eggs and she was able to preserve her fertility that way. It made a tremendous difference in her attitude, she wasn't crying every minute that she was on the unit. And she felt like, even if, later in vitro fertilization is not successful for her, at least we gave her that chance. (#03: 274-290*)*

With most cancer diagnoses, numerous treatment options are presented to affected patients. Sifting through the risks and benefits of various options is a complex task for many patients and families, and nurses offer important support during this process, including guiding patients to seek second opinions. Ms. S. (#06) related an example of information-sharing and communication as advocacy:

I think some times, especially in the older population, so often they don't know what questions to ask, and sometimes they don't understand all the options and they will just go with the first option that is presented to them. And sometimes, that may not be the best way to go. For instance, if a patient has breast cancer and they have been given the option of Adriamycin and Cytoxan, but didn't hear the other option, then it might be your role as a nurse to intercede, especially if you know that the patient has a history of cardiac disease. Then, it may be better for them to take another treatment that is less cardiotoxic. But, I feel like that's the nurse's role to be able to step in when they see that the patient doesn't understand their treatment options. (#06:20-32)

Thematic Concept Five: Navigating, Coaching, Guiding

To most people, the concept of "navigating" relates to getting from one point to another by the safest and most efficient route. Over the past decade, the notion of navigating and the navigator's role are being considered in the healthcare environment, particularly in settings that deal with complex, chronic illnesses where proper management requires the expertise of multiple disciplines. Oncology nurses and oncology social workers are increasingly assuming formalized roles, variously called navigators, case managers, coaches, guides and other titles with varying role expectations. A national workgroup prepared a useful definition of patient navigation that does not specify underlying credentials, but instead focuses on expectations and outcomes:

> Patient navigation in cancer care refers to individualized assistance offered to patients, families, and caregivers to help overcome health care system barriers and facilitate timely access to quality medical and psychosocial care from pre-diagnosis through all phases of the cancer experience. Navigation services and programs should be provided by culturally competent professional or non-professional persons in a variety of medical, organizational, advocacy, or community settings. The type of navigation services will depend upon the particular type, severity, and/or complexity of the identified barriers. (C-Change 2007)

Ms. C. (#04) explained her work experience in two formal "nurse navigator" roles and in this excerpt, describes how she performs in these settings.

It's determining where a patient can go or be for the optimal care for them. I'll

give you an example: A 42 year-old patient called me one day and said that her

doctor told her that she had an abnormal liver scan, and that she needed an

ultrasound. She called me back two days later, and she's got full blown liver

cancer. So, immediately given the fact that she's 42, given the fact that that's a

rare presentation, and her doctor was gonna be out of town and he is a family

practice doctor in a small community… we met and I reviewed her pathology

with her and, you know, kind of determined from her, what she wanted to do. So,

from that way, it's looking at what is the disease process, how immediate is this,

where can this patient best be served in a rural area. … We had to deal with this

very quickly. Before her family practice doctor ever called her, she had an

appointment with a specialist in San Francisco. That wouldn't have happened if I

hadn't stepped in. (#04:151-171; 229-233)

Ms. V. (#14) spoke of aspects of navigation she considers to be part of the

advocacy component of her oncology clinical nurse specialist role:

A nurse as an advocate is a person who works together with or for a patient and

his or her family to accomplish their goals. That almost sounds too simplistic

because sometimes, I think, you have to help them identify what they are. I also

think it's about navigating – you advocate, you are there with them throughout, in

oncology, it's throughout the continuum, in all different phases. (#14:725-731)

Ms. U. (#16) is an oncology nurse practitioner who has oncology programmatic responsibilities in a community hospital oncology service. She described the multifaceted aspects of advocacy in her role, and alluded to a navigational component:

Advocacy is taking a stand for what is either documented as a standard or a patient right in helping manipulate the system to get what is needed to achieve that for the patient and family. And, I like to use the word manipulate and I always tell people that manipulation is not bad – that if you can manipulate something to get the best outcomes with the resources that you know and the network that you have – you do whatever it takes for the patient. So, often I'm helping people navigate, manipulate, and use the system to advocate for what's in the best interest for the patient. Whether that be spiritual, whether it be clinical, whether it be, you know, figuring out educational needs, answering questions - it could be one of a million things. (#16: 56-70)

Research Question 4

What are the client-focused outcomes nurses describe as being influenced by their advocacy efforts?

Study participants unanimously viewed advocacy as an imperative of oncology nursing practice, and agreed as well that their advocacy is vital to the achievement of optimal patient and practice outcomes. Despite the initial research question's focus on client-centered value of nurse advocacy, most participants also expressed that positive advocacy outcomes are valuable to the satisfaction derived from their nursing practice, and conversely, that negative or no outcomes could be frustrating and contribute to the

burnout phenomenon. The value of nurses' advocacy, according to study participants, coalesce around three thematic concepts: (1) *Value to patients and clients;* (2) *Value to health care and delivery systems*; and (3) *Rewards and work satisfaction of nurse advocates.* Again, data excerpts that follow provide rich descriptors of these data clusters.

Thematic Concept One: Value to Individual Patients and Clients as Perceived by Study Participants

Participants' perceived benefits to patients were described subjectively and in non-quantifiable terms and phrases.

> We are the people who see those patients, who are talking to those patients more than anybody else. We assess their needs more than anybody else. And, if we don't let them know that they have a voice, they suffer needlessly. (#02:529-533)

> Some important things are for patients – to let them know that the health care team, we are human beings, just like them. If we say some things that are not right, they need to tell us, correct us, it's OK to correct us. Sometimes there are cultural barriers about that – it's not OK to challenge authority. That's an important part of it - to teach people to go on the National scene, they need to know that all of these powerful Congressmen, they are just people too, and to look for that human element that you can connect with. (#03: 634-642)

> I determine the effects of my advocacy by the outcome of the patient. You know, were their symptoms controlled? Did they get the treatment that they needed? (#06: 188-190)

I think it's really important for a nurse to be involved in a patient's life in regards to oncology because we can advocate for the patient those things that may not be identified – whether it's psychological support, whether it's family support, whether it's long-term rehabilitative support – any of those things, I think that's where we plan a huge role. (#07:32-38)

Thematic Concept Two: Value to Health Care and Delivery Systems

Most participants were clear that outcomes of nurse advocacy can extend beyond individual patients, and affect health policy, health care settings, delivery systems, and populations.

I think every single cancer patient needs a person – a liaison – assigned to them. I think we get caught up in thinking – "Oh my God, we can't do that, that's costly, that's… whatever. You know, if you have that kind of care to begin with, I think that would really play out to require less because you would facilitate the system, and utilize the system more effectively. (#04: 718-726)

The metrics for me are, um, changes in policy, changes in attitude, numbers of people that are involved in prevention and early detection efforts, involved in pain control initiatives, to me, it's a data and numbers game. It's nice to get the "atta-girls", the patients' letters, and your physicians, and stuff like that, but to me, that doesn't sustain it – that's not the sea change. (#15:211-220)

I have an interesting thing… the financial manager of our whole ambulatory practice at _____ - when he first came, he wasn't so sure that we really needed advanced practice nurses at our price tag – not that we have a huge

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price tag – but he wasn't sure we needed them and would be constantly asking my

nurse management person, you know, "what does she do that a nurse can't do?"

You know, and then, his mother-in-law was diagnosed with breast cancer, and

the, Ah Ha! After that first meeting, he looked at me and said "I know my answer

now, and I'll never ask the question again." I did that without trying.

(#07:723-734)

Thematic Concept Three: Rewards and Work Satisfaction of Nurse Advocates.

According to informants', there are important outcomes, both positive and

negative, that relate to nurses on personal and professional levels.

In the office setting, we see patients go in treatment, finish treatment, be

done with treatment, and go on with their lives, so I think that's really

meaningful. (#01:123-126)

I can't believe that nobody was going to do anything [to relieve the

patient's symptoms] – so it's frustrating but motivating I guess, because it makes

me feel like I'm making a difference and I can make a difference with other

people, and that's why I keep doing what I'm doing. (#01: 425-429)

I think it's hard when you're in a situation where nothing that you

advocate for is ever followed through. I think it just wears you down. You get to

the point where you become very cynical, and very negative, and then, you're no

longer good for anybody – no longer able to be an advocate, no longer able to be a

good nurse. I think that's really, really hard. (#06: 346-352)

I can demonstrate all the time what difference I make in a practice – that never takes much effort at all. I do many nursing things that somebody else would have to do if I wasn't doing them. I do things, I'm trying to think if this is a national thing or a must in my state – where the medical students and the rest of the staff are limited now to X-amount of hours a day – you know, so right there, if we weren't doing it, who's going to do it? (#07:709-718)

You kind of have to make your own way. You have to, like I always say, people that make the biggest difference own their position. It's easier to say than to do, but I think it makes a bigger difference in the long run. Because work's not such drudgery then, if it's something that you own and you invest your time. Because then, it's something that you enjoy, you get benefits on a level that you can't even ascertain. A lot of benefits that I've received just from doing a support group, you can't quantify them, it's just there. The meeting [support group] last Thursday - I remember walking out of there and just coming back to my desk with a smile on my face. And it's not that it was a light-hearted meeting. I mean, people really let their souls hang out. One man, two cases of recurrences, just said "what's the truth about it?" That's the kind of thing that I always feel blessed about, you know, honored that they've let me in. (#09:497-511)

It's a struggle. The culture of realizing there's other incentives to improve practice, to feel good about creating something that's going to live on after we're past the time we're working here, all those good things, and certainly, providing

the absolute best that patient care can be, that culture's not there. People are just

trying to get through the day. (#15:192-197).

Codebooks can be found in Appendices I through K. A brief summary of the

codebook progression that occurred during data analysis resulted in the identification of

five abstract categories of meaning is presented in Appendix H. The essence of the data

generated in the participants' responses to the research questions are captured in five

focal content areas: 1) *The meaning of advocacy* to a select sample of oncology nurses;

2) *Nurses' ways of being* that help study participants fulfill the advocacy component of

their practices; 3) *Participant nurses' ways of knowing* clients' needs and determining

subsequent advocacy goals; 4) The behaviors and actions that comprise participant

nurses' ways of doing advocacy; and, 5) The *value of nurses' advocacy* as perceived by

participants in this study. These focal content areas represent participants' perspectives of

advocacy in their own practices and desirable advocacy components in the scope of

oncology nursing, providing context to guide understanding of these oncology nurses'

advocacy.

The Grounded Theory

Strauss and Corbin (1998) define theory as "a set of well-developed concepts

related through statements of relationship, which together constitute an integrated

framework that can be used to explain or predict phenomena" (p. 15). Developing theory,

or "theorizing" is the work of conceiving or intuiting concepts and formulating them into

a logical and explanatory scheme (Strauss & Corbin, 1998, p. 21). Statements of

relationship, according to Strauss and Corbin (1998), explain "who, what, where, when, how, and with what consequences an event occurs" (p. 22).

The culmination of analytical processes used in grounded theory is theorizing – statements of relationship are moved into an explanatory theoretical framework. The phenomenon of oncology nurses' advocacy suggested by findings of this study integrates complex, multidimensional, and non-linear processes, contextual antecedents, and human relationships to arrive at a substantive theory soundly grounded in study data. The five main categories, *the meaning of advocacy, nurses' ways of being, nurses' ways of knowing, nurses' ways of doing,* and the *value of nurses' advocacy* support social and cognitive processes that occur within nurse-patient relationships. Within the context of these intentional relationships, nurses interact with patients or clients to identify, plan for, and address patients' needs, wishes, values and choices. Participants' descriptions of these processes informed the emergence of the core variable and the subsequent theory. The resulting substantive theory emerged during iterative processes involving category reduction, identification of social processes operating within the nurse-patient relationships described by participants, consideration of theoretical and empirical literature, and selective sampling of collected data. The core variable, *Giving Voice to the Vulnerable,* captures what occurs within relationships formed in the context of contemporary oncology nursing clinical practice.

The resulting grounded theory is a multidimensional process of giving voice to the vulnerable, and is represented in the model depicted in Figure 4.1. Nurses in this study consistently entered into this multidimensional process with a belief in the moral

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covenant with patients, a willingness to take risks and go above and beyond the usual care requirements. The multidimensional process included recognition of the inherent vulnerabilities of cancer patients and the importance of addressing needs from patients' perspectives. Further, these nurses recognized the value of the nurse-patient relationship and advocacy as an ethical component of practice. The intention of the process is to give voice to the vulnerable. The desired outcome is that patients may avoid unnecessary suffering and instead, be able to direct their energies to their healing work.

Theory Definition

The substantive theory, *Giving Voice to the Vulnerable,* is grounded in the data as the most central aspect of what is happening in the relationships between the sample nurses and their patients from the nurses' perspectives. This theory captures the story of what takes place within these oncology nurses who possess certain traits and skills and who intentionally enter into relationships with patients with cancer who are perceived by the nurses to be particularly vulnerable, thereby initiating the process of advocacy.

Nurse participants in this study generally alluded to their advocacy as a process that involves many elements. The word *process* as a noun is defined as "a systematic series of actions directed to some end" (Webster's 1997, p. 630), a definition that is particularly useful in the context of advocacy.

Multidimensional Process of Giving Voice to the Vulnerable

Patient

Needs
- Information
- Physical
- Mental
- Emotional
- Spiritual
- Psychosocial

Enhanced probability of directing energy to healing

Nurse

Belief in moral covenant with patient: Willingness to take risks and exceed usual care

Multidimensional Process

Giving voice to the vulnerable

Advocacy as a lifeline of love

- **Recognition of patient's vulnerability**
- **Needs from patient's perspective**
- **Nurse/patient relationship**
- **Ethics of practice**
- **Intention to give voice**

Voice. The word *voice* is most often thought of as a noun meaning: 1) *The sound or sounds uttered through the mouth of living creatures, especially of human beings in speaking, singing, etc.;* and, 2) *The faculty or power of uttering sounds through the mouth by the controlled expulsion of air.* (Webster's, 1997, p. 878) The data clearly indicate that nurse informants' frequent use of the term *voice* was sometimes with literal intent, but was also used metaphorically, consistent with additional accepted definitions:

> Expression in words or by other means; the right to present and receive consideration of one's desires or opinions; an expressed opinion, choice, will, or desire; a person or other agency through which something is expressed or revealed; a person or other agency through which the views of another person or a group are expressed. (Webster's, 1997, p. 878)

> Conversely, the adjective *voiceless* describes a state in which something remains unspoken and unuttered, or a state of having no vote or right of choice (Webster's, p. 878). Many scenarios described by informants were those in which persons in their care were at risk of or actually being deprived of the right of information and informed choice and in which the nurse assumed the agency to express or enact views and wishes of patients.

> *Vulnerable.* In common usage, the term *vulnerable* implies susceptibility to harmful agents, threat, harm, danger, neglect, or health problems (Malone, 2000; Rogers, 1997; Scanlon & Lee, 2007). It is also implied that a vulnerable person is helpless and needs protection (Rogers, 1997). Vulnerability is affected by individuals' perception (Phillips, 1992) and is situational (Aday, 1993).

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Nurse informants described scenarios that impose added vulnerabilities on people

facing cancer, including but not limited to: the physical and emotional toll caused by

cancer; the life and death consequences of decisions that must be made when patients are

under significant emotional and physical duress; lack of knowledge and information

about the disease, treatment modalities, symptom management, and expected outcomes;

entry into the alien world of the health care environment; lack of or impaired

information-seeking, communication, negotiating, problem-solving, decision-making,

and self-advocacy skills; limitations in access to care, expertise, and technology; threats

associated with limited economic resources; and limitations in social resources.

Nurse participants in this study offered rich descriptions of their perspectives of

the professional and personal ethics they bring to their roles. The cognitive and social

processes that affected their relationships with patients and clients, the context of these

relationships and processes, and perceptions of the value of these relationships and

interventions afforded the emergence of the grounded theory: *Oncology Nurse

Advocates: Giving Voice to the Vulnerable.*

Grounded Theory Narrative: A Story of Oncology

Nurses Giving Voice to the Vulnerable

Oncology nurses described personal affinity and passion for providing care for

people facing cancer, somehow being meant to do this work, bringing the conviction that

advocacy is a moral and ethical responsibility of all nurses. These nurses perceive

themselves as possessing expertise, wisdom, competence, and self-confidence borne of

lengthy and intense experience and work history in oncology care. When the "status quo"

of a particular situation is unacceptable to them, oncology nurse advocates are tenacious in their pursuit of making a difference. It is with these characteristics that nurses intentionally enter into new relationships and maintain ongoing relationships with people facing cancer.

Oncology nurse advocates recognize inherent vulnerabilities of people facing cancer. By virtue of their job descriptions and scope of practice, nurses initiate efforts to create and nurture beneficial nurse-patient relationships, initiate assessments to identify vulnerabilities and priorities – needs - from patients' perspectives. In partnership with patients, nurses devise strategies and interventions intended to modify patients' vulnerabilities and address patients' needs.

Specific interventions considered part and parcel of advocacy include, but are not limited to: establishing a relationship with patients and families based on nurses' presence, mutual trust and honesty; provision of information to patients and family members; verification and clarification of communications and information provided by physicians and other providers; assurance that appropriate treatment options – with known risks and benefits - are presented to patients in language that they understand; assuring that patients' questions and concerns are fully addressed; promotion of patients' and families' self-advocacy skills; matching patients and families with available and accessible resources; facilitating second opinion processes; facilitating additional work-up assessment appointments; coordinating treatment and evaluation schedules; providing information about clinical trials; ongoing assessments relating to coping abilities and self-care management of side-effects and toxicities; provision of treatment

summaries and wellness strategies at the end of treatment; attention to family issues that affect patients' overall well-being; assurance of appropriate levels of nursing staff, skill mix, and staff competencies; promotion of professional standards of oncology nursing; and promotion of nurses' participation in health policy that affects nursing, the oncology nursing specialty, cancer research, and cancer care at institutional, local, regional, state and national levels.

Oncology nurse advocates derive great personal and role satisfaction from their successful efforts to make a difference in the lives of patients and clients. They feel honored to be allowed to be in the lives of patients in this population. Patient satisfaction and overall well-being are apparent. Successful advocacy in patient care and delivery system arenas encourages oncology nurses' participation in health policy advocacy arenas at local and national levels.

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

The focus of this study was to explore the nature of advocacy in the context of contemporary oncology nursing practice, with the intent to enhance understanding of its social and cognitive processes. Study findings and theory emerging from the rich data provided by oncology nurse participants are described in this chapter. The grounded theory narrative offered here portrays the complex and fluid processes of oncology nurses as voices for the vulnerable, fulfilling the quest most associated with grounded theory studies – describing what really goes on – in this case, when nurses advocate. Discovering and describing the nature of the interrelated processes from nurses with the lived experience of advocating alludes to the potential multidimensional good associated

with oncology nurse advocacy, and therefore, the importance of continued investigations of the phenomenon. Additional discussion of findings, the relationship of findings to the current body of knowledge, study limitations, and potential for future research are presented in Chapter Five.

CHAPTER FIVE

CONCLUSIONS AND RECOMMENDATIONS

This chapter presents a discussion of study findings and compares these findings with available literature and research. Serendipitous findings and overlapping concepts are identified and my responses to crucial questions frequently posed in the literature are offered. Finally, this chapter includes suggestions relating to the significance of findings for nursing and recommendations for further study.

Discussion of Study Findings

The purpose of this grounded theory study was to explore and describe advocacy as it is perceived and operationalized by experienced expert oncology nurses practicing in direct care clinical settings. The specific aim was to create new and grounded theory-based understanding of the construct of practicing oncology nurses' advocacy behaviors and actions by eliciting these descriptions from oncology nurse clinicians.

Analysis of findings provides a theoretical explanation of nurses' advocacy as a dynamic interplay of social and cognitive processes within a context of individual nurses' philosophical understanding of their professional responsibilities and work settings. Existing literature has consisted primarily of philosophical discussions of nurses' roles and potential as advocates, debates about the legitimacy of the profession's claim to the role and associated actions, and opinions about whether nurses are prepared and qualified to be advocates at all. The findings in this study provide useful considerations about the meaning of advocacy in the cancer care arena and among oncology nurses specifically,

add insight to the interplay of personal traits, social and cognitive processes, and contribute to our understanding of nurses' perception of the value of their advocacy efforts, none of which are readily apparent in existing literature.

Giving Voice to the Vulnerable as the core finding characterizes the phenomenon that is the lived experience of advocacy among the study population of oncology nurses. Identified categories, *the meaning of advocacy (serving as voice; component of ethical nursing practice; empowerment), nurses' ways of being (expert and knowledgeable practitioner; personal values; nurses' practice environment), nurses' ways of knowing (inherent vulnerabilities of cancer patients; knowledge about the population; modeling patients' worlds; holistic nursing philosophy), nurses' ways of doing (nurse-patient relationship; informing, educating, communicating; navigating), and the value of nurses' advocacy (to the health care system; to patients; to nurses)* are interwoven in the multidimensional process through which oncology nurses enact their interpretation of professional nurse advocacy. Among the participant sample, the term *patients* included individuals in clinical situations, groups of individuals in a community, an entire community, and the larger population of persons at risk for cancer, having a diagnosis of cancer, or those with familial or other personal ties to persons affected by cancer.

<center>*Nurses' Description of Advocacy: Giving Voice*</center>

The grand tour question (*If you could tell the oncology nursing world what advocacy is, what would you say?*) provided participants opportunities to describe advocacy very early in interview processes. Participants provided exemplar scenarios of advocacy from their practices, offered opinions about oncology nurses' responsibilities

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and duty to advocate, the impact of nurses' advocacy, and defined nurse advocacy. Findings explicitly reveal that a majority of participants defined advocacy as *being a voice for* or *giving voice to* expressed and unexpressed needs of their patients. Further, most participants described being a voice for or giving voice to these needs as an ethical or moral component of professional nursing aimed at empowering patients, enhancing patients' self-advocacy skills, and supporting patients' rights. Findings also support the notion of advocacy, or *giving voice,* to the collective patients' needs in policy-making at institutional, delivery system, community and national arenas.

Intention Overrides Paternalism

In perhaps one of the most significant findings, participants contradict the most frequently cited concern identified in the literature - that nurse-generated advocacy is inherently paternalistic (Bernal, 1992; Casteldine, 1981; Falk Rafael, 1995; Hewitt, 2002). All study participants adamantly emphasized that *giving voice* occurs only after patients identify their own needs, express their wishes, and establish goals with the guidance of nurses for which nurses then advocate on their behalf. In language familiar to proponents of Modeling and Role Modeling Theory (MRM) (Erickson, Erickson et al., 2006; Erickson et al., 1983) several participants suggested that patients innately know what they need, but may be unable to articulate their needs and to communicate effectively with healthcare providers about their perceived needs. Participants, when asked about how patients' needs are identified, related similar perspectives:

I ask them. I think a lot of times patients don't say because no one asks. And if you ask patients, they kind of are waiting for somebody to bring it up and we think if they need something, they'll tell us. (#02: 34-37)

It's what they need, not what I need. And if they tell me their needs are being met, that's great. Or, if they tell me 'I can live with this level of pain', I've given them the information. I'll tell them what the literature says about addiction and having true pain, that sort of thing. But, the choice is theirs ultimately. I think that's the thing. You're assessing their needs and then letting them know that it's their choice. (#02: 541-550)

Patients tell you their needs…. I've begun to realize that if you listen, patients will tell you what they need. (#04:26-31)

I think you can't work on the patients' needs or behalf really, unless you determine from them what they feel that they need. Health care providers, all too often, I think, assume what a patient needs, or a client needs, or a family member needs… and if you pause for a while, and are sensitive to it, they will clearly tell you what their need is. (#04:67-73)

Although nurses indicated they were aware of the potential for paternalism in their relationships with patients, the nurses clarified that their intentions were to

Determine with the patient where they want to go and how they want to handle their disease, and helping the patient achieve that. (#04:338-340)

These intentions reflect the notion of self-care knowledge proposed in MRM: at some level a person knows what has made him or her sick, lessened his or her

effectiveness, or interfered with his or her growth. This person also knows what will make him or her well, optimize his or her effectiveness or fulfillment (given circumstances), or promote his or her growth. This is self-care knowledge. Through self-care action the individual mobilizes internal resources and acquires additional resources that will help the individual gain, maintain, and promote an optimal level of holistic health (Erickson et al., 1983).

Pushing the Envelope of Scope of Practice

Participants' indicated that the scope of nursing practice as it relates to advocacy in their personal practices is vastly expanded beyond traditional oncology nursing roles, definitions of nursing practice routinely found in states' nurse practice acts, professional organization positions, and job descriptions. The Oncology Nursing Society (ONS) *Statement on the Scope and Standards of Oncology Nursing Practice* (Brant & Wickham, 2004), alludes to advocacy but in a much more limited way than is described by a majority of study participants. Measurement criteria for Standard V (Ethics) notes that the oncology nurse "advocates for patients and families in decision-making discussions" (p. 38). Standard IX (Leadership) criteria suggests that the oncology nurse

> Identifies and advocates for vulnerable, underserved populations (e.g., rural elderly patients who do not speak English or use English as a second language, inner-city underserved individuals, single parents with limited or no social support). (p. 41)

The ONS' *Statement on the Scope and Standards of Advanced Practice Nursing in Oncology* (Jacobs, 2003) Standards of Professional Performance includes "Advocacy":

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Oncology advanced practice nurses (APNs) advocate on behalf of people with

cancer to ensure their quality of life and their access to exemplary care

throughout the continuum of life. They advocate on behalf of the nursing

profession and the oncology specialty to ensure respect and recognition, access to

education, safe working environments, and fair reimbursement. Oncology APNs

also serve as advocates for public policy, particularly in matters of health. (p. 8)

According to the APN professional performance leadership standard (Standard IV), the

advanced practice oncology nurse is expected to serve…

As a liaison to institutional, local, state, and national legislative bodies regarding

issues related to oncology nursing and advanced nursing practice, with the goal of

improved outcomes. (p. 18)

Standard V (Ethics) directs that the oncology APN:

- Ensures that the rights of the patient, family, community, and nurses are

    respected and safeguarded;

- Provides education and information to the patient and family to facilitate

    informed decision making, including information about advanced directives

    and participation in clinical trials and other research projects;

- Assists in ensuring that the institution's policies and procedures, protocols,

    guidelines, and/or standards uphold and enhance ethical practice (p. 19).

ONS-published statements and standards available at this time provide little or no

guidance with regard to advocacy as it was described in this study's findings. Other

documents, including organizational positions offer more advocacy-related direction for

individual nurses and organizationally-sanctioned groups. For example, the ONS Position on Cancer Pain Management (2006) defines optimal pain relief among all people with cancer as a right, asserts the ethical responsibility of healthcare professionals to acquire and use current knowledge and skills in the management of cancer pain, and calls for the elimination of regulatory, legislative and economic barriers to effective pain management. Similarly, the ONS position, *Ensuring High-Quality Cancer Care in the Medicare Program* (2006)*,* articulates an organizational perspective that the Medicare program should provide comprehensive quality cancer care to all persons in need, and asserts that the program as it now exists provides "an insufficient scope of benefits and services". The Position outlines stances consistent with ONS philosophy and offers direction for the organization's health policy agenda but provides minimal guidance for individual nurses.

Risks: Disharmony with Physicians and Moral Distress

Findings suggest that study participants are well aware of potential risks associated with their advocacy behaviors. The risks cited most often have to do with physicians' expectations and reactions to advocacy by nurses, exemplified by these comments:

> I'm one of those people that was never, never has been, had any issue with calling up and asking a question, talking with people, and if someone got upset with me because I was asking questions, it never bothered me. But there're a lot of people that it does, and so, they would rather not approach somebody that would be difficult to approach… and I think we still have some physicians out

there that, you know, they're in charge, they're the ones that make the decision. (#01:329-336)

> We've got several docs who are not 'Mr. Personality' and nurses are afraid to talk to them about what's going on with the patient because they don't want their wrath, you know. Luckily for me, I'm not scared of their wrath, so I just talk to them anyway. (#02:465-469)

> I think I piss a lot of doctors off, in the sense that what I did in [my community] was very avant [*avant guard*]…So, yes, there are lots of risks involved because it's not the traditional nursing role. (#04:209-213; 234-235)

Findings indicate that nurses often resort to manipulative behaviors to avoid or assuage negative physician reactions – behaviors reminiscent of the "doctor-nurse" game first described and labeled by Stein in 1967, and revisited periodically through the next four decades. Larson (1995) described the object of the game:

> The object of the game is to preserve the interactive roles traditionally held by the physician and nurse in clinical practice, with the physician seemingly the sole decision maker and team leader, and the nurse "allowed" to make recommendations as long as she appeared passive. Open disagreement was to be avoided at all costs. Rewards for playing the game well included respect for the nurse (a "damn good nurse") and smooth facilitation of work for the physician. (p 180.

Reeves, Nelson and Zwarenstein (2008) captured the rules of the interprofessional game:

… where dominant male doctors, responsible for diagnosing, operating and prescribing, were being covertly guided in clinical decisions by apparently acquiescent female nurses, supposedly responsible for only 'housekeeping' and patient service. (p. 1)

Findings in the current study suggest that even among experienced, competent and confident oncology nurses, elements of the doctor-nurse game are commonplace today.

But, I think that's one thing too, is teaching [nurses] how to approach a physician, how do you talk to the physician, how do you approach a difficult physician? You phrase it in a question, you make it a learning experience…. So, it's like 'can you tell me why this patient is getting Kytril and not…' it gives you the opportunity to get in there and get your question answered and at the same time, approaching them in a non-threatening way. (#02:476-481)

I'm pretty good at the usual 'I was wondering if we should try'… or, 'the last time I looked at the literature, I saw that they were doing this, what do you think about that?' – trying to make it more the physician's idea than my idea since they are the ones that are ultimately going to be carrying out the plan. Perfect example… is a patient who was having excruciating pain, lower back pain, not getting relief from any type of systemic type of medication and I recommended kyphoplasty, and that was not what the physician had been referring for, but finally took me up on it and the patient got substantial relief from it. Of course, it took me a couple weeks to finally get that seed planted, but I

think it is a planting of the seed process. Sometimes it works, sometimes it

doesn't, but it never hurts to try. I mean, what's the worst that can happen?

(#06:147-161)

In our environment, my usual *m.o.* is to purge [*sic* – I think what she

means is "barge" forward] forward, you know, purge forward and beg to be

forgiven later. Because if you are doing what's right for the patient at the time,

and if you did it in their best interest, then you did what's right. (#13:706-710)

Study participants indicated that they have a moral obligation to protect patients

from the system. Nurse advocates place themselves at risk for personal moral distress

associated with inability, due to perceived personal failings or situational constraints, to

carry out what they believe to be a right course of action. Situations described as those

that elicit nurse advocacy behaviors are those thought to give rise to moral distress:

aggressive treatment of terminally ill patients, unnecessary tests and deception,

incompetent or inadequate treatment, inadequate management of distressing symptoms,

power imbalances among health care professionals, and lack of institutional support

(McCarthy & Deady, 2008). Moral distress can have serious consequences for nurses'

working lives, including leaving a position, changing career, and avoiding patient

interaction (Corley et al., 2001; Kelly, 1998). Conversely, it is argued that the quality of

nursing care is enhanced when nurses are both sensitive to the moral demands of their

work and aware of personal and institutional obstacles to optimal practice (Corley, 2002;

Laabs, 2005).

Nurses performing advocacy in ways similar to those identified by many study participants may be assuming considerable professional risks when their actions exceed those codified in state nurse practice acts, professional organizations' characterizations, and nurses' job or position descriptions. Several participants admitted that many of their advocacy-related actions occur outside of their regular work time. Nurse informants' descriptions of advocacy in this study are, however, consistent with documents framing professional nursing in the United States and statements and standards that define the oncology nursing specialty. The most recent publication of *Nursing's Social Policy Statement* (ANA, 2003), offers this definition of professional nursing:

> Nursing is the protection, promotion, and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through the diagnosis and treatment of human response, and advocacy in the care of individuals, families, communities, and populations. (p. 6)

Only one participant referred to her state's nurse practice act's provisions for nurse advocacy, although examination of that state's professional nursing statute reveals no mention of advocacy. In fact, the Texas *Nursing Practice Act, Nursing Peer Review Act, Nurse Licensure Compact and Advanced Practice Registered Nurse Compact,* effective in September 2007, does not specifically address or define nurse advocacy. Likewise, the Iowa *Nursing Practice for Registered Nurses/Licensed Practical Nurses* (2000) does not address or define nurse advocacy. A second participant referred to ANA and Oncology Nursing Society (ONS) documents that identify "advocacy" as a

component of nursing practice, but acknowledged the ambiguity that exists in these documents:

> I think we weave it in. Scope of practice is sometimes different than what you deliver in practice. Scope of practice means a framework, you know, as opposed to the day in and day out of what we do. I think scope of practice is your framework and you expand yourself to include what you should do and be careful that you don't do things that you shouldn't do. (#07:644-651)

Findings suggest that oncology nurse advocates routinely initiate second opinion processes, propose symptom management interventions – including prescription medications - to physicians, suggest that patients consider changes in providers and/or delivery systems, make referrals to physician and non-physician providers, and guide patients to complementary and alternative therapies resources, often without supporting guidelines or policies. Nurses in this study frequently find themselves working to verify and assure fully-informed decision-making relating to selection of treatment and symptom management options, ethical dilemmas often faced by oncology nurses and noted by Grace and McLaughlin (2005). The ongoing revelations of previously unknown or unacknowledged late effects of cancer therapies present evolving ethical issues for oncology nurses involved in informed consent and treatment decision-making (Haylock et al., 2007). Ethical concerns surround end-of-life issues and are noted in study findings as being among those nurse advocates frequently face, including physician-nurse differences of opinion about discontinuation of active treatment, referrals to hospice, and comfort management. Advocacy around nurse-patient ratios and nurse competencies to

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protect patients from harm and promote well-being, particularly in settings outside of traditional acute care, is noted in these findings. Indefinite strategies and uncertain endpoints are reflected in the literature (Bingham, 2002; Lamkin, Rosiak, Buerhaus et al, 2001, 2002), and provide little or not support for nurse advocates in clinical settings.

Risk, defined as exposure to the likelihood of an unfavorable outcome, serves as a method of social regulation (O'Byrne, 2008). Nurses who advocate are often exposed to potential negative outcomes that threaten themselves, including job loss (Hekkers, 2005), career setback (Baldwin, 2003), and conflicts with physicians, administrators and managers, and peers (Bennett, 1999; Hewitt, 2002). Bennett (1999) argues that until there is a universally accepted definition of nurse advocacy, this will continue to be the case. Existing organizational and professional documents provide little or no guidance for oncology nurses in many of the advocacy issues identified in this study.

Nurses' Covenant with Society: The Lifeline of Love

Findings in this study are indicative of the significance of the nurse-patient relationship and caring to oncology nurse advocates and the processes of advocacy. Findings in this regard are consistent with Coffey's concept analysis of the nurse-patient relationship as a shared covenant in cancer care, suggesting that advocacy is "nursing's covenant with society" (2006, p. 320). Coffey (2006) identified three attributes of the nurse-patient covenant: 1) enduring relationship, 2) caring benevolence, and 3) contextually negotiated reciprocity. Coffey recognized nursing advocacy from both patient and nurse perspectives as a consequence of the nurse-patient covenant.

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Meleis (1997) noted that the nurse-patient relationship is often described as the "essence of caring" (p. 98). Similarly, Cooper (1988) described the nurse-patient relationship as one of undeniable primacy within the discipline. Benner and Wrubel (1989) claimed that caring "means that persons, events, projects, and things matter to people" and as a word for being connected, "fuses thought, feeling, and action – knowing and being" (p.1). Further, Benner and Wrubel noted that caring renders the person at risk and vulnerable, in turn setting up what counts as stressful and available, acceptable coping options. In building a caring paradigm for nursing, Eriksson (1994) assumes that the aim of caring is to alleviate patients' suffering, asserting that the "nature of caring is to promote healing and health" (p. 4), and that the core of nursing is caring (p. 14). The authors of MRM Theory (1983), drawing on the work of Hildegard Peplau (1952), describe the nursing process as "the ongoing, interactive exchange that occurs when a caring, competent nurse relates to a client to nurture and support the client's growth and development toward health (p. 104).

According to MRM Theory, the nurse-client relationship begins when nurse and client first meet, is integral to the nurse's ability to model the client's world, and, according to Kinney (2006), "must be cultivated through care and attention" (p. 279). Kinney (1990) described five phases of nurse-client relationships with associated client outcomes. In the first phase, the nurse and client work on trust, a notion reflected in study findings relating to initial contacts between nurses and clients. From these excerpts, concepts of trust, caring, and nurse presence within the context of the nurse-patient relationship are noted in the study findings.

I think part of what goes into being a good advocate is setting up a good relationship with the patient. So, I think you have to find out about the patient and develop that rapport, and you have a different rapport with every patient you have… so you develop that first before I think you can effectively advocate for their needs. And there's a certain trust: they are not going to let you advocate for them unless they trust you. (#01:37-44)

There are just so many crazy things that can happen with all of the new chemotherapy that we have to really make sure that they [patients]… have everything at their disposal that they need in order to be successful with that. And usually, when you elicit those kinds of assessment questions on their physical well-being, a lot of times… I really feel that if you do a good physical assessment and you develop that relationship of trust, that the needs will come out. (#01: 143-151)

I just look at them as a person, I think that's the difference. I want them to tell me about themselves. What are you feeling right now? Are you scared? What kinds of questions do you have? And the other big thing that I do with patients – I sit down. So, if I'm going to go in and do an intake admission assessment, I ask them if it's OK if I sit down while I do that, and I'll pull a chair out and we'll talk first, before I do a physical assessment… I try to teach the new grads and nurses new to our floor that it makes a difference whether you're standing by the door waiting to leave – see how fast you can get out of the room – or if you're sitting

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down next to the bed talking to somebody so they feel that you are really there for them. (#03:419-426)

My own system is really being open with the patient. It's really the hands-on, talking to the patient and being very pointed about questions. …when you first go in, it's … kind of smiling and introduce yourself, and then, introductory small talk. And then, just really kind of getting down to business to find out what's going on with the patient. That way, you're not wasting time and skirting the issues, and … patients are much more open and comfortable, if you just hit it right on the head when you walk in. I think the first time you talk to the patient, and make them understand or help them understand that you're there to help them, and that you're interested in what's going on with them, and that, the issues that they discuss with you, you will do something about. (#10:169-186)

Over the course of active cancer treatment, oncology nurses often come to be perceived as life-lines for cancer patients. A bond is created and the relationship deepens, perhaps even to what Kinney (2006) suggests are synchronized energy fields between the nurse and client to create a "heart-to-heart relationship" (p. 281). Applying findings from the Institute of HeartMath (Arguelles et al., 2003; McCraty et al., 2005), Kinney (2006) suggests too, that when nurses have

…feelings of compassion and love for our clients and ourselves, and our thoughts are directed at providing care based on unconditional acceptance of self and clients, we generate smooth and harmonious heart rhythms in our own hearts, and establish coherence in the rhythms throughout our bodies. (p. 289)

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This study's findings indicate that oncology nurse advocates often develop special bonds with their patients, sometimes refer to this bond as *love,* perceive particular affinity for persons affected by cancer, and express passion for their work with this population:

I think that the oncology nurse, she just develops a special bond with every single patient she has. You can't put your hands on somebody in that kind of state and not do that. (#01:130-133)

Oh, I love those patients. I absolutely love them, and I know I'm gonna stay here until I retire: I won't be leaving. I just said that to the doctor I was working with today. He said "It's great having you here." I said, "Well, you know, this is my favorite group of patients: I loved them from the very beginning, and they're just my favorite group." (#09:36-40)

Kinney and study participants are not alone in acknowledging the significance of love within the nurse-patient relationship. Stickley and Freshwater (2002) noted that love is vital to the development of individuals and maintain that love heals. The giving and receiving of love, they contend, is embedded in nursing and caring practices, and imply that nurses' advocacy behaviors are acts of love. Watson (2003) too, related love and caring to the soul of nursing and our deep humanity. Watson linked love and caring with holding another's life in our hands. Watson asserted that love and caring are central to the caring professions, which precede and inform clinical judgments and serve as an epistemological foundation for clinical care. Instances of data in this study's findings also reflect the notion of holding another's life in our hands:

It's in our hands, the difference between patients having a good treatment and a bad treatment on a particular day, is in the hands of the nurse, and they need to accept that responsibility. It's their responsibility. (#02:444-446)

It's a tough subject, this advocacy thing. It's a matter of holding the patient, in a way, helping them have their own voice but at the same time, supporting them. It's a matter of trust, holding them, but letting the system support them as well. (#04:582-589)

A multinational group of nurse scholars devised a consensus statement of philosophic unity among various nursing theories as the basic ontology of nursing (Roy & Jones, 2007). Among the points of convergence in the statement is acknowledgement of the nurse-patient relationship as the essence of nursing practice. Descriptions of the nurse-patient relationship allude to it as a process characterized by unfolding, sharing, and moving together over time (de Raeve, 2002; Newman et al., 2008). In contemporary oncology care as described by nurse participants in this study, the development of nurse-patient relationships is necessarily accelerated and tied to the episodic and largely ambulatory nature of cancer care in the United States. Berg, Berntsson and Danielson (2006) noted that only a few studies have been done to explore the caring relationship between nurses and patients with chronic illnesses in ambulatory care settings, and concluded that encounters such as these are of interest for future investigation.

It seems apparent that "caring" is an overlapping concept with, and an important antecedent of, nurse advocacy. Several study participants took great pains to describe ways in which nurses perceived their work – differentiating colleagues for whom nursing

is "just a job" versus those for whom nursing is a profession, even a calling that defines who they are. The "just-a-job nurse" was perceived by many participants as one who, although she may provide required patient care, would be unlikely to advocate, had difficulty or could not empathize with patients, and generally did not extend herself beyond a job description. Advocacy-related actions were noted to occur often outside of normal work hours, and were not universally carried out by colleagues with identical job descriptions in shared settings. Still, failure to advocate for patients' needs was perceived by study participants to indicate inferior or inadequate nursing practice, and advocacy was not perceived to involve going above and beyond the nursing role. It was simply how these nurses nurse. The apparent dichotomy of these perceptions presents the challenge of considering its relevance and place within advocacy.

Significance for Nursing

This study has significance for nursing education, practice, administration and research. The substantive theory, *Oncology Nurses Giving Voice to the Vulnerable,* is grounded in the data, emerging from the complex interplay of social and cognitive elements identified in the findings. This theory presents a foundation for understanding the context and processes of oncology nurse advocacy and its potential impact on individual patients and nurses, delivery systems, populations, communities, and health policy.

Understanding how and when advocacy actions are learned by, considered, and operationalized by nurses, associated risks and benefits to nurses, impact on delivery system and patient outcomes, and contextual and environmental obstacles can provide

valuable insight to nursing workforce issues. Such insight may be used to influence student nurse selection, education and socialization processes, nurse recruitment and retention strategies, work satisfaction and quality of care.

Allusions to the continued existence of "the Doctor-Nurse Game" among experienced and confident oncology nurses are somewhat surprising. Yet, the impact of organizational power structure and continued adherence to the medical model instead of an holistic model of cancer care delivery on questions of *if*, *how*, *when* and *why* nurses advocate despite acknowledged risks are significant: they affect achievement of nurse autonomy, a concern often noted in the context of nursing work satisfaction. Ongoing evidence of caring as an undervalued concept is noteworthy too: often nurses' advocacy was noted to occur outside of formal work hours – during personal time - begging questions concerning the value of advocacy, costs of caring, and costs of not caring.

If the nurse-patient relationship is the essence of caring and of nursing, then the nature of these relationships and nurses' abilities to establish bonds with patients in the context of contemporary and future cancer care is of significance to nurses and for the discipline. It has been estimated that at least 85% of all cancer care episodes occur in ambulatory and physician-office settings (Herzlinger, 2002). Gone are the days of long stays in acute cancer care units, during which nurse-patient relationships evolved over the course of several intense days, with nurses responsible for four to five patients over eight to twelve hour shifts on several consecutive days. Today, most patients receive cancer therapeutics and symptom management protocols in the midst of busy ambulatory settings, where nurses could work with 20 patients each day, the entire care episode

rarely exceeding a few hours. It is important that nurse-patient relationships be accommodated in evolving cancer care settings.

The suggestion that oncology nurse advocacy actions often exceed professional expectations and boundaries established by state nurse practice acts and other policy statements is significant for nursing. The blurring and/or violation of professional boundaries can create unrealistic expectations, disappointment and anger on the part of patients, result in confusion, animosity, anger on the part of peers and colleagues, and lead to frustration and compassion fatigue or burnout for nurses.

Recommendations for Further Research

The multidimensional nature of "advocacy" as it relates to professional nursing offers rich opportunities for additional research aimed at clarification and confirmation of core findings of this study, and further development and validation of the theory. Further research can be used to identify traits that are consistent with advocacy behaviors among perspective and practicing nurses, and to learn when and how best to teach and nourish these traits and skills throughout formal nursing education and socialization processes and in nurses' work settings. How nurses are able to intellectually, physically, and emotionally multi-task to carry out advocacy processes in various cancer care settings is a potentially rich area of study. Value of nurses' advocacy as it was described in these findings has not been defined, verified, or quantified and therefore, is a potentially rich area for further research. Excerpts of data that were not fully explored in this work hinting at related and overlapping concepts suggest additional research questions, use of quantitative and other qualitative methodologies, and varying sample populations.

Potential research questions arise from the growing interest in patient empowerment, the development of self-advocacy skills noted by Clark and Stovall (1996), and nurses' roles in developing and facilitating these constructs.

<center>Study Limitations</center>

Acknowledged study limitations include the small and select nature of the study sample, which, although common to qualitative research methods, does limit generalizability of study findings. Alternatively, qualitative researchers refer to the transferability of study findings to other groups in other settings. The varied experience, work settings, and educational preparation of this study population suggest that findings are indeed transferable to other populations and settings.

The study sample was composed of what could be considered an elite group of nurses – the "cream of the crop" – experienced, skilled, knowledgeable nurses who are acknowledged by colleagues as being among oncology nursing's best. The limitations of this particular sample, however, provide fertile ground for research questions aimed at exploring the knowledge gaps imposed by methodology and contextually imposed constraints.

Finally, the limitation imposed by researcher bias, is acknowledged, although the bracketing process, and use of researcher's memo and journal assisted me in maintaining awareness of and putting aside personal beliefs and judgments throughout data collection and analysis processes. Care was taken to minimize researcher bias by crafting carefully worded questions used during participant interviews.

Conclusions

This research was carried out to explore the meaning and lived experience of advocacy among expert oncology nurse clinicians. My tacit knowledge and awareness of the challenges and rewards experienced by current oncology nurses and the range of vulnerabilities among people affected by cancer, my underlying personal values of social justice, and my profound reverence for nurses' actual and potential contributions to cancer care influenced the formulation of the aim, development of research questions, and study design. Background literature supported the potential significance of this study and contributed to my still-evolving interest in the phenomenon of advocacy.

This study provides new insight into inherent values and acquired competencies, patient care and policy issues that drive nurses' advocacy efforts, ways in which nurses advocate, the challenges, barriers, risks and rewards that appear to be crucial to the phenomenon of nurse advocacy. This study highlights gaps in our knowledge base and practice-related evidence to guide nurses' preparation, abilities, and readiness to advocate most effectively and to be truly strong voices for the vulnerable population that is challenged by cancer.

The literature reveals opponents of nurse advocacy, citing nurses' lack of formal preparation for advocacy, nurses' roles as employees and subsequent lack of power in institutional bureaucracies, questions of nurses conflicting loyalties to institutions, physicians, and patients. Nurses' advocacy is perceived by this study sample of oncology nurses to be critical to the well-being of patients, and the notion of nurses as powerless employees was universally rejected. Further, findings indicate that nurses should be, must

be, and in fact, already are persuasive and effective advocates with or without definitions, guidelines, and employer, collegial, institutional and regulatory support.

After some four decades of philosophizing and editorializing, it is time for the professional nursing community - academicians, educators, theorists, philosophers, researchers, administrators, and clinicians – to acknowledge advocacy as a philosophical and practical foundation of nursing and to collaborate on strategies to fully integrate advocacy into professional nursing. It is apparent that professional nurse advocacy, as has been described here as a component of routine oncology nursing practice, far exceeds the traditional expectations of nurses espoused in contemporary nurse practice regulatory language, documents outlining professional scope of practice, and nurses' job descriptions.

Successful nurse advocacy, in all of its manifestations, is essential to confirm, sustain and strengthen nursing as a viable and valued profession now and in its foreseeable future. It is evident that, based on the experiences reported by the nurse participants in this study, they readily assumed the authority and accountability needed to protect the rights, safety, health and well-being of their patients. But, authority and accountability must be preceded by the recruitment and retention of nursing students who have the potential to acquire the knowledge, self-esteem, and competencies that prepare them for the challenges and risks inevitable in clinical practice along with socializing these students to the values consistent with advocacy. Defining risks and strategies to minimize risks, development of instruments to measure outcomes, and determination of best advocacy practices are critical but are as yet, unaddressed. Work environments must

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allow professional nurse advocacy to flourish. The realities of professional nurse advocacy must be recognized, valued, paid for, and codified in regulatory language and health policy arenas.

Nurses whose words informed this study are not the philosophers, theorists, academicians, researchers, administrators and educators who have created the literature relating to professional nurse advocacy. The informants in this study are exemplar oncology nurse clinicians who tell us that advocacy is an essential and multidimensional process within their nursing practice that consistently integrates three basic elements:

1. A moral covenant with their patients;
2. Intention to give voice; and
3. A lifeline of love.

These nurses act on the belief that outcomes of professional nurse advocacy can assist patients with directing their energies to their healing work rather than being diverted to surviving the health care system.

APPENDIX A: Interview Participant Recruitment Letter

Pamela J. Haylock, RN, MA
18954 State Highway 16 North
Medina, TX 78055
Phone: 830.589.7380
FAX: 830.589.7381
E-mail: pjhaylock@indian-creek.net

>date<

<First name> <Last name>, R.N., <Credential>

<Street address>

<City>, <State> <Zip code>

Dear <Ms.> or <Mr.> <Last name>,

I am a doctoral Nursing Student in the Graduate School of Biomedical Sciences at the University of Texas Medical Branch. I am conducting a study in conjunction with my doctoral dissertation. My study will explore the nature of patient advocacy from the perspective of oncology nurses in the United States, and I ask that you consider whether or not you would like to learn more about the study and possibly participate. If you consent, you will be one 20 registered nurse participants.

The purpose of this study is to gain insight into the social processes and situations that surround advocacy in your work environment. If you choose to participate, you will be asked to complete a brief demographic profile. I will interview you either by telephone or in a setting of your choice in which our privacy can be maintained, and I will audiotape our interview as a way of maintaining an accurate record of our conversation. I anticipate the interview process to be conducted in at least one but no more than two sessions that could take up to 90 minutes each. I plan for all interviews to be completed between November 2004 and May 2005. The audio-recording of the interview(s) will be transcribed so that the data may be analyzed and interpreted. Each transcript and tape will be assigned a code to maintain your anonymity and confidentiality. I invite you to bring samples of documents or other artifacts that you believe to be relevant to your perceptions of your advocacy experiences to the interview setting. These items may provide cues and clues to enrich our interview experience. Participation is strictly voluntary and all information about participants in this study will be confidential.

Findings will serve to contribute to theory relating to the construct of nurses' advocacy behaviors. Reports of findings will be presented in aggregate form and will not identify participants by name. The University of Texas Medical Branch's Institutional Review Board must approve this study before it can be conducted. Their guidelines will be followed at all times. If you wish to discuss this further or are willing to participate in this study, please telephone me at (830) 589-7380 or e-mail me at >pjhaylock@indian-creek.net<. An informed consent form is enclosed. This form must be read, signed, and returned to me before you can participate. I look forward to your response.

Respectfully,

Pamela J. Haylock, RN, MA

Oncology Nurses and Patient Advocacy Study

Be part of a study to explore a component of oncology nursing

- Are you an RN currently working in a direct care oncology setting?
- Have you had at least 5 years experience as an oncology nurse?
- Are you a member of the Oncology Nursing Society?

If you've answered "YES" to these questions, you may be eligible to participate in this research study.

The purpose of this research study is to describe the social processes of advocacy among oncology nurse clinicians. This study involves participation in a semi-structured interview lasting 1 - 1 ½ hours. Participants will not receive remuneration for time spent in the interview, or reimbursement for travel and parking expenses. Exploration of the participants' opinions and perceptions may evoke previously unrecognized feelings about a topic of discussion during interviews, although participants do have the potential to gain insight into the phenomena under discussion. There are no risks or benefits to society or individual participants that can be estimated.

The study is being conducted by Pamela J. (PJ) Haylock, RN, MA, in fulfillment of the dissertation requirement of the PhD program of the University of Texas Medical Branch School of Nursing.

Please call Pamela Haylock at **(830) 589-7380** for more information.

APPENDIX C: Subject Consent Form

SUBJECT CONSENT FORM

You are being asked to participate as a subject in the research project entitled, A Study of Advocacy among Oncology nurses, under the direction of Pamela J. Haylock, RN, MA., a student in UTMB's Graduate School of Biomedical Sciences Doctoral Program in Nursing. The project is being supervised by Carolyn Kinney, RN, PhD, Associate Professor in the School of Nursing.

PURPOSE OF THE STUDY

The purpose of this study is to gain an understanding of patient advocacy as performed by oncology nurses. You are being asked to participate because you have been identified as an oncology nurse who employs advocacy efforts in the routine course of your work. This study will fulfill a requirement for the Doctoral Dissertation for the researcher.

PROCEDURES

1. You will be interviewed by Pamela Haylock to solicit my opinions and experience at a time and place convenient to you. This process will occur during at least one but no more than two 90 minute sessions which will be audio taped and transcribed verbatim. If for any reason you are unable to fully participate in the interview or wish to withdraw from the study, the interview will be stopped immediately.
2. The audiotapes will be coded and any identifying information will be removed from the tape and transcript. The tapes will be kept in locked cabinet in the researcher's office. One copy of the coding scheme will be kept in a separate locked location in the researcher's office. Verbatim transcripts are needed because Pamela Haylock will be examining what you say in an effort to understand oncology nurses' patient advocacy behaviors. Your individual remarks will not be recognizable in the final report because the findings will be presented as aggregate data.
3. Following the interview, Pamela Haylock may be contacting you by email or phone if any information from the interview needs to be clarified for better understanding or to arrange an additional interview for further clarification.
4. You will be asked to complete a questionnaire asking about your age, race, employment, and education. You will be completing this questionnaire at the time of the first interview. The questionnaire will be coded and no identifying information will be kept on the questionnaire. Any information gained in this study that could benefit you will be made available to you at the conclusion of the study.

NUMBER OF SUBJECTS PARTICIPATING

The anticipated number of subjects involved in the study will be twenty.

RISKS OF PARTICIPATION

The potential risks from participation in the study are few. You may become fatigued during the interview, and the interview process may elicit an unexpected emotional response. Due to the small number of participants, your complete anonymity cannot be guaranteed although you should know that the principal investigator will take steps to assure your confidentiality.

BENEFITS TO THE SUBJECT

Other than the chance to gain further insight into patient advocacy in my professional practice, you will not benefit from your participation in this research project.

ALTERNATIVE TREATMENT

There are no alternative treatments for being in this study, but you do have the option to not participate in this study.

REIMBURSEMENT FOR EXPENSES

You will not be reimbursed for participation in this study. You will not be reimbursed for lost time, travel, parking, meals, etc., during your participation in this study.

COMPENSATION FOR RESEARCH RELATED INJURY

Research related injury is not anticipated as a result of your participation in this study. There are no plans to provide other forms of compensation. However, you are not waiving any of your legal rights by participating in this study.

COSTS OF PARTICIPATION

There will be no cost to you for your participation in the study. If you request a referral for professional counseling, you or your insurance company will be charged or held responsible for the costs of the care that you will receive.

USE AND DISCLOSURE OF YOUR HEALTH INFORMATION

Study records that identify you will be kept confidential as required by law. Federal privacy regulations provided under the Health Insurance Portability and Accountability Act (HIPAA) provide safeguards for privacy, security, and authorized access of your records. Your health information will not be accessed, disclosed or used for purposes of completing this research study. Except when required by law,

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you will not be identified by name, social security number, address, telephone number, or any other direct personal identifier in study records disclosed outside of the University of Texas Medical Branch (UTMB). For records disclosed outside of UTMB, you will be assigned a unique code number. The key to the code will be kept in a locked file in Pamela J. Haylock's office.

ADDITIONAL REQUIRED CLAUSES

1. Informed consent is required of all persons in this project. Whether or not you provide a signed informed consent for this research study will have no effect on your current or future relationship with UTMB.

The principal and alternate procedures, including the experimental procedures in this project, have been identified and explained to you in language that you understood.

3. The risks and discomforts from the procedures have been explained to you.

4. The expected benefits from the procedures have been explained to you.

5. An offer has been made to answer any questions that you may have about these procedures. If you have any questions before, during or after the study, or if you need to report a research related injury, you may contact Pamela J. Haylock at 830-589-7380.

6. Your participation in this study is completely voluntary and you have been told that you may refuse to participate or stop your participation in this project at any time without prejudice and without jeopardizing your medical care at UTMB. If you decide to stop your participation in this project and revoke your authorization for the use and disclosure of your health information, UTMB may continue to use and disclose your health information in some instances. This would include any health information that was used or disclosed prior to your decision to stop participation and needed in order to maintain the integrity of the research study. If we get any information that might change your mind about participating, we will give you the information and allow you to reconsider whether or not to continue.

7. If you have any questions regarding your rights as a subject participating in this study, you may contact Dr. Wayne R. Patterson, Senior Assistant Vice President for Research, Institutional Review Board, at (409) 772-3481.

8. You have a right to privacy, and all information that is obtained in connection with this study and that can be identified with you will remain confidential as far as possible within state and federal law. However, information gained from this study that can be identified with you may be released to no one other than the investigator, your personal physician,

and the UTMB Institutional Review Board. The results of this study may be published in scientific journals without identifying you by name.

The purpose of this study, procedures to be followed, risks and benefits have been explained to you. You have been allowed to ask questions and your questions have been answered to your satisfaction. You have been told who to contact if you have additional questions. You have read this consent form and voluntarily agree to participate as a subject in this study. You are free to withdraw your consent, including your authorization for the use and disclosure of your health information, at any time. You may withdraw your consent by notifying Pamela J. Haylock at 830-589-7380. You will be given a copy of the consent form you have signed.

Date	Signature of Subject

Signature of Witness	Signature of Authorized Representative *(if applicable)*

Using language that is understandable and appropriate, I have discussed this project and the items listed above with the subject and/or his/her authorized representatives.

Date	Signature of Person Obtaining Consent

IRB APPR... ...

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1 of 4

FORM VALID THROUGH

OCT 3 1 2005

A Study of Advocacy Among Oncology Nurses

SUBJECT CONSENT FORM

You are being asked to participate as a subject in the research project entitled, A Study of Advocacy among Oncology nurses, under the direction of Pamela J. Haylock, RN, MA., a student in UTMB's Graduate School of Biomedical Sciences Doctoral Program in Nursing.
The project is being supervised by Carolyn Kinney, RN, PhD, Associate Professor in the School of Nursing.

PURPOSE OF THE STUDY

The purpose of this study is to gain an understanding of patient advocacy as performed by oncology nurses. You are being asked to participate because you have been identified as an oncology nurse who employs advocacy efforts in the routine course of your work. This study will fulfill a requirement for the Doctoral Dissertation for the researcher.

PROCEDURES

1. You will be interviewed by Pamela Haylock to solicit my opinions and experience at a time and place convenient to you. This process will occur during at least one but no more than two 90 minute sessions which will be audio taped and transcribed verbatim. If, for any reason you are unable to fully participate in the interview or wish to withdraw from the study, the interview will be stopped immediately.

2. The audiotapes will be coded and any identifying information will be removed from the tape and transcript. The tapes will be kept in a locked cabinet in the researcher's office. One copy of the coding scheme will be kept in a separate locked location in the researcher's office. Verbatim transcripts are needed because Pamela Haylock will be examining what you say in an effort to understand oncology nurses' patient advocacy behaviors. Your individual remarks will not be recognizable in the final report because the findings will be presented as aggregate data.

3. Following the interview, Pamela Haylock may be contacting you by email or phone if any information from the interview needs to be clarified for better understanding or to arrange an additional interview for further clarification.

4. You will be asked to complete a questionnaire asking about your age, race, employment and education. You will be completing this questionnaire at the time of the first interview. The questionnaire will be coded and no identifying information will be kept on the questionnaire. Any information gained in this study that could benefit you will be made available to you at the conclusion of the study.

APPENDIX E: Demographic Data

Age	Ethnicity	Region	Pop	Yr RN	Position	# Yr	RN Pr	Hi De	Cert	Cred	Facil
50	C	W	U	20	CM	3.5	MSN	MSN	Y	ONCC	fcc
50	C	W	U	13	SN	3	BSN	BSN	Y	ONCC	c
53	C	W	S	32	CM	.5	ADN	MPH	Y	ONCC	ch
37	C	SW	U	15	SN	11	ADN	ADN	Y	ONCC	fcc
50	C	SW	U	30	NP	12	ADN	PhD	Y	ONCC	po
45	C	MW	U	24	NP	<1	Dip	MS	Y	ONCC/ANCC	op
49	C	MW	U	29	CNS	3.5	Dip	MSN	Y	ONCC	ch
61	C	W	S	36	CNS	14	BSN	MN	Y	Calif	rt-ch
58	C	SW	U	38	SN	2.5	Dip	BS	Y	ONCC	fcc
58	H	W	S	19	Coor	17	ADN	MSN	N	-	ch
50	C	W	S	10	SN	3	AA	AA+	Y	ONCC	ch
51	C	NE	U	30	SN	11	BSN	BSN	Y	ONCC	t-op
38	C	SW	U	15	Coor	8	BSN	MSN	Y	ONCC	po
46	C	SE	C	24	NP	11	BSN	MSN+	Y	ONCC/ANCC	po
41	C	MW	U	9	SN	5	ADN	BSN	Y	ONCC	ch
50	C	MW	U	25	Coor	10	BSN	BSN	Y	ONCC	ch-op
57	C	NE	U	37	NP	11	Dip	MN+	Y	ONCC/ANCC	t-A
45	Ch	W	U		CNS		BSN	MS	Y	ONCC	ch
49	C	MW	U	27	NP	11	BSN	MSN+	Y	ONCC/ANCC	t

Legend:

Age = age	Position = CM = Clinical Manager	Hi De = Highest Earned Degree
Eth = ethnic group: C = Caucasian, H = Hispanic	SN = Staff Nurse	Cert = Certification
Ch = Chinese	NP = Nurse Practitioner	Cred = Credentialing organization
Region = U.S. region	CNS = Clinical Nurse Specialist	Facil = Type of work facility setting
Population – Urban, Suburban, Community	Coordinator = Patient Care Coordinator	fcc = Free standing cancer center
Yr RN = # of years practice as RN	# Yr = # of years in current role	t = Teaching hospital rt = Rad Tx
	RN Prep = Basic RN preparation	ch = Community Hospital
		po = Physician office op = out pt

APPENDIX F: Interview Guide: Links among the Specific Aims, Research Questions, and Prompts

Specific Aims: Elicit from oncology nurses:	Research Questions	Interview Guide Questions
How is "advocacy" described by nurses working in clinical practice settings?	How do oncology nurses who provide direct care services to people affected by cancer define "advocacy" as it relates to nursing practice?	1. If you could tell the oncology nursing world what "advocacy" is, what would you say? 2. What are some key issues in oncology nursing that trigger nurses advocacy behaviors?
The cognitive processes used when deciding to advocate	What are the cognitive processes of oncology nurses' advocacy behaviors?	1. How do you go about identifying your clients' needs? 2. Describe the processes you believe are important to your assessments, decision-making and advocacy actions.
Descriptions of nurse behaviors consistent with advocacy	How is advocacy operationalized by nurses?	1. How do you implement advocacy into your clinical practice? 2. Can advocacy be taught? How? 3. Describe the environment in which advocacy thrives?
What are the client-focused outcomes nurses describe as being influenced by their advocacy efforts?	How do oncology nurse clinicians describe the influence of their advocacy efforts?	1. How do you determine the effect(s) of your advocacy actions? 2. Describe how you use what you discover about and do for one patient to facilitate future advocacy efforts.

APPENDIX G: Contact Summary Form (sample #1)

Contact type: *Interview*   **Site:** *Miraval – in person*

Participant: *#1*   **Today's date:** *12/4/04*

1. What were the main issues or themes that struck me in this contact?
1. Being the voice for the patient
2. Speaking for the patient who's too ill
3. Nurse's presence – Nurse's caring
4. Nurse is willing to talk about difficult issues

2. Summarize the information I got (or failed to get) on each of the target questions I had for this contact.
Role of management – facilitation Vs barrier?

3. Anything else that struck me as salient, interesting, illuminating or important in this contact?
- The system doesn't catch up with the science
- Autonomous nature of oncology nursing – that's why people love it
- I've transplanted hundreds of patients – I've never been the transplant patient

4. What new (or remaining) target questions do I have in considering the next contact?

   1. Are some nursing roles more likely to support advocacy efforts OR is it just traits of the nurse regardless of designated role?
   2. Roles of docs VS roles of nurse: working around the doc – make it seem like it's the doc's idea – "Planting seeds"
   3. Personality traits of nurse advocate: courage, forceful, assertive, mature, experienced
   4. Impact on nurse work satisfaction – r/t successes in advocacy and positive or negative outcomes of advocacy

APPENDIX G: Contact Summary Form (sample #2)

Contact type: *Interview*   **Site:** *Telephone from work*

Participant: *#4*   **Today's date:** *12/4/04*

1. What were the main issues or themes that struck me in this contact?
Voice of the patient   Listening - sensitivity of the nurse
Boundaries of nurses' roles   Oncology nursing as "a calling"
Vulnerability of patient
Growing into seasoned oncology nurse - evolutionary process

2. Summarize the information I got (or failed to get) on each of the target questions I had for this contact.
** You can't work on patients' needs unless you determine from them
        what they feel they need (alluding to affiliated
        individuation?)*
* Things that get in the way of healing lead to unmet needs
** Dichotomy: "it's not the traditional nursing role" VS "gets
        frustrated when colleagues don't advocate as she does"*

3. Anything else that struck me as salient, interesting, illuminating or important in this contact?
*Informed consent VS Informed decision-making
*Patients tell us their needs
*Role of or for nurse's intuition   ?
*Power issue - nurse, doctor, patient
**Oncology nursing is unlike any other nursing specialty due to
        complexity of disease & care & decisions to be made,
        multidisciplinary nature, continuum of patients' lives*
* "I piss a lot of doctors off" - & "I don't care if they are mad at me"
**Navigation piece - distilling information to determine "where can
        this patient best be served?"*

4. What new (or remaining) target questions do I have in considering the next contact?
Advocacy as it relates to the healing process
Sickness VS Recovery model   Idea of the paternalistic system
Advocacy as a step higher than task-oriented care
Is Advocacy the traditional nursing role?
Is cancer nursing different?

APPENDIX G: Contact Summary Form (sample #3)

Contact type: *Interview*   **Site:** *Telephone from work*

Participant: *#10*   **Today's date:** *4/22/06*

1. What were the main issues or themes that struck me in this contact?
* There's an emotional difference in taking care of cancer patients than other patient populations.
* I have an affinity towards cancer patients - empathy
* I get to know who the patient is - "they tell you most everything

2. Summarize the information I got (or failed to get) on each of the target questions I had for this contact.

3. Anything else that struck me as salient, interesting, illuminating or important in this contact?
Concept of vulnerability of cancer patients

4. What new (or remaining) target questions do I have in considering the next contact?

- *Impact of ONS and access to valid standards & guidelines for practice*
- *Influence of the nurse being a cancer survivor - nurse-survivor population. "I'm a cancer survivor, so I know… there's a special form of empathy*
- *Idea of <u>real</u> oncology nurse is the one who is an advocate*
- *My own spiritual philosophy - "what I do with patients is a ministry"*
- *Idea of reciprocity*

APPENDIX H: Summary of Codebook Progression

Early in the analysis of the data, the emerging themes were linked to the research questions to create Codebook 1. (Appendix I) Informants' references to their definitions of advocacy were grouped into the category relating to the first research question and labeled *Description of Advocacy.* References to thought processes and procedures informants use when considering and planning advocacy actions were grouped into the category linked to research question 2, labeled *Social and Cognitive Processes.* Mention of actions the respondents' considered to be consistent with advocacy were included in the category linked to the third research question and labeled *Operationalization.* References to values or outcomes associated with respondents' advocacy efforts were placed in the category linked to research question four, labeled *Client-Focused Outcomes.*

With additional data collection and constant comparison processes, categories included in Codebook 2 (Appendix J) were labeled with the intent of capturing new and more intricate data. For example, subcategories in *Description of Advocacy* in Codebook 1 expanded from six to ten in Codebook 2, and related to informants' more conceptual definitions of advocacy – categorized as *What is advocacy?* The category *Social and Cognitive Processes* in Codebook 1 with seven identified sub-categories increased in abstraction with thirteen sub-categories within the focal content area and was re-labeled as *Thoughts and Procedures* in Codebook 2.

The content area *Operationalization* in Codebook 1 included twelve sub-categories, but through ongoing analytic processes, were expanded to the fifteen sub-categories in focal content labeled nurse *Behaviors* in Codebook 2. Emerging behavioral sub-categories that warranted designation of the new label included nurses' professional organizational involvement, nurses' self-confidence, and high levels of practice autonomy.

In Codebook 1, the content area *Client-focused Outcomes* included four sub-categories, citing feedback provided by clients, measurable contributions to health care delivery and cost-effectiveness, and nurses' acknowledgement that they had indeed made a difference. As data collection and analyses proceeded, informants made it clear that patients/clients were perceived to benefit from nurses' advocacy on their behalf. Importantly, informants perceived that nurses and health care delivery systems could also benefit from nurses' successful advocacy. Hence, the category was re-labeled "Outcomes/Value" in Codebook 2 to indicate a higher level of abstraction relating to the impact of nurses' advocacy.

As data collection and constant comparison processes continued to the point of theoretical saturation, described by Strauss and Corbin (1998) as the point in coding when no new information is seen in the data , clusters of like data were collapsed into five abstract categories of meaning. These five categories are: 1) *The meaning of advocacy* to a select sample of oncology nurses; 2) *Nurses' ways of being* that help them fulfill the advocacy component of their practice; 3) *Nurses' ways of knowing* clients'

needs and determining subsequent advocacy goals; 4) *Nurses' ways of doing* that includes

the behaviors and actions that comprise advocacy; and 5) The *value of nurses' advocacy*

as perceived by informants in this study.

Codebook I: Conceptual Categories Relating to the Research Questions

RQ#1: How is advocacy described by nurses working in clinical practice settings?

A. Description of advocacy

A1 - Voice of patient

Data examples:

- You needed to be their voice when they did want to have a voice, or they were afraid to have one (#01: 427-428)
- …assisting the patients in finding their voice, so that their voice is heard in the bigger picture (#02: 12-13)
- I will tell the patient, 'if you want, I can speak on your behalf' (#02:110-111)
- We need to tell your patient's story (#03:47-48)
- … advocacy is really giving a voice to people (#04: 12-13)
- Oncology nurses have to take a stand…in the community and also…in those places where there's not a voice for patients… and we have to speak for patients. (#05: 23-28)

A2 - Informed decision-making (Vs informed consent)

Data examples:

- …we have to make sure that they've [patients] gotten information, good information, about their diagnosis so that they can make informed consent and that they know there are different options out there. (#05: 10-13)…
- [giving information about managing the side effects of their treatment…] [Patient says: I guess I'm supposed to nauseated so they never bring it up.] I always say, "we've got a lot of weapons in our arsenal, there's different things that we can try." (#02: 65-68)
- So, I go back to the docs and say, "You know, you didn't get informed consent for this chemo… you didn't tell him about all of the side effects." (#03:263-265)

A3 - Going to bat for

Data examples:

- I learned to say to patients "now, if this is really what you want to do, I'm going to bat for you one-hundred percent." (#04:401-402)
- [it's understanding the disease process, the treatments, recognize their needs] and have an intelligent discussion with the physician and actually go to bat for the patient. (Elaine: 12-14)

- I think a caring attitude, concern, knowledge seeker, positive, positive attitude. I think any of those attributes you've gotta have in order to stand at bat for the patient and their families. (#DS: p 6)

A4 - Practice & Policy

Data examples:
- The nurse's role is to speak up and to do lobbying and to bring things to the attention of people in power. (#03: 46-47.
- [r/t the ratio law in CA] People got on the bandwagona dn said they were not going to putup with this anymore, and they,l we just harassed Sacramento so badly they told us to stop calling and e-mailing: they got the message! So we have a nursing ratio law. (#03:126-129)
- That's the level sometimes you have to go to for your patients because sometimes the system doesn't catch up with the science. And you have to be an advocate, like being right there on that front line to explain that, [dealing with insurance coverage and approval]. (#01:396-407)

A5 - Ramifications specific to cancer care

Data examples:
- In oncology, there are often times patients are too ill and you have to be the voice for them and hope they can recover to the point where they can indeed become self advocates. (#04:16-19)
- In cancer, it permeates the entire medical care system for the whole continuum of that patient's life. It's a different disease process. (#04:332-335)
- We are putting people in these decision-making situations when people are not at their best…They are choosing between, you know, clinical trials with huge ramifications, or drug therapies that their insurance may not cover, or lots of things. (#04: 438-444)
- It happens a lot in oncology, at least it has in my practice, because the patient doesn't totally understand. (#DS: p 2)
- It's really important for a nurse to be involved in a patient's life in regards to oncology because we can advocate for the patient those things that may not be identified –whether it's psychological support, whether it's family support, whether it's long term rehabilitative support – any of those things, I think that's where we play a huge role. (#JL: 32-38)
- I think that the oncology nurse, she just develops a special bond with every single patient she has. You can't put your hands on somebody in that kind of state and not do that. (#01:130-133)
- There's just so many crazy things that can happen with all of the new chemotherapy that we have, you know, to really make sure that they are getting through that. (#01:142-145)

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- I think the overlay that comes with the oncology patient is the psychological overlay. (#07:604-606)
- I think that most people aren't facing death in a lot of other entities, and I think that's where they're different. (#7:619-620)

A6 - It's part of your job, duty, your role as an oncology nurse
  Data examples:
- I think that nurses don't realize that they are really advocates – they just think that they're doing their job. (D: 400-402)
- It's our responsibility. (JL: 122)
- It's inherent in what we do. I always just looked at it like, it's partly what I do, but I just take it on as something that I want to do. (KB: 524-529)
- It's your job to advocate for the patient within the broader perspective of the health care team. (#03: 12-14)

Reference to a definition of what advocacy is to the nurse

RQ # 2: What are the social and cognitive processes used by oncology nurses' when deciding to advocate?

B. Cognitive processes of advocacy behaviors - Ways of knowing
  B1 - Needs assessment - "I ask them"
    Data examples:
- I ask them. And I bring up issues that, I mean, we see trends. (#03:314-321)
- I ask them. I think a lot of times, patients don't say because no one asks. I ask them, you know, are your needs being met? Is there anything in particular that you have questions about. And boy, I usually get a slew of questions after that, and they are just glad that somebody finally asked. (#01:51-58)

  B2 - Compare needs with knowledge of the disease process & treatment
    Data examples:
- I kind of look to the basic assessment to kind of give me little hints as to where I might need to go, and then, if nothing pops up, then you kind of go to the next level and actually elicit those questions. I kind of let them try to surface first on their own, because I think it puts the patient in a more comfortable position to help." (#01: 219-226)

  B3 - Consideration of ramifications if I do or don't advocate
    Data examples:
- One of my patients – 26 years old, Ewings Sarcoma, no insurance…we waited six weeks to get approval from Medicaid for a PET Scan. Did

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that hasten his death? I don't know, but it sure didn't help his prognosis to have to wait that long to find out whether he was truly in remission at the end of his treatment. So, I think that story needs to be told. (#03:49-54)

- Now, we put so much emphasis on the patient being able to make decisions – it's huge for patients now, it's huge. Patients will say to you – "I don't know what to do." It'd be like me trying to deal with some complicated IRS form. (#04:427-430)
- It's a continual reminder of sensitivity and your own values involved in patients, and owning your own, knowing who you are, and yet, patients really need your strength sometimes, your expertise. (#04:484-488)
- I could tell that [the patient] didn't really have all the information that she needed. And she was lost. (#06:127-129)
- We are the people that are seeing those patients, or talking to those patients more than anybody else. We assess their needs more than anybody else. And, if we don't let them know that they have a voice, they suffer needlessly. (#02:530-533)

B4 - Listening/hearing – sensitivity
    Data examples:
- I think our role in being experts in what we are doing develops trust with the patient. If they are confident that we, when we are doing such technical things to them, giving them agents that are potentially very, very harmful for them – understanding how they work, understanding what it's going to do to them. Taking our knowledge of working with other patients that have been through similar experiences to help them. I think it's being present and letting them know that you understand what you're doing, and that you are confident in what you're doing – to kind of ease that fear. (#01: 284-296)
- It's a combination of assessment skills and listening. Assessment skills such as, um, some of this is just second nature.. (#RvG: 133-135)
- I think the biggest tool is just listening. Listening to the, seeing what they need, listening to what their anxieties are. (#06: 168-169)

B5 - Care not to cross the line to paternalism
    Data examples:
- There's a delicate balance of nurses helping patients achieve their voice, at times recognizing that sometimes, you have to be the vice for them. Advocacy to me, isn't always that the patient has this, you know, they're cured, but rather that they have a realistic sense of what's achievable. Advocacy is helping them understand. (#04:770-779)
- The medical care system and nursing care system, is, um, set up to be paternalistic, you know, it's set up to be like "Doctors – and "I am God, so to speak, and I'll make the decisions for you." (#04: 758-761)

- That's a very fine line. I think that when you're talking about treatment options, I think it's harder. When you're talking about symptoms, I don't think the patient knows, and I think, encouraging the patient "you've got to tell the physician that you're throwing up 20 times after treatment or we can't do anything about it" is different from the breast cancer patient I talked about [with decisions around treatment options]. There's a fine line there. And I think it depends on what the situation is as to whether you are putting words into their mouth. (#06:277-287)
- I think in some ways, what might be perceived as paternalism is actually good care, in the sense that patients need us to be strong with them, for them. (#04:650-653)

B6 - Taking time to know the patient
   Data examples:
- I just take the time to do it. No matter how busy I am in the infusion room, I always sit down with my patients before I start their chemo and ask them questions and make sure they don't have any questions. I check in with them frequently.. probably to the annoyance of my co-workers that I'm a little bit slower in what I'm doing, but I don't want my patients to feel like I'm rushing through. I don't think I'm inefficient, but I think I'm a little bit more caring, I guess. I just take the time necessary to check in with them and make sure that their needs are being met. (#02:255-267)
- I know what it feels like to be in that bed, and to be in that whole new world and not know what's going on. (#03:325-327)
- I just look at them as a person, I think that's the difference. I want them to tell me about themselves. What are you feeling right now? Are you scared? What kinds of questions do you have? And another big thing that I do with patients, I sit down. … I'll pull out a chair and we talk first, before I do a physical assessment. (#03:419-426)
- You can't work on patients' needs or behalf really unless you determine from them what they feel that they need. (#04:67-69) My bias is that, even if it's the most off the wall thing, even if it's they, well, not off the wall, but what is important to them. In Montana, it may be who's gonna take care of their farm. That's not necessarily a nursing need, but I don't think you can peel through those layers until you can figure out what the patient perceives their needs to be. If you don't meet that, you don't get very far, because that's obviously what's in the way of their healing. And it's their life. (#04:73-83)

B7 - Recognition of patient as vulnerable
   Data examples:

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- They are entering a whole new world that is totally alien to them and they don't even know what to ask, they don't know what to expect. (#03:313-315)
- Sometimes they're too sick and you have to anticipate their needs. (#04: 31-32)
- We are putting people in these decision-making situations when they are not at their best. (#04:438-440)
- I just got outraged about this. (#03:91)

References to what thought processes and procedures the nurse uses when considering and planning advocacy actions

RQ:3: How is advocacy operationalized by nurses?

C. Descriptions of nurse behaviors consistent with advocacy
    C1 - Knowing how to use/manipulate the system
        Data examples:
- I'm pretty good about the usual "I was wondering if we should try…" or "the last time I looked at the literature, I waw that they were doing this, what do you think about that?" and trying to make it more the physicians' idea than my idea since they are the ones that are ultimately going to be carrying out the plan. (#06:145-152)
- It took me a couple weeks to finally get that seed planted, but I think it is a planting of the seed process. (#06: 157-159)
- If there's some dialogue going on, I try to get on the committee, or suggest that at least a nurse be there. I've been known to call a lot of secretaries and just have my name appear on a list and get there. I write a fair number of letters. (#05:239-242)
- I was lucky because my brother was in the newspaper business. So, I kind of know a little bit about who to contact at the newspaper, and I know the media.(#03:70-73)
    C2 - Expertise & knowledge built over time (novice to expert)
        Data examples:
- I ask… "how are you coping with your disease?" That never gets asked… So, I don't know, someone's gotta do it and I'm pretty good at it. (#02:135-136)
- In the course of time, I've begun to realize that if you listen, patients will tell you what they need. Sometimes they're too sick and you have to anticipate their needs. (#04:29-32)
- I know for me, growing into a seasoned oncology nurse, it's recognizing… I think many years ago, I fostered dependency of patients upon me and now, I don't want to do that any more. (#04:37-41)

- I don't know if I would have known or have had as much knowledge as I do about which treatments are available. I think that makes a big difference too. There's just so much more that patients can do now. I don't know if I would have been as forceful. (#06:312-316)

C3 - Sensitivity to your own values
    Data examples:
    - [in re to paternalism] – it's a continual reminder of sensitivity and your own values involved in patients, knowing who you are, and yet, patients really need your strength sometimes, your expertise. (#04:484-488)
    - I think you have to process, especially for younger nurses, you have to process how you feel about things, and where you come from to effectively help people get through what they need. (#01:324-328)
    - But you have to understand where you're coming from, and what your belief system is and where your buttons are. I think you have to know that before you can effectively move somebody out of that area that you might be uncomfortable with. (#01:334-343)

C4 - Collegial respect
    Data examples:
    - So often, the physician may be unable to present to the patient on a level that the patient understands. And I think nurses are better capable of doing that. So often, physicians are caught up in other things, especially in a community setting with all the regulations going on with Medicare. So often, they're looking at options of what drugs they can obtain at a better price for the patient, and maybe not actually looking at everything that a patient needs. Sometimes, facilitating the patient to look at other options and give them available information, or even going for a second opinion. I don't think that jeopardizes what the nurses do, I think it just can be done in a manner that is not jeopardizing the physician's role but enhancing what the patient's ultimate decision's gonna be. (#06:54-68)

C5 - Being a team member
    Data examples:
    - The worst case scenario is that you could possibly loose your job. But I think in the long run, most medical professionals are there for the benefit of the patient and I think that we are all working together for the best for the patient, so I think that the risks outweigh the ultimate outcome of benefiting the patient. (#06:82-87)
    - I give people the perception that, A., we're a team, and you are an important part of the team as a patient. I always remember that and pass it on to patients that they are an important part of the team. (#03:334-340)

C6 - Knowing & weighing risks and benefits (pick the battles)
    Data examples:

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- I think I piss a lot of doctors off. What I did [in my community] was very avant, so to speak. I wasn't just a nurse in an office giving chemotherapy – not that I'm minimizing that role, it's just that I took it a step higher in advocating for patients and letting them see a place where they could be. (#03:209-215)
- There's lots of risks involved, because it's not the traditional nursing role. (#03:234-235)
- A physician said to me "How do you empower the patient without disempowering the physician?" And I thought that was an incredibly provocative question in the sense that I don't look at it as a power struggle; I look at it as balancing and the more power you give to the patient, the more empowering you are as a health care provider. (#03:284-290)
- I think you have to pick your battles. I'm one of those people who likes to take the battles that nobody else is fighting. (#05:69-71)

C7 - Comfort with difficult topics
  Data examples:
  - [the doctor said he wasn't good at talking to patients about end-of-life issues]… and I said – "Well, I am, so let me." I just got to a point where I was so frustrated that I felt I had to do something about it. (#02:195-199)

C8 - Taking time
  Data examples:
  -

C9 - Recognition of oncology patients' "special" or "unique" needs & situation
  Data examples:
  - They are entering a whole new world that is totally alien to them and they don't even know what to ask, they don't know what to expect. (#03: ____)
  -

C10 - Nurse's presence
  Data examples:
  - I try to teach the new grads and nurses who are new to our floor that it makes a difference whether you're standing by the door waiting to leave… see how fast you can get out of the room… or if you're sitting down next to the bed talking to somebody so they feel that you are really there for them. (#03:441-445)
  - I try to look at patients' faces in a code situation, and recognize when they're scared, and touch them and talk to them, and let them know,

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"We're trying to get this under control – We're gonna be here with you." (#03:457-460)

C11 - Development of nurse-patient relationship
    Data examples:
- I think part of what goes into being a good advocate is setting up a good relationship with the patient. So, I think you have to find out about that patient and develop that rapport. (#01:37-39)
- I introduce myself, and say that I just want to make sure that your needs are being met. "Is there anything in particular you want to talk about?" and just kind of open it up that way. And, it's surprising… these people… you would think that I'd needed to have some sort of established relationship, for them to open up to me, but, not at all. I mean, people speak pretty freely if you ask what you can do to help. (#02:86-93)

C12 - Establish an environment of trust with the patient
    Data examples:
- I think our role in being experts in what we are doing develops trust with the patient. (#01:284-285)
- There's a certain trust: they are not going to let you advocate for them unless they trust you. So, I think that's a huge part of it is developing that first, as part of the springboard to being able to help them achieve what they need to achieve. (#01:42-46)

References to things the nurse actually does that she/he considers being consistent with advocacy

RQ #4: What are the client-focused outcomes nurses describe as being influenced by their advocacy efforts?

D. What are the client-focused outcomes nurses describe as being influenced by their advocacy efforts?
    D1 - Patient provides feedback
    Data examples:
- It's the outcome of the patient… You know, were their symptoms controlled, did they get the treatment that they needed? An, I think it really has to do with the outcome of the patient. (#06: 188-190)
- [determined by] Just by monitoring the patient and the follow-up. It's a lot easier when you're in a clinic because you are actually going to see the patient. (#06:192-194)

- It's unrealistic to do that constant follow-up by phone. I mean, you just have to trust that the patient's gonna get back with you. That is a big time constraint. (#06:216-218)

D2 - Delivery systems & U.S. health care system

Data examples:
- The medical care system and nursing care system, is set up to be paternalistic. (#04:757-759)
- The cure rates for cancers, I think, are skewed along economic lines. And I think, people who don't have insurance, they don't go to the doctors, because they are the type of people who… they need to work as many hours as they can to support their family… It's a kind of two classes of health care in this country. (#3:34-42)

D3 - Cost-effectiveness - value of advocacy actions

Data examples:
- In Amarillo, they had a person that each patient was assigned to, and no matter where they were in the system, they could call that person. It was like their liaison or whatever. And I think every single cancer patient needs that. I think there should be some studies don on it, because I believe that that actually, in effect, would really play out to require less, because you would facilitate the system and utilize the system more effectively. (#04:714-726)

D4 - Knowing I made a difference

Data examples:
- [rewards] – Knowing that the patient has found some relief. Knowing that the patient is OK with the treatment that they're about to undergo. Just seeing the outcome being so positive, I think, is so rewarding, and knowing that you had a little bitty part in it. (#06:322-327)
- It's just frustrating but motivating I guess, because it makes me feel like I'm making a difference and I can make a difference with other people and that's why I keep doing what I'm doing. (#02:426-429)
- It's in our hands, the difference between them [patients] having a good treatment and a bad treatment on a particular day, is in the hands of the nurse and they [nurses] need to accept that responsibility, and it's their responsibility. It's part of being a nurse. It's odd to me that everybody doesn't do it. (#02: 433-448)
- I would love to go in to all those [practice settings] and say "this is how you advocate for your patients", "this is the importance of it", "this is how you make a difference" and give them real life stories, because I think that's really meaningful when they see… wow, that really works." (#02:458-464)
- I see a lot of times too, that the nurses are scared of the physicians… we've got several docs who are not "Mr. Personality" and nurses are

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afraid to talk to them about what's going on with the patient because they don't want their wrath, you know. Luckily for me, I'm not scared of their wrath, so I just talk to them anyway." (#02:465-469)

- Our patients were not safe. We had a pregnant leukemic on the floor and one night shift, there was not one chemo-certified nurse working. And, what if this girl had., A., gone into labor? What if she developed DIC? Who's gonna know what to do about that? It's just totally not safe. So, you are advocating for the patient when you are advocating for having appropriate staffing on the floor. It's the same thing. (#03:135-142)
- You want to take the best care of patients that you can, and make them safe, and you want people to stop leaving nursing. I mean, that's part of it. People get frustrated and think they're powerless – they give up and walk away. If you show them that they actually can make a difference if they stay and fight, it makes a difference. (#03: 142-147)
- [I want to] make it better – make other people's experience better than mine was and than my sister's was. So, that's why I went to nursing school. (#03:382-384)
- I don't think I'm in a powerless role. And I think that if you believe that, you're not gonna get anywhere. You have to believe that you have the power, that one person has the power to make a difference. (#03:111-114)

*References to the **value** associated with nurses' advocacy efforts*

APPENDIX J: Codebook II

A. Description of advocacy
        A1 - Voice for patient
        A2 - Voice for a population
        A3 - Informed decision-making
        A4 - Going to bat for
        A5 - Practice & Policy (Broader focus than one-on-one)
        A6 - Huge ramifications (life & death) in cancer care
        A7 - It's part of your job - your role as an oncology nurse
        A8 - Level of advocacy
        A9 - Conditions necessary for
        A10 - Component of ethical practice

Reference to a definition of what advocacy is to the nurse

B. Cognitive processes of advocacy behaviors - Ways of knowing
        B1 - Needs assessment - "I ask them"
        B2 - Compare needs with knowledge of the disease process & treatment
        B3 - Consideration of ramifications if I do or don't advocate
        B4 - Listening/hearing - sensitivity
        B5 - Care not to cross the line to paternalism
        B6 - Taking time to know the patient
        B7 - Empathy
        B8 - Recognition of vulnerability
        B9 - Cognitive emotive
        B10 - Emotional-ethical barometer
        B11 - Competency in oncology nursing (skills & knowledge)
        B12 - Conditions necessary for advocacy
        B13 - Going after the issues

References to what thought processes and procedures the nurse uses when considering
        and planning advocacy actions

C. Descriptions of nurse behaviors consistent with advocacy
        C1 - Knowing how to use/manipulate the system
        C2 - Expertise & knowledge built over time
        C3 - Significance of professional organization involvement (ONS)
        C4 - Sensitivity to your own values
        C5 - Autonomy
        C6 - Collegial respect

C6 - Team member
C8 - Knowing & weighing risks and benefits (pick the battles)
C9 - Comfort with difficult topics
C10 - Taking time
C11 - Recognition of oncology patient "special" unique needs/situation
C12 - Expertise r/t benefits of ONS membership
C13 - How nurse represents the patient to others
C14 - Self-confidence
C15 - Presence

References to things the nurse actually does that she/he considers to be consistent with advocacy

D. What are the client-focused outcomes nurses describe as being influenced by their advocacy efforts?
D1 - Patient provides feedback
D2 - Delivery systems & health care system
D3 - Cost-effectiveness
D4 - Valuing
D5 - Making a positive difference in the lives of patients, families, survivors
D6 - Self-advocate - empowerment of the patient within the system
D7 - Modeling the patient's world

References to the value *associated with nurses' advocacy efforts*

APPENDIX K: Final Codebook

A. Meaning of advocacy
       A1 - Voice for patient and/population
           -   Going to bat for
           -   Practice & Policy - broader focus than one nurse, one patient
           -   Going after the issues
       A2 - It's part of your job - a component of ethical nursing practice
       A3 - Level of advocacy

What is advocacy?

B. Traits, characteristics, & conditions necessary for advocacy - what the nurse brings to
      this role
       B1 - Expertise, knowledge, wisdom relating to systems and "patient" needs
           gained through practice experience (novice to expert)
           -   Self-confidence
           -   Ability to assess risks and benefits of advocacy behaviors (pick the
               battles)
           -   Comfort with difficult topics
           -   Ability to establish/maintain presence
           -   Competency in oncology nursing (skills)
           -   Caring
           -   Practice environmental factors/work culture
       B2 - Practice autonomy and interdependence within a multidisciplinary
           environment
           -   Team member
           -   Collegial respect
       B3 - Professional commitment
           -   Significance of professional organization involvement (e.g., ONS,
               certification/credentialing)
           -   Career commitment to oncology nursing/cancer care
           -   Lifelong learner

      What's special about these nurses?

C. Ways of knowing
       C1 - Knowing the population: Needs assessment - "I ask them"
           -   Compare needs with knowledge of the disease process & treatment
           -   Consideration of ramifications if I do or don't advocate
           -   Empathy

- Listening/hearing - sensitivity
- Recognition of vulnerability among this population

C2 - Recognition of one's personal values
- Emotional-ethical barometer

C3 - Avoiding paternalism

References to thought processes the nurse uses when considering and planning advocacy actions

D. Ways of doing
D1 - Establish and maintain presence
D2 - Establish and nourish the nurse-patient relationship
D3 - Modeling the patient's world based on holistic needs assessment
D4 - Risk/Benefit analysis (personal risks to nurse Vs chances of success)
D5 - Represents patients accurately to others
D6 - Match needs to available resources (or create needed resources)

What does the nurse do? How do these nurses enact (operationalize) advocacy?

E. What is the value of these oncology nurses' advocacy efforts?
E1 - Delivery systems & health care system
- Patient satisfaction
- Cost-effectiveness
- Effects on adverse events experienced by patients
E2 - Optimize patients' levels of (or experience of?) self-determination
- Informed decision making
- Empowered Patient / Population (self-advocacy competencies)
E3 - Work/role satisfaction for nurses
- Making a positive difference in the lives of patients, families, survivors
- Valuing/being valued
- Negative impact

What is the value *associated with nurses' advocacy efforts - the "so what" of oncology nurses' advocacy?*

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SUMMARY OF DISSERTATION

There are over 40,000 American nurses currently working in the oncology specialty arena. Professional documents that support oncology nursing practice indicate that nurses are expected to advocate for patients, but fail to define advocacy practice or offer guidance for teaching and measuring advocacy, or determining its effectiveness. Most contemporary literature supports the notion of advocacy as a foundation for nursing and anecdotal reports suggest that successful advocacy is a critically important element of nurse work satisfaction and provision of quality care regardless of practice setting or specialty arena. The purpose of this grounded theory study was to delineate a grounded theory of advocacy as practiced by oncology nurses as they provide nursing care to people affected by cancer. The study is informed by healing as a central nursing construct, historical precedent, philosophical prescription, the nursing theory perspective of Modeling and Role Modeling. The sample population was purposely selected, and consisted of nineteen oncology nurse participants from varied geographic locations and practice settings, with a variety of educational and experiential characteristics. Although the purposively selected sample limits generalization of findings, data is clearly transferable and depicts complex social process that are central to oncology nursing. Findings reveal the professional and personal satisfaction derived from oncology nursing and attainment of optimal outcomes among patients or clients, family members and loved ones, and communities facing the challenges imposed by cancer. Findings provide

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direction for additional research about how best to teach, facilitate, promote,

operationalize, and codify advocacy among nurses.