

CONSUMER PERSPECTIVES OF PATIENT ADVOCACY: A GROUNDED THEORY

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## Consumer Perspectives of Patient Advocacy: A Grounded Theory

### ABSTRACT

**Background:** Patient advocacy remains conceptually ambiguous in the nursing literature. Research has been professionally dominated with few accounts of consumer beliefs and expectations of patient advocacy in the acute care hospital setting.

**Aim:** The purpose of this study was to develop a substantive-level grounded theory focused on consumer perspectives of patient advocacy in order to advance the concept in nursing towards most effectively meeting nursing's responsibility to the public.

**Method:** The grounded theory methodology of Corbin and Strauss (2008) guided the study.

**Findings:** The core concept of *Falling through the cracks of the system* indicates that aspects of care described as patient advocacy by consumers, represented by the related concepts and processes of *Being heard*, *Receiving information*, and *Participating*, are missing or lacking, and a patient advocate is needed. Consumers were aware of the interconnectedness between team functioning and the quality of care that they experienced. Notably, nurses were often perceived as too busy to be patient advocates.

**Conclusion:** The aspects of care identified by consumers as patient advocacy mirror competencies and standards of professional nursing practice. If patient advocacy in nursing is interpreted as a metaphor for these competencies, then no additional training is needed for the role. However, if patient advocacy is a unique concept for the purpose of meeting the unmet needs of patients, then the skill set differs. Care delivery models in which nurses influence interprofessional teams with nursing values, consumer needs, and evidence-based practices highlight patient advocacy as a tool for change.

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## **CHAPTER I**

### **Introduction**

Quality health care in multidisciplinary environments is associated with collaborative, team-based models (American Association of Colleges of Nursing [AACN], 2011) that focus on clarity, care coordination, transparency, and accountability across the traditional boundaries of organization, discipline, and role (Berwick, 2002). With new models of patient-centered care framed by teamwork and collaboration (AACN, 2011), the need for conceptual clarity and shared meaning, both within and across disciplines, is warranted. As participants and leaders of interprofessional health care teams (IOM, 2011), nurses have a responsibility to be clear about the meaning of concepts. One important concept that deserves attention is patient advocacy. The value of patient advocacy in delivering quality health care is widely recognized in nursing (American Nurses Association [ANA], 2001, 2010), in other health care disciplines (Institute of Medicine [IOM], 2011), and in health care organizations (Centers for Medicare and Medicaid [CMS], 2012).

### **Statement of the Problem**

Conceptual ambiguity regarding patient advocacy has persisted in the nursing literature for more than three decades. From the 1970s to 2011, nurse authors have described patient advocacy as lacking a consistent meaning (Abrams, 1978; Spence, 2011). Evidence of the confusion are descriptions that range from patient advocacy as the philosophy of nursing practice (Gadow, 1980), to an activity that has the potential to end in job loss (Mallick, 1997).

Influential factors for the formal adoption of patient advocacy in nursing include a response to the notion that nursing was comprised of tasks that could be performed by others

(Curtin, 1979; Gadow, 1980), the paradigm shift in nursing from loyalty to physicians to loyalty to patients (Woodrow, 1997), the consumer rights movement in the U.S. (Mallick, 1997), and the establishment of patient rights in hospitals (Annas & Healy, 1974). Although there is little empirical data from the consumer perspective (Jugessur & Iles, 2009), hospitalized patients are assumed to need protection of their rights to autonomy and self-determination (Hanks, 2010), to need assistance with having their needs and best interests honored (Bu & Jezewski, 2007), and to need assurance of the provision of safe, quality care (Schroeter, 2001). Actions taken by nurses to assure that these aspects of health care are met are described using both dyadic and triadic perspectives.

The dyadic perspective is based on patient advocacy as the philosophy of nursing practice (Curtin, 1979; Gadow, 1980), and is manifested by proactive interventions that empower patients to determine their care preferences and make choices that reflect their personal beliefs and values (Snowball, 1996). Patient education is described as a primary activity that supports this view (Kohnke, 1980). The perspectives of these early authors are extensively cited in the nursing literature.

A major limitation of the dyadic view is that patient advocacy is embedded in nursing practice (Foley, Minick, & Key, 2002). As such, patient advocacy has not been clearly differentiated from other concepts (Breeding & Turner, 2002), serving more as a metaphor (Woodrow, 1997) than as a unique concept. The lack of conceptual differentiation detrimentally impacts the theoretical advancement and operationalization of patient advocacy in nursing (Breeding & Turner, 2002). The triadic view of patient advocacy is reactive, and is based on the need for action involving a third party or situation that infringe upon patients' rights, needs, or best interests (Vaartio & Leino-Kilpi, 2005). This perspective reflects the

etymological origin of advocacy to defend another (Online Etymology Dictionary, 2011), which is argued to be poorly translated in health care (Grace, 2001; Woodrow, 1997).

There are major differences between the dyadic and triadic perspectives in terms of skill requirements. Dyadic patient advocacy, enacted through the nurse-patient relationship (Gadow, 1980), parallels the meaning and skills required to enact other concepts in nursing, such as caring (Sellin, 1995) and empowerment (Falk-Rafael, 1995). Triadic patient advocacy, on the other hand, is associated with skills that are not routinely taught in nursing education programs (Foley et al., 2002), such as conflict resolution and negotiation (Schlaret, 2009). As a result, the constraints and risks associated with triadic patient advocacy were found to be repeatedly documented in the literature (Chafey, Rhea, Shannon, & Spencer, 1998; Hanks, 2007; McGrath & Phillips, 2009).

Most patient advocacy research has focused on the nurse's perspective, with little attention to the consumer's view of this concept (Jugessur & Iles, 2009; Vaartio & Leino-Kilpi, 2005). While it is not appropriate for others to determine nursing practice (Crigger & Godfrey, 2010), it is important to broaden the research field with the views of the recipients of nursing care (Duffy, 2009).

### **Specific Aims**

The goal of this dissertation study was to develop a substantive-level grounded theory of patient advocacy from consumer perspectives. The specific aim of the study was to determine under what circumstances, and to what extent, consumers want or need nurses to act as their advocates when they are hospitalized. Findings of the study may benefit the theoretical advancement, practical application, and measurement of patient advocacy through the explanatory and predictive functions of grounded theory.

## **Summary**

This chapter introduced the background, significance, and purpose of a dissertation study of consumer perspectives about patient advocacy in the hospital setting. A lack of consensual meaning and a discordant theoretical basis for patient advocacy is accompanied by a prominent gap in the literature regarding consumer perspectives.

The theoretical perspectives gained from the study may 1) assist nurses in recognizing and predicting situations requiring patient advocacy, 2) enhance communication between nurses and other health care professionals, and 3) identify variables for the measurement of patient advocacy actions that improve safety, quality, and patient satisfaction with health care.

## **CHAPTER II**

### **Literature Review and Concept Analysis**

Chapter II begins with a literature review of patient advocacy in acute care nursing practice and concludes with a multidisciplinary concept analysis of patient advocacy in the acute care hospital setting.

## **Patient Advocacy in Acute Care Nursing Practice: A Literature Review**

### **ABSTRACT**

**Background.** Patient advocacy is a core tenet of nursing practice, yet there continues to be confusion about the meaning of this concept after more than 30 years of research.

**Aim.** A literature review was conducted to identify possible factors contributing to the confusion about the meaning of the nurse's role of patient advocate in the acute care setting.

**Method.** Medline, CINAHL, and The Cochrane Library were searched for articles published in English from January 1974 through June 2011. Categories were identified by analyzing similarities and differences in descriptions of patient advocacy. Thematic analysis was not attempted due to the conflicting characterizations of this concept.

**Findings.** A lack of differentiation from other concepts and a lack of attention to critiques of the patient advocacy role of nurses were identified. The majority of the patient advocacy research was qualitative and focused on nursing perceptions of patient advocacy. Quantitative studies were aimed at instrument development. Instruments to measure various aspects of patient advocacy were developed, wholly or in part, from literature described as confusing. There was a deficiency in the perspectives of patients, and of other health care providers who may also subscribe to patient advocacy..

**Conclusion.** Differentiating patient advocacy from other concepts commonly associated with patient care, analyzing and responding to opposing views about the meaning of patient advocacy, and exploring consumer and interdisciplinary perspectives may be useful in moving towards conceptual clarity of patient advocacy in acute care nursing practice.

Key words: nursing, patient, client, advocacy, hospital, acute care, research

## **Patient Advocacy in Acute Care Nursing Practice: A Literature Review**

### **Introduction**

Patient advocacy is a core principle in American nursing practice (American Nurses Association, 2001) and in the nursing practice of other countries, including Australia (Seal, 2007), Britain (McGrath & Phillips, 2009), Canada (MacDonald, 2006), Finland (Vaartio, Leino-Kilpi, Suominen, & Puukka, 2009a), Iran (Negarandeh, Oskouie, Ahmadi, & Nikraves, 2008), Ireland (O'Connor & Kelly, 2005), Japan (Davis, Konishi, & Tashiro, 2003), Korea (Lee, Lee, Kong, Kim, & 2009), Sweden (Segensten, 1993), and Turkey (Altun & Ersoy, 2003). Although the nurse's role as patient advocate has been studied for more than 30 years, ambiguity about the meaning of this concept persists (Abrams, 1978; Mallick, 1997; O'Connor & Kelly, 2005; Spence, 2011; Ware, Bruckenthal, Davis, & O'Conner-Von, 2011).

In two literature reviews, authors concluded that patient advocacy was not adequately defined, effectively operationalized, or informed by the recipients of nursing care (Jugessur & Iles, 2009; Vaartio & Leino-Kilpi, 2005). Authors have also noted that patient advocacy, a concept borrowed from the legal profession, has not been optimally translated into nursing practice (Grace, 2001; Mallick, 1997; Winslow, 1984; Woodrow, 1997). Diverse definitions of patient advocacy range from serving as the philosophy of nursing practice (Curtin, 1979; Gadow, 1980), to resulting in job loss (Mallick, 1997) or litigation (Cavico, 1995). The aim of this literature review is to discover possible factors that have contributed to the conceptual ambiguity associated with patient advocacy in nursing.

## **Methods**

The MedLine, Cumulative Index of Nursing and Allied Health Literature (CINAHL), and The Cochrane Library electronic databases were accessed using the key words *nursing*, *patient*, *client*, *advocacy*, *hospital*, *acute care*, and *research*. Since 11,167 articles were located, the search was limited to key words in the title or abstract. The search was completed in August of 2011, and includes theoretical papers and empirical evidence published since 1974, written in English, and pertaining to the nurse's role of patient advocate in the acute care hospital setting. A secondary literature search was done by examining the reference lists of key articles. Abstracts were reviewed to determine if articles met the inclusion criteria. The sample for this review is 99, which includes 33 qualitative studies, ten quantitative studies, eight mixed method studies, and 48 narrative articles.

Selected articles were read in their entirety. Categories were derived from the data using a systematic process of identifying and analyzing differences and similarities of the definitions, empirical referents, and contexts of patient advocacy. Thematic analysis was not attempted due to the conflicting characterizations of this concept. The following categories were identified: 1) Historical influences, 2) Role formalization, 3) Dyadic and triadic perspectives, 4) Protection of patient rights, 5) Research type and quality, 6) Differentiation from other concepts, and 7) Facilitators and barriers.

## **Findings**

### **Historical Influences**

Supporting patient experiences as the primary focus of nursing practice was reflected in the paradigm shift from loyalty to physicians to loyalty to patients (Winslow, 1984). Catalysts supporting this shift included a landmark court decision and the consumer rights

movement in the U.S. The legal case of Somera in 1929 is believed to have instigated the shift in nursing practice from loyalty to physicians to loyalty and advocacy for patients (DeWolf-Bosek & Savage, 2007). Winslow (1984) provides an account of the case of Lorenza Somera, a newly graduated nursing student who was found guilty of manslaughter. A physician had mistakenly called for cocaine instead of procaine during a tonsillectomy, and Somera verified the order. The physician administered the fatal injection and was acquitted, but Somera was found guilty because she failed to question the order. Although Somera was eventually pardoned, the case highlighted that nurses could “never again be taught to simply follow doctor’s orders” (p. 34).

Influenced by the consumer rights movement of the 1960s, the National Welfare Rights Organization identified 26 patient rights in 1970, followed by acceptance of some of those rights by the Joint Commission on Accreditation of Hospitals that same year, and by the American Hospital Association in 1973 (Faden & Beauchamp, 1986). Concerned that hospitals provided few mechanisms to safeguard patient rights, Annas & Healy (1974) recommended the development of a “patient advocate” role (p. 25). A person who was independent of the health care organization was considered the best choice in order to minimize potential conflicts of interests. Annas (1974) later recommended that given their medical knowledge and continuous management of patients, nurses with additional training in such topics as law and psychology would be suitable for the patient advocate role. Nurses embraced the patient advocate role as an ideal of nursing practice, and not as a separate professional role (Grace, 2001).

## **Role Formalization**

Various editions of the American Nurses Association (ANA) *Code of Ethics for Nurses* and the International Council of Nurses (ICN) *Code of Ethics for Nurses* were the most frequently cited sources of the nurse's duty to advocate for patients. Loyalty to patients was inferred in the 1950 version of the ANA *Code of Ethics for Nurses* by the mandate that "Incompetency or unethical conduct of associates in the health profession should be exposed, but only to the proper authority" (Pence & Cantrell, 1990, p. 6). The ANA Committee on Ethical Standards (1953) condemned this attempt as not strong enough, recommending that "the patient first" be the nurse's slogan in recognition of the "sacredness of patients' rights" (p. 6).

The most recent revision of the ANA *Code of Ethics for Nurses* (2001) establishes a direct mandate for patient advocacy in stating that, "The nurse promotes, advocates for, and strives to protect the health, safety, and rights of the patient" (Provision 3). The most explicit referral to patient advocacy in the Code states that, "Nurses must advocate for patients in cases of incompetent, unethical, illegal, or impaired practice by healthcare practitioners, the health care system, or others that put the rights or best interests of patients in jeopardy" (Provision 3.5).

The ICN *Code of Ethics for Nurses* (2005) specifies the promotion of human rights, including confidentiality, dignity, respect, and informed consent (Element 1); professional competence (Element 2); and safeguarding against incompetent practice (Element 4). The word "advocacy" is used with the expectation that national nurse associations will "advocate for a safe and healthy environment" (p. 5). Despite the focus on advocacy in the title of the ICN (2007) publication, *Describing the nursing profession: Dynamic language for advocacy*,

the word “advocacy” was used only once as a sample verb in the category of character traits described as 1) showing self-reliance when working independently, 2) cooperating in group activities, 3) using an objective approach to problem solving, and 4) revising judgments and changing behavior in light of new evidence (p. 11).

### **Dyadic and Triadic Perspectives**

Descriptions of patient advocacy in the literature reflected both dyadic and triadic perspectives in protecting patients’ legal or human rights, needs, and/or best interests. Dyadic perspectives focused on interactions between the nurse and the patient, reflecting a proactive mode of patient advocacy geared towards meeting patients’ needs and preventing problems (Gadow, 1980; Snowball, 1996). Triadic perspectives were characterized by the inclusion of a third party or situation that posed a real or potential patient risk, representing a reactive mode of patient advocacy (Chafey, Rhea, Shannon, & Spencer, 1998; Mallick, 1997; Vaartio et al., 2009a).

### **Protection of Patient Rights**

The legal and human rights most often associated with patient advocacy were autonomy, dignity, respect, trust, (Bu & Jezewski, 2007; Hanks, 2010) and safe, quality health care (Black, 2011; Schroeter, 2001). Reasons that patients needed advocacy included vulnerability from the effects of illness (Copp, 1986; Gadow, 1980; Segensten, 1993), the complexity of health care organizations (Rushton, 1995; Thacker, 2008), and the incompetent practices of others (Beyea, 2005; Schroeter, 2000). Authors pointed out that these antecedents have not been validated by research (Vaartio et al., 2009a) and that it is not clear what patients expect from nurses concerning patient advocacy (Bernal, 1992; Hamric, 2000; Jugessur & Iles, 2009; O’Conner & Kelly, 2005; Winslow, 1984; Woodrow, 1997). From a

different perspective, patient advocacy defined as protection against incompetent practice elicited a critique from Bird (1994), who argued that “this duty exists quite independently of any notion of advocacy” (p. 154).

**Autonomy.** Autonomy denotes the freedom to make independent choices about one’s life (Burkhardt & Nathaniel, 2008). In the U.S., the Patient Self-Determination Act (1991) gives patients a legal right to autonomy for health care decisions, a right which is upheld by the doctrine of informed consent (ANA, 1991). Three early models of patient advocacy were premised on patients’ right to self-determination (Curtin, 1979; Gadow, 1980; Kohnke, 1980). These three models were found to be extensively cited in the nursing literature (Bu & Jezewski, 2007; Hanks, 2010a; Lee et al., 2009; Vaartio et al., 2009a; Ware et al., 2011).

A complicating factor associated with the patient advocacy role in upholding autonomy was described as the “fine line” between preserving autonomy in truly representing patients’ wishes versus paternalism in pursuing what is believed to be in patients’ best interests (Schwartz, 2002, p. 38; Zomorodi & Foley, 2009, p. 1746).

Paternalism occurs when patient preferences are denied out of concern for that patient’s well-being (Breier-Mackie, 2001). Justification for paternalism comes from the ethical principle of beneficence, meaning that one must act in ways that benefit another, and is closely related to professional duty (Burkhardt & Nathaniel, 2008).

Recommendations for balancing the principles of autonomy, beneficence, and paternalism in the patient advocacy role highlight the comprehensive consideration of each patient’s unique situation, particularly when patients are unable to speak for themselves or are incompetent (Benner, 2001; Jugessur & Iles, 2009). Potential complications in achieving this balance included that patients may have inaccurate assumptions that are unknown to the

advocate and that may influence decisions (Bird, 1994), and patients may change their minds from day or day (Woodrow, 1997). Strategies to manage these risks included knowing the patient, continually clarifying information, educating all parties involved, and discussing advocacy versus paternalism during interdisciplinary rounds (Zomorodi & Foley, 2009).

**Human rights.** A claim in the literature that nursing could one day be carried out by others motivated two nurses to recommend that nursing be defined philosophically, more specifically as patient advocacy, and not by tasks (Curtin, 1979; Gadow, 1980). Both the human advocacy model (Curtin, 1979) and the existential advocacy model (Gadow, 1980) are characterized by a focus on the moral duty of nurses to support patients' human rights. These rights include self-determination, dignity, trust, and respect, which were described as being manifested within the therapeutic nurse-patient relationship. In this relationship, nurses "assist patients to find meaning or purpose in their living or in their dying" (Curtin, 1979, p. 7) and "participate with the patient in determining the personal meaning which the experience of illness, suffering, or dying has for that individual" (Gadow, 1980, p. 87).

The perspectives of Curtin (1979) and Gadow (1980) were extensively cited in the literature, along with Kohnke's (1980) functional advocacy model. Considering the widespread popularity of these models, Curtin's (1983) subsequent critique of the "new" role of the nurse as patient advocate is salient to the problem of conceptual ambiguity when she states that:

Looking for meaning where there is none is cruel and destructive – of self, of relationships to and with others, of faith itself. I suppose I'm not much of a patient advocate because I can see no reason in patients' suffering, so there is no way I can help them find meaning in it. What comfort I gave was in providing *excellent* nursing

care and in sharing some measure of their burden. But that's not new, that's as old as nursing. (p. 9)

Curtin (1983) clearly questioned the prevailing meaning of patient advocacy, but no specific responses to her critique were found in the literature. Other authors, as well, questioned patient advocacy as the philosophical foundation of nursing practice. Breeding and Turner (2002) suggested that if patient advocacy is about moral relationships between nurses and patients, then it is ethics rather than advocacy that forms the philosophical basis of nursing practice. Mitchell and Bournes (2000) raised concerns that patient advocacy as the philosophical foundation of nursing lacks justification of why nurses and no other professionals are advocates.

Similarly, Gadow's (1980) premise that "the nurse alone, among all the health professionals, is uniquely suited for the role" (p. 80), was viewed as inappropriate and adversarial in multidisciplinary organizations where other professional disciplines also subscribe to patient advocacy (Abrams, 1978; Bernal, 1992; Bird, 1994; Day, 2006; Grace, 2001; Pagana, 1987). Schwartz (2002) questioned whether patient advocacy is necessary since "the salutary values that advocacy embodies are already a part of good professional health care" (p. 37). No responses to these critiques were found in the literature.

Allegations that nurses were seeking professional advancement by empowering themselves with protecting patients' rights surfaced in the literature (Bernal, 1992; Mallick & Rafferty, 2000). Gaylord and Grace (1995) refuted the motive of professional advancement on the basis that nursing advocacy was more than protecting patient's rights, arguing that "it is an ethic of practice that supports an individual to promote his or her well-being, as

understood by that individual” (p. 11). Given that self-determination was a legal right in the U.S. at the time, the response did little to answer the allegation.

**Safe, quality health care.** Nurses described patient advocacy as protecting the right to safe, quality health care through providing excellent nursing care (Chafey et al., 1998), maintaining professional expertise (Hellwig, Yam, & DiGuilio, 2003), facilitating changes in organizational policies (O’Conner & Kelly, 2005), coordinating care (Negarandeh et al., 2008), protecting patients from harmful practices or situations (Hanks, 2010b), and whistleblowing (Black, 2011). Protecting patients from the poor infection control practices of others was also described as patient advocacy (Beyea, 2005; Dunlap, 2007). Despite evidence that hospital acquired infection is preventable, the problem remains both costly and deadly (Cardo et al., 2010). Beyea (2005) argued that infection control is an ethical problem requiring patient advocacy because the public expects that nurses will protect them from such risks.

Whistleblowing, the disclosure of organizational practices that endanger patient safety (Wilmot, 2000), was discussed as a professional and ethical responsibility for nurses (Davis et al., 2003). The under-reporting of quality and safety problems was a common finding due to the fear, anxiety, and intimidation associated with organizational retaliation in attempting to silence nurses after reports of wrongdoing (Black, 2011; McDonald & Ahern, 2000). While in many cases limited protection exists for whistleblowers (Wilmot, 2000), recent nursing research in Nevada has resulted in legislation to protect whistleblowers (Black, 2011).

## Research

Only two studies were found that explored consumer perceptions of patient advocacy. In a qualitative study in the context of procedural pain care, patients (n = 22) described patient advocacy as “more than good care” when nurses helped to promote individual pain control preferences (Vaartio, Leino-Kilpi, Salanterä, & Suominen, 2006, p. 282). Secondly, a mixed methods study examined the preferences of women with newly diagnosed breast cancer (n = 103) for an “advocacy” model, described to “promote a better understanding of treatment options”, “increase patients’ sense of composure and involvement”, and “provide emotional support”, compared to a “conventional” model (Ambler et al., 1999, p. 447). Quantitative findings did not show significance, but qualitative data supported a preference for the advocacy model.

The majority of the patient advocacy research was qualitative (n = 33) and focused on descriptions of nurses’ perceptions of their patient advocacy role. The stated purpose for these studies was to clarify the meaning of patient advocacy. There were quantitative studies (n = 10) that focused on the development of instruments to measure patient advocacy, and mixed methods studies (n = 8) provided qualitative validation of questionnaire or survey items concerning patient advocacy. The lack of a theoretical framework for many of the studies may be a factor in the persistent confusion about the meaning of this concept. Paley (1996) argues that conceptual clarity requires theoretical commitment because the structure of theory gives concepts meaning, informs operationalization, and supplies a method for measurement. Likewise, Mitchell & Bourne (2000) pointed out that advocacy, like caring, is a concept that requires theoretical ties before its meaning can be understood. Theoretical

perspectives or the lack thereof, definitions, and the main findings of the published research on patient advocacy in the hospital setting are summarized in Table 1.

**Qualitative research.** Models that reflected both dyadic and triadic perspectives of patient advocacy were developed from qualitative research (Bu & Jezewski, 2007; Chafey et al., 1998; Snowball, 1996). Theories of patient advocacy models found in the literature are displayed in Table 2. Most qualitative studies provided details of the sample, but some literature reviews (Jugessur & Ilkes, 2009; MacDonald, 2006; Mallick, 1997) and some concept analyses lacked a sample size or time frame (Baldwin, 2003; O’Conner & Kelly, 2005). Other studies did not explain the specific methodological approach (Ambler et al., 1999; Hanks, 2005; Vaartio et al., 2006), and/or the data analysis methods were not detailed enough to replicate (Ambler et al., 1999; Hanks, 2005; Lee et al., 2009; Sorenson & Iedema, 2007). A number of studies had small sample sizes, and data saturation was not addressed (Breeding & Turner, 2002; Hanks, 2005, 2008; Lee et al., 2009; Mallick, 1998; McGrath & Walker, 1999; Negarandeh et al., 2008).

Few studies included consumer perspectives of patient advocacy. Notably, the concept of patient advocacy was not identified in a sample of studies that explored patients’ perceived care needs in hospital settings (Fagerstrom, 1998; Milburn, 1995; Schmidt, 2003), including the development of the nurse-patient relationship (Lotzkar & Bottorff, 2001).

**Quantitative research.** Most quantitative studies focused on the development of instruments to measure patient advocacy. A list of these studies is shown in Table 3. Comprehensive psychometrics were reported for some instruments (Bu & Jezewski, 2008; Hanks, 2010b; Vaartio, Leino-Kilpi, Suominen, & Puukka, 2009b), while other studies reported only reliability or internal consistency coefficients (Ambler et al., 1999; Black,

2011; Kubsch, Sternard, Hovarter, & Matzke, 2004; McDonald & Ahern, 2000; Ware et al., 2011). Some instruments had low reliability coefficients (Ambler et al., 1999; Thacker, 2008; Sellin, 1995), while no reliability statistics were reported for other instruments (Altun & Ersoy, 2003; Davis et al., 2003; Gosselin-Acomb, Schneider, Clough, & Veenstra, 2007; Millette, 1993; Monterosso et al., 2005; Seal, 2007; Spence, 1998).

Some research instruments were described as informed in part by literature reviews (Davis et al., 2003; Hanks, 2010b; Thacker, 2008; Vaartio et al., 2009b), or from concept analysis (Bu & Wu, 2008). Questions of validity can be raised with instruments developed from literature that has repeatedly characterized patient advocacy as confusing.

### **Differentiation from Other Concepts**

Descriptions of patient advocacy as an umbrella term for a variety of nursing functions were critiqued as failing to differentiate between concepts (Breeding & Turner, 2002). For example, patient advocacy characterized as enabling and supporting autonomy was noted to be blurred with empowerment (O'Conner & Kelly, 2005; Vaartio & Leino-Kilpi, 2005). Some authors perceived empowerment and patient advocacy to be analogous concepts (Altun & Ersoy, 2003; Chafey et al., 1998; Lindahl & Sandman, 1998; Sellin, 1995). Falk-Rafael (1995) maintained that empowerment and dyadic patient advocacy were synchronous concepts, suggesting empowerment as a more appropriate model for practice due to the diverse and conflicting nature of patient advocacy. Bird (1994) clarified that helping people exert control over the factors which affect their lives is empowerment, and not advocacy.

In a literature review from 1998 to 2005, Vaartio and Leino-Kilpi (2005) found that it was sometimes impossible to distinguish definitions of advocacy from definitions of

accountability, trust, dignity, or fidelity. Sellin (1995) found similarities between terms used to define advocacy and terms used to define caring. This was exemplified by the use of concepts such as protecting, supporting, facilitating, enabling, encouraging, having empathy, helping, communicating, listening, and maintaining clinical competence to describe patient advocacy.

Similarly, nurses in a study conducted by Foley et al. (2002) reported difficulty with describing patient advocacy because “it is so embedded in nursing practice that it becomes invisible” (p. 182). Penn (1994) also found patient advocacy difficult to describe because it is embedded in nursing practice, Brown (1986) proposed that nursing and advocacy are one and the same, and Penticuff (1990) described patient advocacy as the willingness and commitment to care. Other authors expressed concerns that such broad definitions devalue and make it difficult to engage in meaningful exploration of concepts (Allmark & Klarynski, 1992; Breeding & Turner, 2002; Vaartio & Leino-Kilpi, 2005).

Additionally, descriptions of patient advocacy were found to parallel descriptions of patient-centered care. For example, in a literature review of patient-centered care, Pelzang (2010) explicated the standards of practice that characterize patient-centered care. These standards were found to be similarly cited as empirical referents of patient advocacy in the nursing literature, and included giving information, developing therapeutic nurse-patient relationships, responding to patient needs and preferences, facilitating shared decision-making between patients and the multidisciplinary team, ensuring that patients’ physical and emotional needs were met, upholding the right to informed decision making and autonomy, coordinating services around the needs of patients, and showing compassion and concern.

## **Facilitators**

Effective patient advocacy was cited to depend on the personal and professional attributes of nurses and on conditions in the practice environment. Personal attributes included self-knowledge, personal values, and confidence (Chafey et al., 1998; Foley et al., 2002); empathy (Spence, 1998); trust (Monterosso et al., 2005); assertiveness (Kubsch et al., 2004); compassion (Thacker, 2008); moral agency (McGrath & Walker, 1999); interpersonal communication skills (MacDonald, 2006); and willingness (Sellin, 1995). Professional attributes included recognition of patient needs (Ware et al., 2011); team communication skills (McGrath, Holewa, & McGrath, 2006; Schlairet, 2009); higher education (Mallick, 1997); expert clinical knowledge (Hellwig et al., 2003); and knowledge of ethics (Altun & Ersoy, 2003; Seal, 2007).

In order to become aware of patient needs, knowing the patient was considered essential for patient advocacy (Chafey et al., 1998; Gadow, 1980; Snowball, 1996; McGrath & Walker, 1999). However, this was not always the case. For example, patient advocacy described as protecting patients from the poor infection control practices of others (Beyea, 2005; Dunlap, 2007) does not necessarily require knowing a patient.

A supportive work environment (Chafey et al., 1998; Mallick, 1997; Penticuff, 1990; Seal, 2007; Sellin, 1995) and physician responsiveness (Davis et al., 2003; Hellwig et al., 2003; McGrath et al., 2006) were widely cited as facilitators of patient advocacy. From a different perspective, the need for patient advocacy at all was believed to result from the failure of health care organizations to function properly (Abrams, 1978; Bird, 1994; Schwartz, 2002). McGrath and Philips (2009) and Welchman and Griener (2005) affirmed

the importance of focusing on the ethical nature of organizations, as opposed to an exclusive focus on individuals.

### **Barriers**

Many barriers to patient advocacy were identified, including an inadequate knowledge of law and ethics (Altun & Ersoy, 2003; Seal, 2007); lack of education about how to be a patient advocate (Foley et al., 2002), lack of expertise in expert communication strategies such as conflict resolution, mediation, and negotiation (Schlairet, 2009; Zusman, 1982); and the lack of nursing autonomy (Hanks, 2007; Mallick, 1997; Negarandeh, Oskouie, Ahmadi, Nikraves, & Hallberg, 2006). Notably, Bernal (1992) argued that the lack of autonomy is a reality for all health care professionals, not only for nurses. One constraint worth serious consideration was the assumption that if patients need protection from the system or from other health care professionals, it is possible that they may need protection from nurses (Woodrow, 1997).

Triadic patient advocacy was linked to potential professional problems, up to and including the loss of employment (Hewitt, 2002; Mallick, 1997). A primary reason for difficulty in enacting the patient advocacy role was cited to be the divided loyalty between nurses' obligations to multiple patients, institutions, peers, and physicians (McGrath & Phillips, 2009; Rushton, 1995). Additionally, the varying perspectives of health professionals, patients, and caregivers was implicated in making ethical decision-making difficult and stressful (Shay, 2006).

Given the reality of these risks, patient advocacy enacted as a multidisciplinary and collaborative decision-making process was recommended to ensure a comprehensive and inclusive consideration of each patient's situation (Day, 2006; Schlairet, 2009). Research by

McGrath et al. (2006) found that the multidisciplinary team was viewed by all professional groups as the key to operationalizing care that meets patients' needs. Importantly, teamwork was highlighted as having a greater potential than individual effort in changing structures that fail to meet patients' needs (Snowball, 1996; McGrath & Phillips, 2009).

### **Limitations**

Patient advocacy and social advocacy cannot be totally separated because of the strong influence that social factors have on organizations (Grace, 2001; Mahlin, 2010; Welchman & Griener, 2005). However, due to the large amount of literature focused on patient advocacy, it was necessary to limit this review to patient advocacy in the hospital setting. Although there are multiple articles concerning ethics and morality in nursing that mention patient advocacy, this review focused on data sources that explicitly identified patient advocacy as the topic of interest. Unpublished dissertations were not included, and these papers may contain helpful perspectives.

### **Discussion**

The results of this literature review confirm that patient advocacy in nursing continues to be characterized in diverse ways and remains resistant to formal definition. The review offers factors that may have contributed to this problem. Differences in nurses' experiences, the lack of theoretical frameworks in research, failure to respond to opposing views, poor differentiation among concepts, and the lack of consumer perspectives seem to have all contributed to the conceptual ambiguity of patient advocacy in nursing.

While the perspectives of practicing nurses are valuable, it is important to consider the influence of patient advocacy education that has been described as "haphazard and situationally dependent, rather than methodically taught in nursing education programs"

(Foley et al., 2002, p. 181). The repeated documentation of themes associated with nurses' patient advocacy experiences without critical evaluation of the meaning and utility of patient advocacy seems to have resulted in what Paley (2001) calls the "chain of associations and resemblances that comprise elusive concepts" (p. 196).

Dyadic models based on the nurse-patient relationship have not differentiated patient advocacy from other concepts embedded in the nurse-patient relationship. Triadic models of patient advocacy, which include a third party or situation, lack operational guidance and are associated with the potential for serious conflicts in the workplace. Despite the assumption that patients need advocates, research has focused more on health care professionals' perceptions of favorable outcomes than on what patients value (Spilsbury & Meyer, 2001).

Interpretation of the word 'advocacy' from its etymological roots and use in the legal profession requires further justification in order for the phenomenon of patient advocacy to achieve conceptual clarity. Analyzing and responding to opposing views and considering the value of the multiple perspectives inherent in multidisciplinary teams, both of which are largely missing in the literature, may offer much in terms of meeting patient needs.

Research by Propp et al. (2010) concluded that nurses occupy a central position in collaborative health care teams. The study identified ensuring quality decisions and promoting synergistic teams as important processes that nurses contribute. The single most critical contribution to patient safety has been identified as the nurse's ability to coordinate the multiple aspects of quality, both within nursing care and across the care delivered by others (Mitchell, 2008). Such findings support current initiatives for nurses to function as key members and leaders of interdisciplinary teams (Institute of Medicine, 2011), and

underscores the need to achieve conceptual clarity for concepts that contribute to meeting patient needs (Berwick, 2009).

Metaphors convey meaning by describing one thing in terms of another (Milton, 2009), which is the case when patient advocacy represents a myriad of other concepts. Becker (1993) observes that “using a metaphor is a serious theoretical exercise”, a view echoed by Nisbet (1976) and Richardson (1994) (as cited in Sandelowski, 1998, p. 378). The capacity of metaphors to focus on some aspects of reality while obscuring others (Lakoff & Johnson, 1980) is acknowledged by Wurzbach (1999), who suggests that patient advocacy as a metaphor in nursing has concealed the potential conflicts inherent in the role. Envisioning patient advocacy as a metaphor, and not as a unique concept, obscures the specialized skills needed to consistently and effectively assist patients when their legal or human rights are jeopardized. Moreover, measurement of the outcomes of nursing care requires that variables are clearly defined.

### **Conclusion**

Because there are different agendas operating in health care organizations in addition to the rights and best interests of patients (Kramer & Chinn, 2010), patient advocacy is an important concept that warrants further development. In order to achieve conceptual clarity and effective operational guidelines, it is suggested that efforts be made to 1) differentiate patient advocacy from other concepts, 2) explore consumer expectations of patient advocacy, 3) investigate the beliefs and perspectives of other health care professionals who may also subscribe to patient advocacy, and 4) engage in critical discourse regarding the implications of various perspectives of patient advocacy through the lens of changing professional roles and responsibilities within complex organizational systems.

**Table 1. Patient Advocacy Research: 1974-2011**

Title/Author/Country	Purpose	Method/Sample	Theoretical Framework	Definition	Findings
<p>Factors that influence patient advocacy by pain management nurses: Results of the American Society for Pain Management Nursing Survey. Ware, Bruckenthal, Davis, &amp; O'Connor-Von (2011) U.S.</p>	<p>1) What is the meaning of advocacy?                  2) How does advocacy relate to optimum pain management?                  3) What are educational needs &amp; barriers of advocacy in pain management?</p>	<p>Quantitative Descriptive                  American Society for Pain Management Nursing (ASPMN) Survey Instrument                  Content validity = 10 experts  <math>a = .81-.92</math>  <math>r = &gt;.45</math>    <math>n = 188</math> ASPMN members</p>	<p>Advocacy Competencies (Lewis, Arnold, House, &amp; Toporek, n.d.)                  Advocacy Domains (Ingram, 1998, unpublished)                  Pain Management Competencies (Maryland Board of Nursing, 2001)</p>	<p>Serving as pt. guardian; Confronting physicians if needed to achieve optimal pain control; Assisting pts to evaluate their pain management preferences (p. 25).</p>	<p><u>Nurses' advocacy activity:</u>                  1) Apprise of rights &amp; treatments – 57.1%                  2) Continue to advocate if needs not met – 88.5%                  3) Let pts know they are there for them – 84.9%                  4) Use evidence-based practices – 87.4%                  5) Consult w/ team members – 83.3%                  6) Inform of right to pain care – 80.8%  <u>Barriers:</u>                  Lack of time (51.3%)                  Lack of support (24.4%)                  No role model 21.8%);                  Power struggles (21.2%)</p>
<p>Tragedy into policy: A quantitative study of nurses' attitudes towards patient advocacy activities. Black (2011) U.S.</p>	<p>Describe registered nurses experiences of reporting unsafe pt care practices in the workplace</p>	<p>Quantitative Survey instrument  <math>r = .93</math> for Likert items 21-33                  Yes/No for other items    <math>n = 564</math> Nevada RNs</p>	<p>None</p>	<p>Whistleblowing is reporting unsafe pt care conditions. (p. 27)                    Study findings resulted in whistleblower protection legislation in Nevada</p>	<p>34% of respondents would not report a potentially harmful pt. situation (<math>p &lt; .01</math>)                  Reasons for not reporting:                  Workplace retaliation = 44%                  Nothing would come of reports = 38%</p>

Title/Author/Country	Purpose	Method/Sample	Theoretical Framework	Definition	Findings
<p>The medical-surgical nurse perspective of advocate role. Hanks (2010a) U.S.</p>	<p>“When I am acting as an advocate for my patients: 1) I am performing the following actions... 2) Support for my patient advocacy at my workplace can be described as: 3) I assure that I am following patient wishes by:</p>	<p>Qualitative Quantitative content analysis of theme frequencies &amp; percentages of narrative responses (Weber, 1990)  n = 325 medical surgical nurses</p>	<p>Conceptual Structural Model of Client Advocacy (Cho, 1997, unpublished); Advocacy Domains (Ingram, 1998, unpublished); Sphere of Nursing Advocacy (Hanks, 2005)</p>	<p>Providing information Providing technical care Assuring quality of care Mediating Acting on behalf of pts - Speaking on behalf of pts (p. 101)</p>	<p>Highest frequencies: <u>Advocacy actions</u> 1) Educating pts/families (32.3%) 2) Communicating w/ HC team (28.9%) 3) Questioning/ensuring adequate care (24.6%) <u>Perceived support for advocacy:</u> Positive (27%) Poor (13.8%) Fair (8%) <u>Pt. views of advocacy:</u> Communicating (39.1%) Assessing wishes (34.8%)</p>
<p>Development and testing of an instrument to measure protective nursing advocacy. Hanks (2010b) U.S.</p>	<p>Determine psychometrics of the Protective Nursing Advocacy Scale (PNAS) - 43 items CVI = 0.79 <math>a = .80</math> for PNAS <math>a = .7 - .93</math> for subscales Convergent validity (<math>p &lt; .01</math>); Principal components analysis</p>	<p>Quantitative instrument development  n = 419 medical-surgical RNs</p>	<p>Conceptual Structural Model of Client Advocacy (Cho, 1997, unpublished); Advocacy Domains (Ingram, 1998, unpublished); Sphere of Nursing Advocacy (Hanks, 2005)</p>	<p>Communicating with &amp; informing pts Protecting pts Speaking out for patients Building relationships with pts (p. 256)</p>	<p>43 item PNAS (<math>a = .80</math>) <u>Subscale 1:</u> Acting as an advocate (<math>a = .91</math>) <u>Subscale 2:</u> Work status &amp; advocacy actions (<math>a = .93</math>) <u>Subscale 3:</u> Environment &amp; education (<math>a = .70</math>) <u>Subscale 4:</u> Supports &amp; barriers (<math>a = .73</math>)</p>

Title/Author/Country	Purpose	Method/Sample	Theoretical Framework	Definition	Findings
Nursing advocacy in procedural pain care. Vaartio, Leino-Kilpi, Suominen, & Puukka (2009a) Finland	1) How is advocacy implemented from patients & nurses perspectives? 2) What are background factors? 3) Are there differences in perceptions?	Quantitative Advocacy in Procedural Pain Care (APPC) CVI = .93 – 1.0 $\alpha = .60 - .92$ Factor analysis *psychometrics in Vaartio et al., 2009b n = 405 patients n = 118 RN	Literature review (Vaartio & Leino-Kilip, 2005) Interview data (Vaartio et al., 2006)	Protecting pts' legal rights Satisfying pts' existential needs (p. 342)	Advocacy was dependent on: <u>Nurse views:</u> 1) patient interest & expression of wishes 2) nurse empowerment <u>Patient views:</u> 1) being asked about care preferences
Nurses' perceptions of informed consent and their related roles in Korea: An exploratory study. Lee, Lee, Kong, Kim, Kim (2009) Korea	Describe nurses perception of informed consent	Qualitative semi-structured interviews  n = 12 female nurses	None	Verifying that pts have received the information they need to ensure informed consent (p. 1580)	There were conflicts among pts, caregivers, physicians, & nurses with informed consent Nurses can take an advocate role as a facilitator of communication
Ethical decision-making in an emergency department. McGrath & Phillips (2009) U.K.	Explore organizational processes for responding to ethical issues in the emergency department	Qualitative Open-ended interviews  n = 7 RNs n = 4 MDs	Phenomenology	Representing consumers, respecting, informing, comforting, explaining, communicating, & maintaining professionalism (p. 16)	Nursing advocacy: 1) depended on democratic qualities of physicians 2) was not always translated into effective action 3) required support of other nurses & HC team

Title/Author/Country	Purpose	Method/Sample	Theoretical Framework	Definition	Findings
Advocacy in mental health nursing: An integrative review of the literature. Jugessur & Ilkes (2009) U.K.	Critique of nursing advocacy models & recommendations for research	No sample size No time-frame	None	There is no universal understanding of pt advocacy Nurses practice pt advocacy based on their own interpretation (p.192)	1) Advocacy models do not offer practical guidance 2) Insight into the experiences of pts is needed
Development & psychometric evaluation of the instrument: Attitude Toward Patient Advocacy. Bu & Wu (2008) U.S.	Develop an instrument to measure nurse's attitudes towards patient advocacy Attitude Toward Patient Advocacy scale (APAS) CVI = .85 Principal Axis Factoring	Quantitative Random selection of Oncology Nursing Society members  n= 200 RNs n= 2,500 RNs	Mid-range theory of patient advocacy (Bu & Jezewski, 2007) Theory of Reasoned Action (Ajzen & Fishbein, 1980)	Microsocial (individual) advocacy is: - Safeguarding pts. autonomy - Acting on behalf of patients when they are unable Macrosocial (social) advocacy is: - Championing social justice (p. 65)	Attitude toward Patient Advocacy Scale (APAS): $a = .96$ <u>Subscale 1:</u> Attitude toward Microsocial Advocacy (AMIA): $a = .92$ <u>Subscale 2:</u> Attitude toward Macrosocial Advocacy (AMAA): $a = .95$ * (p<.001)
The lived experience of nursing advocacy Hanks (2008) U.S.	Describe the experiences of nursing advocacy as practiced by RNs	Qualitative Pilot study Semi-structured interviews  n = 3 RNs	Phenomenology	Known areas of advocacy: - Teaching & education - Influencing others - Influencing factors - Consequences (p. 469)	Themes: 1) Speaking out & speaking for pts 2) Acting on unmet needs 3) Fulfillment/frustration 4) The patient is changed 5) Learned on the job

Title/Author/Country	Purpose	Method/Sample	Theoretical Framework	Definition	Findings
Nurses' advocacy behaviors in end-of-life nursing care. Thacker (2008) U.S.	Explore perceptions of advocacy in end-of-life nursing practice among novice, experienced, and expert nurses	Quantitative Comparative Descriptive Ethics Advocacy Instrument (EAI), (Wlody (1993) ( $\alpha = .374$ ) $n = 317$ )	7 Domains of Caring (Benner, 2001)	Assisting patients and families to overcome barriers impeding the care path (p. 174)	No sig. differences between groups <u>Supports:</u> Compassion, communication, education <u>Barriers:</u> Lack of communication, lack of time, physicians, families, personal fear
The meaning of patient advocacy for Iranian nurses. Negarandeh, Oskouie, Ahmadi & Nikravesh (2008) Iran	Investigate nursing experience with patient advocacy in order to help clarify the meaning of the concept	Qualitative Grounded Theory Semi-structured interviews & reflective diaries $n = 24$ (18 staff RNs, 3 head nurses, 3 supervisors)	None	There is not a universal and explicit definition for patient advocacy in nursing practice (p. 465).	Themes: Informing & educating Valuing and respecting Supporting Protecting Promoting continuity of care
Developing a mid-range theory of patient advocacy through concept analysis. Bu & Jezewski (2007) U.S.	1) Clarify & refine the concept of patient advocacy 2) Develop a mid-range theory of patient advocacy	Qualitative Concept analysis (Walker & Avant, 1995)  $n = 220$ articles 1974-2006	Human Advocacy (Curtin 1979); Existential Advocacy (Gadow, 1980); Functional Advocacy (Fowler, 1982); Social Advocacy (Fowler, 1989)	Patient advocacy lacks a consistent definition (p. 102)	<u>Microsocial level:</u> 1) Safeguarding patients' autonomy 2) Acting on behalf of patients <u>Macrosocial level:</u> 3) Championing social justice

Title/Author/Country	Purpose	Method/Sample	Theoretical Framework	Definition	Findings
Barriers to nursing advocacy: A concept analysis Hanks (2007) U.S.	Identify barriers of nursing advocacy	Qualitative Concept analysis (Walker & Avant, 2005) 1963-2005 n = 36 articles	None	Most commonly associated with protecting patients' rights (p. 173)	<u>Barriers:</u> 1) Institutional constraints 2) Lack of time 3) Threat of punishment 4) Lack of education 5) Lack of power 6) Lack of support
Nursing advocacy in North Carolina. Gosselin-Acomb, Schneider, Clough, & Veenstra, 2007 U.S.	Identify ways oncology nurses advocate for patients and the resources they use	Mixed method Semi-structured questionnaire: 20 fixed-choice & 3 open-ended questions n = 141 members of the Oncology Nursing Society	None	Supporting patients directly and indirectly as part of the nursing role (p. 1071)	<u>Advocacy issues:</u> Pharmaceuticals Transportation & housing Teaching Communicating <u>Resources:</u> awareness, referrals, self-assessment of advocacy skills
Patient advocacy and advance care planning in the acute hospital setting. Seal (2007) Australia	Explain the nurse's role of patient advocate in advance care planning	Mixed method Survey pre/post Respecting Patient Choices Program (RPCP) Pretest Control 81 Pretest Pilot - 82 Posttest Control - 69 Posttest pilot - 74 Focus Groups - 18	Respecting Patient Choices Program Advance Care Planning Processes	Promote & protect pts' well-being Facilitate a peaceful death Counsel to ensure patients make educated decisions Protect & support pts' rights (p. 30)	<u>Post RPCP intervention:</u> Ensure informed choices (84%) Uphold pts' wishes (73%) Job satisfaction (67%) <u>Pre-intervention/control groups (42-55%)</u>

Title/Author/Country	Purpose	Method/Sample	Theoretical Framework	Definition	Findings
The role of the nurse as advocate in ethically difficult care situations. McSteen & Peden-McAlpine (2006) U.S.	Identify activities of expert nurses who act as patient advocates in ethically difficult situations involving dying patients	Qualitative Unstructured interviews  n = 7 expert nurses	Hermeneutic Phenomenology	The concept of patient advocacy in nursing is broadly defined and varies from nurse to nurse. (p. 259)	In advocating for dying patients, nurses: 1) Acted as guides to access information for pts 2) Acted as liaisons by representing pts' wishes & goals to others 3) Supported pts' choices
Nursing advocacy: How is it defined by patients and nurses, what does it involve, and how is it experienced? Vaartio, Leino-Kilpi, Suominen, & Salanterä (2006) Finland	1) What is nursing advocacy? 2) How is nursing advocacy pursued? 3) How is nursing advocacy experienced?	Qualitative Inductive content analysis of interviews Procedural pain care context  n = 22 patients n = 21 nurses	None	Nursing advocacy can be expressed by voicing responsiveness. Advocacy is the right of a patient & the duty of a nurse (p. 291).	Nursing advocacy was expressed by nurses as: analyzing, counseling, responding, shielding, & whistle-blowing. Patient descriptions: more than good care, continuous care, individual care.
Nursing advocacy in an Australian multidisciplinary context: Findings on medico-centrism McGrath, Holewa, & McGrath (2006) Australia	1) Explore the ethical decision-making of health professions within an acute care medical unit 2) Develop a model for responding to ethical concerns	Qualitative Descriptive Open-ended interviews MD n = 5 nurses n = 8; allied health n = 5 patients n = 6	Phenomenology	Representing the patient to others Respecting pts' choices Giving information Communicating Providing comfort (p. 399)	<u>All groups except MD</u> : MDT necessary for pt. centered care <u>MD group</u> : MDT adds confusion to decisions <u>Patients</u> saw advocacy as an ethical issue <u>Nurse</u> advocacy role represented a means to limit medico-centrism

Title/Author/Country	Purpose	Method/Sample	Theoretical Framework	Definition	Findings
Patient advocacy: Barriers and facilitators. Negarandeh, Oskouie, Ahmadi, Nikravesh, & Hallberg (2006) Iran	Explore influencing factors of patient advocacy among Iranian nurses	Qualitative Grounded Theory Semi-structured interviews  n = 24 hospital RNs	None	No definition offered. Various perspectives in the nursing literature are presented. Advocacy is a complex, controversial, & risky component of nursing practice.	<u>Facilitators</u> : nurse-pt. relationship; pts' needs; physician as colleague; knowledge; responsibility <u>Barriers</u> : powerlessness; lack of communication, time, motivation, or support; physicians; peers
Relational ethics and advocacy in nursing: Literature review. McDonald (2006) Canada	Analyze themes from accounts of nursing experiences of advocacy	Qualitative Synthesis of qualitative studies from 1993-2005 No sample size, but 7 studies discussed	None	A lack of clarity persists about the nature of advocacy in nursing practice. The nature of relationships influences the enactment of advocacy (p. 119).	Role of the nurse as advocate requires: 1) Knowledge of relational ethics 2) Skill development in relationship building 3) Navigation of workplace culture
Bridging the gap: A study of general nurses' perceptions of patient advocacy in Ireland. O'Connor & Kelly (2005) Ireland	1) Investigate nurses' perceptions of patient advocacy 2) Investigate how nurses enact the advocacy role 2) Compare perceptions with existing literature	Qualitative Interviews: 3 focus groups: n = 20 Concept analysis (McKenna, 1997) *no sample size or time frame	None	Bridging the gap between patients and others (p. 463)	Principle role of the nurse as advocate: Acting as an intermediary between pt. and health care environment. Risks: Conflict and confrontation can be detrimental to nurses professionally & personally

Title/Author/Country	Purpose	Method/Sample	Theoretical Framework	Definition	Findings
The role of the neonatal intensive care nurse in decision-making: Advocacy, involvement in ethical decisions and communication. Monterosso et al. (2005) Australia	Research questions: 1) To what extent are nurses involved in complex ethical decisions? 2) What is patient advocacy? 3) What categories of infants are most concerning?	Mixed method 1) Modified Decisions in Caring for Sick Newborn Infants (Spence, 1998) *no psychometrics 2) Case studies  n = 61 NICU nurses	None	Acting in the best interests of the infant and family to procure the best possible outcome (p. 113) Primary role: acting on behalf of pts when they are unable to decide or speak for themselves (p. 115).	1) Nurses clearly articulated ethical problems & used clinical knowledge & experience to guide decision-making. 2) A perceived barrier was that nurse's views were not considered during ethical decision-making.
Nursing advocacy: A review of the empirical research: 1990-2003. Vaartio & Leino-Kilpi (2005) Finland	1) Develop a model of nursing advocacy 2) Develop an instrument to measure advocacy	Qualitative Literature review 1990-2003 n = 139	None	Nursing advocacy is a professional action in order to support or defend client rights, however there is a need for concept clarification (p. 713).	<u>Themes:</u> 1) Right to information 2) Right to autonomy 3) Right to safety Consumer perspectives are missing in the literature
Patient advocacy in the perioperative setting. Boyle, 2005 U.S.	1) Define patient advocacy 2) Investigate behaviors & experiences that represent patient advocacy	Qualitative  n = 33 perioperative nurses males = 4 females = 29	Phenomenology	Speaking up for someone who is unable to speak for himself or herself (p. 250)	<u>Themes:</u> 1) <u>Protection:</u> fighting for pts' rights & safe care 2) <u>Communication:</u> giving voice: speaking for pts; being a liaison 3) <u>Doing:</u> acting ethically on pts behalf 4) <u>Comforting:</u> giving pts peace of mind

Title/Author/Country	Purpose	Method/Sample	Theoretical Framework	Definition	Findings
Sphere of Nursing Advocacy model. Hanks (2005) U.S.	Develop a model to explain advocacy on behalf of a client	Qualitative Grounded Theory  n = 3 case studies	1) Florence Nightingale's concept of physical & emotional environmental manipulation to improve outcomes 2) Betty Neuman's Systems Model	1) Assist clients to discover the significance of their life processes 2) Assist clients to exercise self-determination 3) Provide information and support client's decisions (p. 75)	<u>Sphere of Nursing Advocacy Model:</u> 1) Continual protection from the external environment by a semi-permeable sphere of nursing advocacy 2) Clients are allowed to self-advocate if they are able
A holistic model of advocacy: Factors that influence its use. Kubsch, Sternard, Hovarter, & Matzke, (2004) U.S.	Examine the use of an expanded definition of advocacy	Quantitative Descriptive Correlational Surveys: n = 52 RNs 1) Advocacy Scale 2) Perceived Moral Stage Development Scale 3) Job Security Scale 4) Perceived Assertiveness Scale Content validity = 3 experts $r = .89$ Case studies: n = 40 BSN students	1) Kohlberg's (1981) Theory of Moral Stage Development 2) Holistic Model of Advocacy (HAM): 1) Moral-ethical 2) Legal 3) Political 4) Spiritual 5) Substitutive (Curtin 1979 & Fowler 1989)	<u>Legal advocacy:</u> Guard the right to competent care, informed consent, privacy & the right to reject care <u>Moral-ethical advocacy:</u> Uphold pts' values in decision-making <u>Political advocacy:</u> Facilitate equal access to health care <u>Spiritual advocacy:</u> Provide access to spiritual support and reassurance <u>Substitutive advocacy:</u> Protect interests of pts who are incapable of speaking for themselves (p. 39)	Moral-ethical advocacy used most often (surveys - $x = 2.83/5$ ; case studies 35%). Correlations: 1) Work setting & moral-ethical advocacy ( $p < .05$ ) 2) Age & moral stage development ( $p < .05$ ) 3) Level of education & perceived assertiveness ( $p < .05$ ) 4) Work setting & job security ( $p < .01$ ) 5) Moral stage development & substitutive advocacy ( $p < .01$ )

Title/Author/Country	Purpose	Method/Sample	Theoretical Framework	Definition	Findings
Patient advocacy: A concept analysis. Baldwin (2003) U.K.	Clarify the concept of patient advocacy & develop a patient advocacy model	Qualitative Eclectic method No sample size	None	Valuing a therapeutic relationship to secure pts self-determination Apprising pts of their right to be involved in decision-making Interceding to overcome barriers (p. 34)	<u>Essential Attributes:</u> 1) Valuing 2) Apprising 3) Interceding <u>Antecedents:</u> vulnerable population, willing nurse <u>Consequences:</u> positive & negative for pts & nurses
A pilot study of selected Japanese nurses' ideas on patient advocacy. Davis, Konishi, & Tashiro (2003) Japan	1) Determine the nature & extent of nursing advocacy in the Japanese nursing literature a) How do Japanese nurses understand advocacy? b) What does that understanding mean within the Japanese cultural context?	Mix Methods Phase one: Review of Japanese nursing literature on nursing advocacy 1995-2001 (n = 20) Phase two: Fixed & open-ended questionnaire based on literature review n = 24 graduate nurses and clinical teachers	None	Protecting pts' rights or benefits Speaking for pts Helping pts make decisions Protecting pts' dignity & privacy (p. 406)	Nurses have an advocacy role = 79% Nurses should have an advocacy role = 92% Only if pt wishes = 8% <u>Extent of role enactment:</u> Very often = 8% Often = 63% Seldom = 29% <u>Whistleblowing</u> (reported in Davis & Konishi, 2007) Would report incompetent practice of a nurse = 14 Would not report = 6 Would report incompetent practice of physician = 17 Would not report = 1 <u>Barrier:</u> Power imbalances among HC professionals

Title/Author/Country	Purpose	Method/Sample	Theoretical Framework	Definition	Findings
Undertaking the role of patient advocate: A longitudinal study of nursing students. Altun & Ersoy, 2003 Turkey	1) Explore tendencies of nursing students with respect to patients' rights 2) Determine changes in attitudes during nursing education	Quantitative Longitudinal study Questionnaire Start: n = 77 BSN students males = 23 females = 54 After 4 yrs: n = 55	1) Turkish Patients' Bill of Rights 2) Turkish Standards of Patient Rights 3) Turkish Nursing Professional Ethical Codes	The ideal patient advocate is a nurse who is able to empower patients to exercise their individual rights to self-determination (p. 468).	Patients have the right to self-determination: 1 <sup>st</sup> yr 81.8% 4 <sup>th</sup> yr 94.5% (p < .04)
How nurses learn advocacy. Foley, Minick, & Kee (2002) U.S.	Describe how nurses develop the skill of advocating for patients	Qualitative Interviews  n = 62 U.S. military nurses during an operation	Heideggerian Hermeneutic Phenomenology	Nurses have difficulty describing advocacy because it is so embedded in nursing practice that it becomes invisible (p. 182).	Developing advocacy practices was viewed as: 1) Haphazard 2) Situationally dependent rather than methodically taught in nursing education programs. 3) Standing up for others
Registered nurses' lived experience of advocacy within a critical care unit: A phenomenological study. Breeding & Turner (2002) Australia	Distill the essence of advocacy from the critical care nurse's perspective	Qualitative Phenomenology Open-ended interviews  n = 5 nurses	Phenomenology	Acting on behalf of a client in response to practices or decisions undertaken by other members of the health care team Giving information Maintaining privacy (p. 113)	Findings: 1) Patient advocacy as a multi-faceted process in various nursing activities 2) Participants felt it is an appropriate role for nurses. 3) The concept remains difficult to meaningfully explore.

Title/Author/Country	Purpose	Method/Sample	Theoretical Framework	Definition	Findings
Nursing advocacy during a military operation. Foley, Minick, & Kee, 2000. U.S.	Describe the advocating practices of military nurses.	Qualitative Interviews n = 43 active duty U.S. Army nurses	Heideggerian Hermeneutic Phenomenology	Experts provide no consistent definition of advocacy (p. 492).	Themes: 1) Protecting 2) Attending to the whole person 3) Being the pt's voice 4) Preserving personhood
Diffusion of the concept of patient advocacy. Mallik & Rafferty (2000) U.K.	Trace the size, growth patterns, & diffusion process of patient advocacy in nursing in the U.S. & U.K.	Qualitative Bibliometric analysis 1976-1995	McKinlay's (1981) multi-phase model for tracing the diffusion of innovations	Due to the indeterminate nature of the discussions in journal articles, no attempt was made to define the term patient advocacy (p. 399)	Patient advocacy has transitioned from a promising idea through professional endorsement and legitimization to criticism & denunciation.
Specialist nurse counselor interventions at the time of diagnosis with breast cancer: Comparing 'advocacy' with a conventional approach. Ambler, et al. (1999) U.K.	Identify the most effective method of intervening at the time of diagnosis with breast cancer. Advocacy n = 37 (pre-diagnosis interventions) Conventional n = 66 (post-diagnosis interventions)	Mixed method 2 w & 6 mo post-op Hospital Anxiety & Depression Scale $a = .3 - .76$ $r = .7 - .74$ Rotterdam Symptom Checklist $a = .71 - .94$ Interviews n = 103 patients	None	Promote a better understanding of treatment options, process & outcomes Increase sense of personal composure & involvement Provide emotional support at the time of diagnosis	ANOVA: no significant differences between groups Qualitative data supported the advocacy method. Patients benefitted by having their individual concerns specifically addressed.
Nurses' perceptions and experiences of advocacy. McGrath & Walker (1999) Australia	Identify factors involved for nurses implementing the patient advocate role	Qualitative interviews n = 5 RNs	Orlando's Nursing Process Theory (1961, 1972, 1990)	Ensuring informed consent; supporting pts' decisions; safeguarding pts' interests (p. 72).	Themes: Moral obligation, Triggers, Knowing the patient, Consequences, Difficulties, Effectiveness, & Outcomes

Title/Author/Country	Purpose	Method/Sample	Theoretical Framework	Definition	Findings
Characterizations of advocacy by practicing nurses. Chafey, Rhea, Shannon, & Spencer (1998) U.S.	Explore the characterizations, conditions, events, & values believed by nurses to influence the process of advocacy	Qualitative Open ended interviews n = 17 hospital & community nurses	None	Coordinating with the system, intervening, speaking for, listening, & empowering clients (p. 48)	Conceptual model: Influencing interactions between: <u>Client</u> <u>Nurse</u> <u>Environment</u>
Ethical Issues for Neonatal Nurses. Spence, 1998 Australia	Explore nurses involvement in ethical decision-making & the extent of their advocacy role	Mixed method Questionnaire Open-ended questions No psychometrics	None	Standing up for the best interests of the infant and family (p. 213)	1) Nurses were more involved in clinical versus ethical decision making 2) Nurses saw themselves as patient advocates (92%)
Communication breakdown or ideal speech situation: The problem of nurse advocacy. Martin (1998) U.K.	Explore how nurses can be effective advocates for patients without facing conflicts of loyalty	Qualitative Written narratives n = 20 registered nurses hospital n = 11 nursing home n = 5 hospice n = 2 community n = 2	None	Promoting & protecting the interests of pts (p. 147)	Themes: 1) Parentalism = making care decisions for pts 2) Dependency = created by institutions 3) Language = nurse & MD control knowledge  <u>Model for Change</u> Equal rights of discourse Absence of role privilege No coercion or constraint

Title/Author/Country	Purpose	Method/Sample	Theoretical Framework	Definition	Findings
Advocacy in nursing: Perceptions and attitudes of the nursing elite in the United Kingdom. Mallik (1998) U.K.	Explore perceptions & attitudes of nursing leaders in the UK regarding the patient advocate role	Qualitative Semi-structured interviews n = 6 nurses political n = 2 academic n = 2 research n = 2	Keller's (1968) classification of the elite	Meanings and models of advocacy in nursing are indeterminate (p. 1001). Triadic conflict models are being operationalized in nursing practice. (p. 1010)	1) Advocacy integral to nursing's moral values but lacks professional support systems 2) An exclusive claim to patient advocacy risks interprofessional conflicts
Advocacy in nursing: A review of the literature. Mallik (1997a) U.K.	Critical review of the literature on advocacy in nursing	Qualitative Literature review (no time frame) (no sample size)	None	Multiple interpretations have led to a lack of clarity of the nurse's role of patient advocate (p. 130).	Patient advocacy: 1) is an innovation imported from the U.S. 2) is a potentially risky role due to inadequate institutional, public, & legal support 3) remains a moral choice for each nurse
Advocacy in nursing: Perceptions of practicing nurses. Mallik (1997b) U.K.	Outline a functional model of patient advocacy for nurses practicing in the U.K.	Qualitative 7 focus groups N = 104 nurses from: mental health n = 24, learning disability n = 12 adult care n = 56 pediatrics n = 5 midwifery n = 6 other n = 1	None  *Walker & Avant's (1998) method of concept analysis as a structure for a model of patient advocacy	1) Representing patients' needs and choices from the particular 'power broker' within the advocacy situation 2) Dyadic interpretations are safe, while triadic interpretations have potential risks & require support (p. 312).	Attributes 1) Direct & indirect action 2) Upholding pt choices & defending pt rights 3) Advocacy activities: Protecting Representing Collaborating Empowering

Title/Author/Country	Purpose	Method/Sample	Theoretical Framework	Definition	Findings
An exploration of the way in which the concept of patient advocacy is perceived by registered nurses working in an acute care hospital. Watt (1997) Australia	Explore how registered nurses perceive patient advocacy	Qualitative Semi-structured interviews Grounded theory n = 8 RNs in adult acute care	None	Protection of individual rights (p. 119)	Advocacy was based on: 1) Respect for persons and human rights 2) Quality of the nurse-pt relationship Categories that emerged : 1) informing 2) supporting, 3) representing
Asking nurses about advocating for patients: Reactive and proactive accounts. Snowball (1996) U.K.	Describe nurses' understanding and experiences of patient advocacy	Qualitative Semi-structured interviews with Hermeneutic interpretation n = 15 12 females 3 males	Hermeneutic interpretation	Respecting pt rights Representing pts Protecting dignity Protecting privacy Defending from distressful interventions (p. 70)	Conceptual diagram of influences: 1) Reactive & proactive patient advocacy 2) Nurse-pt. therapeutic relationship 3) Environmental factors
Out on a limb: A qualitative study of patient advocacy in institutional nursing. Sellin (1995) U.S.	Explore definitions of patient advocacy & factors that influence patient advocacy decisions by nurses	Mixed method Semi-structured interviews n = 40 RNs, Decision-Making Inventory (Johnson et al. in Coscarelli, 1987) $a = .41$ to $.71$ Factor analysis	None	Protecting and defending a patient's best interests as defined by the patient or family Standing up for patient's rights against the system (p. 23)	Properties of the <u>Patient Advocacy Model</u> : Information gathering, educating, supporting, & protecting with two way arrows between variables Similarities were found between definitions of caring and of advocacy.

Title/Author/Country	Purpose	Method/Sample	Theoretical Framework	Definition	Findings
Moral distress, advocacy, and burnout: Theorizing the relationships. Sundin-Huard & Fahy (1995) Australia	Discover how moral distress is experienced by nurses who advocate for patients & if moral distress is related to burnout	Qualitative Unstructured interviews w/ focus group validation n = 10 critical care RNs	Interpretive Interactionism	Intervening when patients suffer unnecessarily as a result of inappropriate medical interventions (p. 8)	Unsuccessful patient advocacy was associated with: 1) Moral distress 2) Frustration & anger 3) Scapegoating 4) Burn out 5) Relocation
Patient advocacy: An important part of the daily work of the expert nurse. Segensten (1993) Sweden	Identify characteristics of patient advocacy situations for expert nurses	Qualitative Interviews n = 32 RNs	None	Upholding the maximum transfer of knowledge to clients; client participation in and freedom to implement decisions	Elements of advocacy: 1) Powerless pt 2) Problem concerning pt's own will or what is good for him or her 3) An adversary
Client advocacy and the moral orientation of nurses. Millette (1993) U.S.	Explore the context & orientation of nurses' moral choices	Mixed methods Advocacy Assessment Instrument (no psychometrics) n = 212 Moral Choice Interview (Gilligan 1981) n = 24	Gilligan's (1981) Theory of Moral Development Murphy's (1987) models of advocacy: 1) Bureaucratic 2) Physician 3) Client	Client advocacy involves acting on ethical principles, standards, and values (p. 607).	Nurses preferred: 1) Client versus Bureaucratic or Physician advocacy model 2) Caring versus justice orientation. Paradoxically, nurses who preferred Client advocacy chose actions from Bureaucratic or Physician models

Title/Author/Country	Purpose	Method/Sample	Theoretical Framework	Definition	Findings
Deciding what to do when the patient can't speak: A preliminary analysis of an ethnographic study of professional nurses in the neonatal intensive care unit. Raines (1993) U.S.	How do NICU nurses: 1) Interpret the best interests of infants, 2) View their role as patient advocate, 3) Decide what to do for infants who cannot communicate their needs.	Qualitative Ethnography Structured interview topics: work environment, patients, best interests, advocacy) n = 5 nurses from different institutions	None	Enacting the desires, needs, or best interests of another person; preserving dignity, communicating protecting, providing comfort; and minimizing futile interventions (p. 46) In caring for infants, the other person is often the parents.	Themes 1) The 'best interests' of infants was the catalyst for all nursing actions 2) 'Best interests' is different for each infant 3) Descriptions of 'best interests' reflected values & clinical knowledge 4) Practice environment was related to inconsistent meanings of pt. advocacy
Nursing autonomy and patients' rights: Development of a nursing autonomy scale. Pankratz & Pankratz (1974) U.S.	Explore how much freedom nurses see for themselves and how much freedom nurses can allow for patients	Quantitative 69-item Nursing Autonomy Scale 3 subscales: $a = .93; .81; .81$ Factor analysis n = 702 nurses in 5 different settings Moo's Work Environment Subscale (1971) (no psychometrics)	None	Taking initiative and responsibility for patients' rights. An autonomous role allows nurses to be a patient advocate (p. 212)	Nurse leaders scored highest on all 3 subscales: 1) Nursing autonomy & patient advocacy 2) Patient rights 3) Rejection of traditional role limitations (no significance values) -Highest degree was correlated with all 3 subscale -No correlations between Moo's Work Environment Scale and any of the 3 subscales
Key: Pt: patient; MDT: multidisciplinary team; CVI = content validity index; RN: registered nurse					

**Table 2. Patient Advocacy Models in Nursing**

<b>Author/year</b>	<b>Model</b>	<b>Features</b>
Curtin, 1979	Human advocacy	Dignity, respect, loving and caring for others
Gadow, 1980	Existential advocacy	Helping pts clarify values & make decisions based on these values
Kohnke, 1980	Functional advocacy	Informing and supporting decisions
Bramlett et al., 1989	Consumer-centric advocacy (based on the theoretical frameworks of King, Newman, Orem, and Rogers)	Maximum transfer of knowledge to clients; client participation in decision-making & freedom to implement decisions
Sellin, 1995	Properties of Patient Advocacy	Two-way arrows between information gathering; educating; supporting; & protecting
Snowball, 1996	Reactive and Proactive Patient Advocacy	Proactive (individual level) & reactive (organizational level) advocacy
Chafey, 1998	Conceptual model of advocacy categories & interaction arenas	3 interacting variables: 1) client, - 2) nurse, & 3) environment.
Hanks, 2005	Sphere of Nursing Advocacy	Protection from the environment by a semi-permeable sphere; clients self-advocate when able
Bu & Jezewski, 2007	Mid-range theory of patient advocacy	Microsocial: Safeguarding patients' rights; acting in patients best interests Macrosocial: Championing social justice

**Table 3. Published Instruments to Measure Patient Advocacy in Nursing**

<b>Author/year</b>	<b>Instrument</b>	<b>Variables</b>
Ware et al., 2011	American Society for Pain Management Nursing survey instrument (ASPMN) <i>a</i> = .8 - .92	Types of advocacy activities; barriers in pain management
Black, 2011	Survey instrument to measure patient advocacy <i>r</i> = .93	Whether nurses would report issues; reasons for not reporting
Hanks, 2010b	Protective Nursing Advocacy scale (PNAS) <i>a</i> = .8 PCA	Actions, environment, work status, education, supports, & barriers
Vaartio et al., 2009	Advocacy in Procedural Pain Care (APPC) <i>a</i> = .6-.92 FA	Protection of legal rights Satisfying existential needs
Bu & Wu, 2008	Attitude Toward Patient Advocacy scale (APAS) <i>a</i> = .96 PAF	Dyadic & triadic advocacy safeguarding patient rights Acting in pts best interests
Gosselin-Acomb et al., 2007	20 fixed choice & 3 open-ended questions no psychometrics	Activities & resources in advocacy for oncology patients
Seal, 2007	Respecting Patient Choices Program survey (RPCP) no psychometrics	Pre & post Respecting Patient Choices Program in Advance Care Planning
Kubsch et al., 2004	Advocacy scale Perceived moral development Job security Perceived assertiveness <i>r</i> = .89	Preferences for types of advocacy: 1) Moral-ethical, 2) Legal, 3) Political, 4) Spiritual, 5) Substitutive
Davis et al., 2003	Fixed and open-ended questions based on a literature review no psychometrics	What extent nurses believe have or should have an advocacy role
Altun & Ersoy, 2003	Longitudinal questionnaire based on the Turkish Bill of Rights no psychometrics	Focuses on the right to self-determination
Millette, 1993	Advocacy Choice Instrument no psychometrics	Choices between client, bureaucratic, or physician advocacy & caring versus justice orientation
*PCA: principal components analysis; FA: factor analysis; PAF: principal axis factoring		

## A Multidisciplinary Concept Analysis of Patient Advocacy

### ABSTRACT

**Background.** Patient advocacy in nursing practice remains conceptually ambiguous. Conceptual clarity of key concepts is necessary for effective interdisciplinary practice.

**Aim.** To clarify the concept of patient advocacy in nursing through the lens of a multidisciplinary perspective.

**Data Sources.** The electronic databases of Medline, CINAHL, The Cochrane Library, and specific disciplinary practice journals were searched for descriptions of patient advocacy for nursing, medicine, physical therapy, respiratory therapy, and social work.

**Method.** Walker and Avant's (2005) method of concept analysis.

**Findings.** Patient advocacy is often used as a metaphor and tends to parallel descriptions of other concepts. After differentiating patient advocacy as a unique concept, the defining attributes are "*taking justified action*" and "*legitimately influencing another or others*" in order to meet an unmet patient right, need, or best interest. Antecedents are patient vulnerability, practitioner awareness, caring, and organizational culture. Consequences can be positive or negative.

**Implications.** The proposed definition of patient advocacy makes the work of patient advocacy visible, acknowledges the complexity of clinical practice, and promotes the development and testing of predictive models that link patient outcomes to practice contributions.

**Keywords:** concept analysis, patient advocacy, acute care, hospital, nurses, physicians, physical therapists, respiratory therapists, social workers

# **A Multidisciplinary Concept Analysis of Patient Advocacy**

## **Introduction**

Patient advocacy is considered a central driver for all aspects of quality improvement in health care (Roper, 2008). As a foundational principle in nursing practice, patient advocacy supports the delivery of high quality nursing care (American Nurses Association [ANA], 2001, 2010). However, the concept of patient advocacy is consistently cited in nursing as lacking conceptual clarity (Spence, 2011; Ware, Bruckenthal, Davis, & O'Connor-Von, 2011). Moreover, although the nature of nursing work is unique, a variety of other health care professionals also claim the role of patient advocate (Day, 2006; Grace, 2001 Woodrow, 1997).

In multidisciplinary health care environments, high quality care is associated with collaborative, team-based models (American Association of Colleges of Nursing [AACN], 2011) that focus on clarity, care coordination, transparency, and accountability across the traditional boundaries of organization, discipline, and role (Berwick, 2009). Because concepts provide a common language for discussion (Corbin & Strauss, 2008), a multidisciplinary approach to patient care highlights the value of exploring concepts such as patient advocacy. The goal of this concept analysis is to help clarify patient advocacy in acute care nursing practice through the expanded lens of a multidisciplinary perspective.

## **Methods**

Concept analysis is a means of clarifying vague concepts and distinguishing similar concepts from one another (Walker & Avant, 2005). Although a number of methods of concept analysis exist, the strategy developed by Walker and Avant (2005) was chosen to guide this analysis. Walker and Avant (2005) acknowledge both the contextual nature of

concepts and the importance of looking beyond one's own discipline to determine uses of a concept. The method includes eight iterative steps: (1) selection of a concept, (2) determination of the aim or purpose of the analysis, (3) identification of all uses of the concept that can be discovered, (4) determination of the defining attributes, (5) construction of a model case, (6) construction of additional cases, (7) identification of antecedents and consequences, and (8) definition of empirical referents.

The published literature on patient advocacy in acute care settings from nursing, social work, medicine, physical therapy, and respiratory therapy was used for this analysis. These disciplines were chosen because they form the core of most interprofessional teams. A literature search was conducted using the electronic databases of CINAHL, Medline, and the Cochrane Library from 1972 through August 2011. The key words "patient advocacy" and "hospital" or "acute care" in the title were augmented by the addition of the separate descriptors "nurse", "physician", "social worker", "physical therapist", and "respiratory therapist". Due to the small number of articles found for medicine, social work, and particularly for physical therapy and respiratory therapy, journals for these disciplines were searched separately. Inclusion criteria were that articles must be peer-reviewed, published in English, and focused on patient advocacy in the acute care hospital setting. A secondary literature search was done by examining the reference lists of key articles. Abstracts were reviewed to determine if the article met the inclusion criteria. The sample size is 109, with 70 articles from nursing, 11 from medicine, 16 from social work, five from physical therapy, and seven from respiratory therapy.

The selected texts were read in their entirety. Accounts and characterizations of patient advocacy were organized, analyzed, and categorized based on similarities and

differences in the descriptions in order to identify empirical referents, antecedents, and consequences. The process of identifying the defining attributes of patient advocacy was facilitated by differentiating patient advocacy from other concepts, a strategy endorsed by Walker & Avant (2005).

### **Uses of the Concept**

The terms patient advocacy (Bu & Wu, 2008), client advocacy (Chafey, Rhea, Shannon, & Spencer 1998), nurse advocacy, (Hewitt, 2002), nursing advocacy (McGrath & Phillips, 2009), and physician advocacy (Pearson, 2000) were all found to refer to advocacy for individuals who receive health care in the hospital. This analysis uses the term ‘patient advocacy’ to refer to advocacy for individual patients in the acute care hospital setting.

The Merriam-Webster online dictionary (2011) defines the verb, advocacy, as “to plead in favor of”, and the noun, advocate, as “one that pleads the cause of another”. “Advocate” is cited to be a technical Roman term from the mid-14<sup>th</sup> century meaning “one whose profession is to plead cases in a court of law”, derived from the Latin term “advocatus” meaning “one called to aid; a pleader” (Online Etymology Dictionary, 2011). These definitions are consistent with the various dictionary definitions of advocacy documented in the nursing literature (Grace, 2001; Hanks, 2007; Snowball, 1996).

The translation of the legal definition of advocacy in nursing is considered to be problematic for a number of reasons. Different from the lawyer-client relationship, patients do not generally choose their nurses (Winslow, 1984), or retain their nurses to act as their advocate (Sanchez-Sweatman, 1997). As well, nurses often provide care for multiple patients (Hewitt, 2002), and nurses represent the views of other health care professionals in order to inform patients’ decision-making and bring about cooperation (Ellis, 1995).

Advocacy is associated with actions that are taken at both the individual level and the social level. At the social level, advocacy is found in health care, academia, research, and politics, encompassing such actions as educating and influencing public opinion, research, setting agendas, and lobbying (Reid, 2000). Health care advocates often generate awareness and raise funds for a specific aspect of health or disease (National Patient Advocate Foundation, 2010).

At the individual level, various health care disciplines subscribe to patient advocacy as part of their professional practice (Grace, 2001; Mallick, 1997). Kane (2004) points out that compared to social advocacy, individual advocacy is more difficult to describe and to enact when the advocate is also a service provider fulfilling a variety of other functions, as is the case for health care providers in the provision of health care.

Consumer, or independent advocacy, is a service generally provided for a fee by lay persons or independent health care professionals to ensure that patients' rights and needs are met during hospitalization (Carver & Morrison, 2005). Some hospitals employ advocates or patient representatives to help the organization meet individual patient needs (Martin & Tipton, 2007).

### **Adoption of Patient Advocacy by Discipline**

#### **Nursing**

Multiple events influenced the adoption of patient advocacy as a concept in nursing. The civil rights movement of the 1960s in the U.S. led to increased respect for individual rights, and strengthened the conceptualization of nursing as led by the patient rather than by the institution (Hewitt, 2002; Mallick & Rafferty, 2000). When the rights of hospitalized patients were formally recognized in 1973 by the American Hospital Association (AHA)

(AHA, 1998), Annas and Healy (1974) proposed that a patient advocate, independent of any institution, should protect those rights. Subsequently, Annas (1974) suggested that nurses could effectively serve as patient advocates if they had additional training in law and psychology. Nurses embraced the role of the patient advocate, although without the additional recommended training (Norrie, 1997). Today, the *ANA Code of Ethics for Nurses* (2001) mandates that the nurse “promotes, advocates for, and strives to protect the health, safety, and rights of the patient” (Provision 3).

Winslow (1984) reported that nurses were not satisfied with the military ethic of loyalty and obedience to higher authorities, and that the language of advocacy was a way to express the importance of patients’ needs and the growing responsibility of nurses to meet these needs. Additionally, during this time suggestions that nursing could be performed by others motivated both Curtin (1979) and Gadow (1980) to propose that nursing should be defined by a philosophy, specifically one of patient advocacy, and not by tasks.

A variety of patient advocacy models were found for nursing, but none were found for any of the other disciplines reviewed. The human advocacy model (Curtin, 1979), the existential model of advocacy (Gadow, 1980), and the functional model of advocacy (Kohnke, 1980) are extensively cited throughout the nursing literature on patient advocacy. Table 2 describes the patient advocacy models found in the nursing literature, and Table 3 lists instruments to measure patient advocacy in nursing. No models or measurement instruments were found for any of the other disciplines reviewed.

## **Medicine**

Patient advocacy is cited to govern the patient-physician relationship in the practice of medicine (Li, 1998). Dating back 3,500 years to the era of Hippocrates in ancient Greece,

Li (1998) explains that advocacy comes from the word “parakletos” which means “one who stands alongside to help or support someone in need or in trouble” (p. 1022). The *American Medical Association Code of Medical Ethics* (2001) gives physicians an ethical obligation to place patients’ best interests above their own self-interests or obligations to other groups, and to advocate for patients’ welfare (Opinion 10.015).

Paternalism, or making decisions for another (Burkhardt & Nathaniel, 2008), is described as stemming from a biomedical model of illness that highlights physician expertise in formulating a diagnosis of the underlying pathology of the patient’s illness (Hellin, 2002). Within this model of care, doctors make decisions on behalf of their patients (Kaba & Sooriakumaran, 2007). During the last two decades, the importance of patient rights and consumer choice has led to a more patient-centered approach that is characterized by greater patient control, reduced physician dominance, and mutual participation (Mead & Bower, 2000). Issues related to third-party payers was found to predominate advocacy discussions in medicine.

### **Social Work**

Sosin & Caulum (1983) maintained that patient advocacy is the activity that distinguishes social work from other helping professions. Netting (1990) expressed that social workers must constantly maintain an advocacy stance, and Nelson (1999) espoused that no other profession in the hospital places such a strong emphasis on the advocacy role. Explicit use of the term advocacy found in the *National Association of Social Workers Code of Ethics* (2008) states that social workers will “advocate for resource allocation procedures that are open and fair” (3.07) and will “advocate for living conditions conducive to the

fulfillment of human needs, and should promote social, economic, politically, and cultural values and institutions that are compatible with the realization of social justice” (6.01).

The hospital cost-containment strategies of the 1990s resulted in a shift of social work responsibilities to those with other areas of expertise (Berger, Robbins, Lewis, Mizrahi, & Fleitt, 2003). Competition between nurses and social workers for roles in addressing psychosocial outcomes and the discharge planning needs of patients was reported to be an increasing reality due to continued hospital restructuring efforts (Judd & Sheffield, 2010).

### **Physical Therapy**

Early physical therapy practice in the United States is cited to have evolved from the needs of the public during the poliomyelitis epidemic of the 1800’s through the 1950’s, and from the physical injury and disability sustained by those involved in numerous wars (Moffat, 2003). The role of the physical therapist progressed from reconstruction aides to the current role of the physical therapist as an independent professional practitioner (Moffat, 2003).

Explicit obligations for patient advocacy were not found in the *American Physical Therapy Association Code of Ethics* (2010). Rather, the code describes adherence to principles of normative ethics, referring to moral responsibility and moral agency when discussing patients’ rights, needs, and best interests. The importance of ethics training for physical therapists was emphasized (Trizenberg (2000). Physical therapists are guided to apply ethics based on personal philosophies, beliefs, and virtues, professional training, ethical principles, contextual factors, codes of ethics, and workplace norms (Nalette, 2010). Accordingly, physical therapists discussed ethics and moral issues, with the exception of

Michaels & Billek-Sawhney (2006) who described advocating for the reduction of falls in elderly patients. Nonetheless, these behaviors were entered into the graph displayed in Figure 1.

### **Respiratory Therapy**

Beginning as workers who delivered oxygen and managed equipment, the practice of registered respiratory therapists was advanced by the support of the American Medical Association (Wyka, Mathews, & Clark, 2002). Professional overlap with nursing is cited to be a historical problem for respiratory therapy that has resulted in interdisciplinary friction (Mathews, 2001).

Respiratory therapists were described as “bedside patient care advocates” with an emphasis on clinical competency (Rees & Serna-Flood, 2010, para. 3). The *American Association of Respiratory Care Statement of Ethics and Professional Conduct* (2000) states that practitioners will uphold the personal and legal rights of patients, and will “act as an advocate in all situations involving respiratory care” (Provision 9). The patient advocacy role of respiratory therapists is viewed as distinct from, but overlapping with the patient advocacy roles held by nurses and physicians (Mathews, 2001).

### **Findings**

Descriptions of patient advocacy constitute a panacea of phenomenon in the literature from nursing, social work, medicine, and respiratory therapy. Although describing similar phenomenon, physical therapists used the terms moral agency and ethics rather than patient advocacy. Despite the abundance of literature on patient advocacy in nursing, the meaning of this concept continues to be ambiguous after more than three decades of discourse (Abrams, 1978; Hewitt, 2002; Mallick, 1997; Spence, 2011; Ware, Bruckenthal, Davis, & O’Connor-

Von, 2011). This is an alarming finding considering that nurses are increasingly being held liable for failure to advocate for patients (Cavico, 1995; Croke, 2003).

The social work literature also revealed that patient advocacy lacks a consensual meaning (Herbert & Levin, 1996; Nelson, 1999). Definitions for both social work and nursing ranged from a broad description encompassing most activities carried out in professional practice, to a narrow description borrowed from the legal profession where specific conflicts or grievances are addressed (Mallick, 1997; Nelson, 1999). Given this situation, it is not surprising that Black (2006) found similarities in the ways that nurses and social workers describe patient advocacy.

Associated with protecting patients' legal rights, needs, and best interests (Bu & Wu, 2008), patient advocacy is portrayed in dyadic (Pearson, 2000; Snowball, 1996) and triadic terms (Mallick, 1997). Dyadic activities refer to interactions between practitioner and patient, reflecting a proactive form of patient advocacy in which patients' needs are anticipated and addressed. Examples of the dyadic perspective are reflected in the seminal works of nurse authors who described patient advocacy in terms of developing the nurse-patient relationship, giving information, and supporting patient decisions (Curtin, 1979; Gadow, 1980; Kohnke, 1980). Dyadic advocacy activities paralleled terms used to describe caring (Watson, 2007) and empowerment (Falk-Rafael, 1995).

The triadic perspective includes a third party or situation that puts patients' rights, needs, or best interests at risk, representing a reactive form of patient advocacy. Examples of triadic advocacy are acting on behalf of patients (Bu & Jezewski, 2007), questioning care (Hanks, 2010a), and confronting the behaviors of others (McGrath & Phillips, 2009). Many descriptions of patient advocacy include both dyadic and triadic activities ((Boyle, 2005;

McDonald, 2006; McSteen & Peden-McAlpine, 2006; Monterosso et al., 2005; Seal, 2007; Vaartio, Leino-Kilpi, Suominen, & Puukka, 2009a).

### **Categorical Descriptions**

Descriptions of patient advocacy were determined to be accurately represented by the broad conceptual categories of 1) protection, 2) empowerment, and 3) caring. Descriptions associated with each of these categories for each discipline are quantified in Figure 1. Some authors described patient advocacy in more than one way, and thus the graphic representation includes authors in more than one category. Each author or author group, however, is counted only once per category, regardless of the number of occurrences in the respective category. Due to the large number of articles found for nursing and the smaller number of articles found for the other disciplines reviewed, the graph is most useful in showing descriptions of patient advocacy within disciplines rather than between disciplines.

#### **Protection**

The category of protection comes from patient advocacy described as protecting patients' right to autonomy and the right to safe and quality health care. Autonomy is an ethical principle in health care that refers to the right of self-determination and the capacity of a rational persons to make informed decisions and choices about issues that affect their lives (Burkhardt & Nathaniel, 2008). Whistleblowing, described as advocacy action in reporting organizational wrong-doing to an external source (Black, 2011), is associated with a large volume of literature. Therefore, whistleblowing was included in this analysis only when the authors explicitly referred to this concept as patient advocacy.

## **Empowerment**

The category of empowerment comes from patient advocacy described as teaching, educating, and supporting patient decisions, which are terms also found to describe empowerment (Falk-Rafael, 1995; O'Connor & Kelly, 2005). For example, Rodwell (1996) identified the attributes of empowerment as partnership, mutual decision-making, and the freedom to make choices. These attributes are similarly found in the dyadic descriptions of patient advocacy (Gadow, 1980; Kohnke, 1980) that are pervasive in the nursing literature. Similarly, empowerment is described by Gibson (1991) as helping patients gain control over factors that affect their lives. This view is shared by Bird (1994), who argues that helping patients gain control over factors that affect their lives is empowerment, and not patient advocacy. Falk-Rafael (1995) suggested that empowerment and existential patient advocacy are synchronous terms, but that empowerment is a more appropriate model due to the conflicting uses of the concept of patient advocacy.

## **Caring**

The category of caring comes from patient advocacy described as valuing and building therapeutic relationships with patients in order to become aware of and respond to their needs and preferences. This view of patient advocacy has a philosophical basis, with nursing actions stemming from a "shared common humanity" (Curtin, 1979, p. 3) where nurses "participate with the patient in determining the personal meaning which the experience of illness, suffering, or dying is to have for that individual" (Gadow, 1980, p. 49). The rationale for this category is validated from the work of Leininger (2007) who describes caring as improving the human condition based on individual values and life patterns, and

from Watson (2007) who describes caring as responding to patients in a way that helps them find meaning in illness and suffering.

Concerns were found about the lack of distinction between caring and advocacy. Chafey et al., (1998) notes that the “lack of differentiation between relationship issues and advocacy components and processes mirrors the confusion noted in the body of literature on advocacy” (p. 50). Similarly, Hewitt (2002) comments that it is “difficult to separate humanistic advocacy from simple caring and the use of effective interpersonal skills” (p. 442). Even Curtin (1983), author of the human advocacy model, questioned the meaning of patient advocacy in concluding that creating an atmosphere in which human values can be realized is not a “new” role for nurses, it is “plain, not-so-simple, good nursing practice” (p. 123).

### **Defining Attributes**

The next step in Walker and Avant’s (2005) method is to identify the cluster of attributes that allow the broadest insight into the concept, and that differentiate the concept from other similar or related ones. Due to the many characterizations of patient advocacy that paralleled descriptions of caring and empowerment, differentiating between concepts was a crucial step in determining the unique attributes of patient advocacy.

Parallel conceptual descriptions make it difficult to see differences between concepts, and consequently to develop precise meaning. Paley (2001) argues that extending associations and resemblances of a concept without attempts at differentiation tend to result in concepts that are destined to remain “permanently elusive” (p. 196). Notably, Schwartz (2002) maintains that creating opportunities for patients to enact choices through empowerment and caring practices decrease the need for patient advocacy.

Herbert & Levin (1996) posit that patient advocacy is needed when patients encounter an unresponsive system, and Taylor & Ferszt (1998) recommend changing systems that make patient advocacy necessary. If patient advocacy is required when organizational systems fail to meet the needs of patients, the concept seems clearly associated with a different set of attributes than those attributed to other concepts involved in the delivery of patient care.

After critically analyzing the differences between these concepts, the unique attributes and definition of patient advocacy were identified as *“taking justifiable action” to “legitimately influence another or others” in order to meet the unmet rights, needs, or best interests of patients that would otherwise not be met.* A conceptual model of patient advocacy using this definition is shown in Figure 2. The definition reflects that if patient needs are met, there is no need for patient advocacy (Chafey et al., 1998; Hewitt, 2002; Schwartz, 2002). In such a model, patient advocacy is not a metaphor or umbrella term for other concepts, but is a visible process by which the unmet needs of patients can be acknowledged, addressed, and evaluated.

### **Taking Justifiable Action**

Taking action means intervening in specific situations in order to meet the unmet needs of patients (Baldwin, 2003; Nelson, 1999; Schroeter, 2000). The nature of each situation determines the particular strategy for action (MacDonald, 2006; Sellin, 1995). Unmet rights, needs, or best interests generally involve ethical decisions and require action that can be justified (Bernal, 1992). Actions are justifiable when they are based on the values and genuine well-being of a specific patient in a specific context (Husted & Husted, 2008). Context is so relevant to justifiable action that even a small difference between two situations

can result in different conclusions to guide action (Hospers, 1972, as cited in Husted & Husted, 2008).

Strategies for action are determined by practitioner characteristics that include knowledge of ethical principles (Altun & Ersoy, 2003; Nalette, 2010), moral reasoning and ethical decision-making skills (Kohnke, 1980; Mallick, 1997), personal beliefs and values (Chafey, et al., 1998), commitment to professional standards (Schroeter, 2000), confidence (Trizenberg, 2000), willingness (Vaartio, Leino-Kilpi, Salanterä & Suominen, 2006), communication skills (Schlairet, 2009), and professional competence (Li, 1998; Lindahl & Mathews, 2001; Sandman, 1998; Trizenberg, 2000).

Organizational policy, structure, and ethical culture are important considerations when planning advocacy interventions (Simmonds, 2008). Dallery (1986) warns that the professional as an autonomous moral agent, abstracted from the social structure of professional work, is “dangerous and unrealistic” (p. 70). Similarly, Bernal (1992) cautions that a claim to moral guardianship “burdens nurses with unrealistic demands and erects barriers between nurses and other health care professionals” (p. 21). A benefit of working collaboratively is that action supported by the intellectual resources of the multidisciplinary team has greater potential to challenge and change constrained healthcare environments that put the rights, needs, and best interests of patients at risk (Bernal, 1992; Day, 2006; Snowball, 1996).

Taking action to protect patients’ rights and safety can also be taken at the organizational level through ethics committee and clinical policy development (O’Connor & Kelly, 2005). In some cases, it may be necessary to take action by utilizing the organizational chain of command to effectively meet patient advocacy needs (Schlairet, 2009). If internal

methods are unsuccessful, whistleblowing is an action that may ultimately be necessary to protect patients' rights and safety (Black, 2011; McDonald & Ahern, 2000).

### **Legitimately Influencing Others**

Taking action as a patient advocate brings with it a presumed insight into patient-perceived interests (Schwartz, 20002), and may require influencing others so that they may come to better understand patients' needs (Schneider & Lister, 2000). Influencing is described as an intentional process that seeks to have an effect on the behavior of others (Day, 2006; Sullivan, 2013). In health care, influence requires legitimacy that is based on the use of law, ethical principles, professional practice standards, clinical knowledge, and context (Kagan & Chinn, 2010; Weaver, Morse, & Mitcham, 2008).

Wright and Brajtman (2011) found that nurses have the opportunity to encourage team-based reflection that is influenced by nurses' moral understanding of patients' needs and experiences. Influence that includes an appreciation of the concerns of others can provide new information, alternative perspectives, and alternative strategies to positively affect outcomes (Bernal, 1992; Day, 2006). Bringing together different perspectives, however, also brings the possibility of compromise (Croke, 2003). Winslow and Winslow (1991) maintain that compromise is compatible with moral integrity if there is 1) a sharing of moral language, 2) mutual respect on the part of those who differ, 3) acknowledgement of factual and moral complexities, and 4) recognition of the limits of compromise (p. 307).

Legitimately influencing others includes recognizing that blind loyalty to patient wishes without acknowledgment of the professional responsibility to promote health can undermine the provision of safe health care (Day, 2006; Grace, 2001; Schwartz, 2002). For example, a patient's view of what is in his or her best interest may result in the patient's

demise, or can diminish the rights or safety of others (Jugessur & Iles, 2009). Moreover, patients may be misinformed (Snow, Warner, & Zilberfein, 2008). Such outcomes conflict with the responsibility of health care providers to uphold professional standards of care and to uphold the ethical principle of beneficence, a foundational principle in bioethics that gives health care providers the duty to act in ways that benefit others (Burkhardt & Nathaniel, 2008). Influence that stems from beneficence can in some cases be viewed as paternalistic, or as acting for others (Burkhardt & Nathaniel, 2008). Clarifying the “thin line” that exists between autonomy and paternalism (Zomorodi & Foley, 2009, p. 1729) highlights the value of interprofessional collaboration in complex patient care situations.

### **Antecedents**

Antecedents are conditions that must be met occur prior to the occurrence of the concept (Walker & Avant, 2005). The antecedents for patient advocacy are vulnerability for unmet rights, needs, or best interests, awareness, caring, and organizational culture.

### **Vulnerability**

Perceived violations of patients’ dignity or rights are powerful activators for patient advocacy (Hanks, 2008; MacDonald, 2006; Thacker, 2008). Patient vulnerability arises from such causes as the impact of illness (Mallick, 1997; Snowball, 1996); loss of communication (Chafey et al., 1998); anxiety, insecurity, time disorientation, and altered self-image (Abrams, 1978; Lindahl and Sandman, 1998); illiteracy or language barriers (Bu & Jezewski, 2007); sedation, anesthesia, or unconsciousness (Schroeter, 2000); limited knowledge of health care (Bu & Jezewski, 2007); complexity of the health care system (Copp, 1986; MacDonald, 2006; Mallick, 1997); and impaired comprehension due to mental incapacity

(Jugessur & Iles, 2009). These situations make patients vulnerable, and can result in unmet patient needs requiring patient advocacy.

### **Awareness**

Unmet patient needs are a trigger for patient advocacy, provided that the practitioner is aware of these needs. Awareness of the need for patient advocacy depends upon characteristics of the practitioner, including moral and ethical sensitivity (Jones & Back, 1996; Weaver, Morse, & Mitcham, 2008), the ability to see and understand multiple perspectives (Bergmans et al., 2009; Day, 2006), and knowledge of ethical principles and the rights of patients (Foley, Minick, & Key, 2002; Snow et al., 2008; Trizenberg, 2000). While unmet needs often come to awareness through therapeutic patient relationships (Baldwin, 2003; Gadow, 1980; Lindahl & Sandman, 1998; Sellin, 1995), practitioners can become aware of patient needs in other ways. For example, recognizing the need to protect a patient from the inadequate infection control practices of others (Beyea, 2005; Dunlap, 2007) is an important patient advocacy activity that does not necessarily require direct patient communication.

### **Caring**

Caring as an antecedent for patient advocacy comes from the work of Benner (2001) who illustrates advocacy as one of six different qualities of power associated with caring: transformative, integrative, advocacy, healing, participative/affirmative, and problem-solving. Rather than characterizing patient advocacy as a parallel term for caring, advocacy is a unique type of caring power that is used to “remove obstacles or stand alongside and enable” when patients need someone “to run defense” (p. 212).

## **Organizational Culture**

Organizational culture exerts a strong influence on whether or not health care workers take on the patient advocacy role (Hanks, 2008; Hewitt, 2002; Kubsch, Sternard, Hovarter, & Matzke, 2004). Competing or conflicting perspectives between members of the health care team can present an overwhelming barrier to patient advocacy (Day, 2006; Grace, 2001; Gregorian, 2005), and may require balancing the needs of patients within the limitations of the system of care (Simmonds, 2008).

An organizational culture that supports patient advocacy is one that promotes collaborative relationships among practitioners (McGrath & Phillips, 2009; Nelson, 1999; O'Connor & Kelly, 2005), provides staffing ratios that allow practitioners the time to develop strategies to solve problems (Windle, Mamaril, & Fossum, 2008), and offers policies and procedures that provide guidance and support for complex patient situations and ethical dilemmas (Schlairet, 2009).

## **Consequences**

Consequences are the phenomena that result from enactment of the concept (Walker & Avant, 2005). Patient advocacy can potentially result in either positive or negative consequences for patients and practitioners. Positive consequences for patients include an improved quality of life (Baldwin, 2003; Bu & Jezewski, 2007; Lindahl & Sandman, 1998), empowerment (Falk-Rafael, 1995), and receiving safe, quality health care (Hanks, 2010; Kubsch et al., 2004; Schroeter, 2000; Windle et al., 2008; Ware et al., 2011). Personal and professional satisfaction are positive consequences for practitioners (Bu & Jezewski, 2007; Chafey et al., 1998; Rushton, 1995; Snowball, 1996).

Negative consequences for patients can occur when patient advocacy efforts are unsuccessful, and include that patients' rights, needs, or best interests are not met (Bu & Jezewski, 2007; Chafey et al., 1998; Hanks, 2010a), quality of life is decreased (Schroeter, 2000), and satisfaction with health care is compromised (Vaartio & Leino-Kilpi, 2005). Negative consequences for practitioners are marked by frustration (Hanks, 2008), disciplinary action up to and including job loss (Baldwin, 2003; Hanks, 2007; Hewitt, 2002; Mallick, 1998; Segensten, 1993), and moral distress (Hewitt, 2001; Mallick, 1998; Simmonds, 2008; Woodrow, 1997).

### **Related Concepts**

Related concepts have a connection to the concept being studied, but do not contain all of the defining attributes (Walker & Avant, 2005). For example, caring and empowerment share the attribute of "*taking justified action*" in providing appropriate interventions, but these concepts do not share the attribute of "*legitimately influencing others*" to meet patients' unmet rights, needs, or best interests in the proposed definition of patient advocacy.

### **Empirical Referents**

Empirical referents are phenomena that by their existence demonstrate the occurrence of a concept (Walker & Avant, 2005). Given the proposed definition of patient advocacy, the actions associated with patient advocacy are triadic in nature, and include challenging (Herbert, 2005; McGrath & Phillips, 2009), representing (Craig, 2007; Foley, Minick, & Key, 2000) intervening (Baldwin, 2003; Nelson, 1999), safeguarding (Bu & Jezewski, 2007), questioning (Faust, 2007; Hanks, 2010), confronting (Li, 1998; Schroeter, 2000), defending (Benner, 2001; Snowball, 1996; Sosin & Caulum, 1983), mediating (Schlairet, 2009), and influencing (Day, 2006) in order to meet patients' unmet rights, needs, or best interests.

## **Model Cases**

Two model cases are presented. The first case involves a nurse and comes from the work of Phillips and Benner (1994), while the second is a modified example from Caplan et al. (2005). One related case is also presented. Related cases have some, but not all, of the defining attributes of the concept (Walker & Avant, 2005).

### **Model case #1.**

A mother was dealing with the death of her infant when a psychiatrist came to take her to an acute crisis intervention. When the psychiatrist offered to place the child back into the crib, the nurse could see how distressed and resistant the mother was to leave her baby. The nurse looked directly and compellingly at the psychiatrist and said, "Please, she has just lost her son." The psychiatrist formulated an alternative plan.

In this case, the nurse is aware of the mother's vulnerability and unmet need. She takes justified action through verbal and nonverbal expression by influencing the psychiatrist through the conviction gained by her knowledge of the grieving process.

### **Model Case #2**

A patient with end-stage cardiac disease was experiencing severe episodes of respiratory distress. He repeatedly told the nurse and respiratory therapist that he did not want CPR or to be put on a ventilator. The nurse called the physician to report the patient's wishes, but the physician refused to change the patient's code status. When the physician came in but did not go in to see the patient, the respiratory therapist supported the nurse's request, and provided direct excerpts from his interaction with the patient, convincing the physician to at least go in and talk with the patient. The physician subsequently changed the code status.

In this situation, the respiratory therapist takes action by speaking to the physician, and exerts legitimate influence by collaborating with the nurse and by accurately and concisely relating the course of events and the patient's wishes to the physician.

### **Related Case**

One to two tablets of oral analgesia every four hours was ordered for a patient who had been receiving one tablet every four hours. The nurse finds the patient to appear very uncomfortable, but reporting a pain level of only 2/10, using the pain scale of 0 = no pain to 10 = worst pain. After sitting with the patient for several minutes, the nurse discovers that the patient does not understand how to use the pain scale. The nurse takes the time to educate this patient how to use the pain scale, which is subsequently reported as 7/10. The nurse administers two tablets of the analgesia which relieves the pain to a level of 0/10.

In this case, the nurse becomes aware that her patient may not be experiencing adequate pain relief. She takes justifiable action by providing education to empower her patient. She displays caring by initiating a therapeutic relationship, but does need to exert influence in order to meet her patient's needs.

### **Limitations**

Due to the expansive literature in nursing related to patient advocacy, not all of the literature could be reviewed, including unpublished dissertations. Perceptions of patient advocacy for medicine, social work, physical therapy, and respiratory therapy may have been missed, as these discussions were found to be predominantly embedded in discussions about other topics.

## Discussion

In complex health care delivery systems, the capacity for high quality patient care is increased by valuing the contributions of interprofessional partners (AACN, 2011; IOM, 2003, 2011). As new competencies for interprofessional education are developed, conceptual clarity of key concepts is important for building a shared foundation of clinical practice that crosses disciplinary boundaries in putting patients first (Tilden, 2011).

When portrayed as a metaphor (Winslow, 1984; Wurzbach, 1999), or as an umbrella term (Hewitt, 2002; O’Conner & Kelly, 2005) for other concepts, conceptual ambiguity limits the use and measurement of patient advocacy. This concept analysis demonstrated that patient advocacy can be differentiated from other concepts. The definition of “taking justified action to legitimately influence another or others in order to meet the unmet rights, needs, or best interests of patients” reflects a specific function of patient advocacy. Importantly, this definition gives insight into the skills required to meet the unmet needs of patients.

The knowledge and skills necessary to improve the quality of care delivered are reported to be limited in nurse training programs (Hall, Moore, & Barnsteiner, 2008). Pavlish, Brown-Saltzman, Hersch, Shirk, & Nudelman (2011) found that while nurses are in a key position to identify early indicators of patient concerns, they often feel powerless in the face of ethical conflict. Academic preparation that focuses on awareness of contextual clues (Weaver, Morse, & Mitcham, 2008), ethical decision-making (Crigger & Godfrey, 2010), and highly developed communication skills that include mediation, negotiation, and conflict resolution (Schlairet, 2009) are key educational topics to support the leadership role of nurses in enacting the role of patient advocate in interprofessional practice environments.

A related concern is that the centrality of the patient advocacy role in nursing varies from country to country. Nurses from such countries as Nigeria, India, Philippines, and some Asian countries who work in the Western healthcare system may not agree with patient advocacy, or may not embrace the direct and open communication that patient advocacy often requires (Priest, 2005). For example, Xu, Gutierrez, and Kim (2008) found that communication and differences in professional values and roles were key issues for Chinese nurses working in the United States. Although cultural diversity is valued in nursing, more attention to patient advocacy training for immigrant nurses is needed to assure patient rights and, since patient advocacy in nursing is recognized by the courts, to protect nurses from liability (Cavico, 1995).

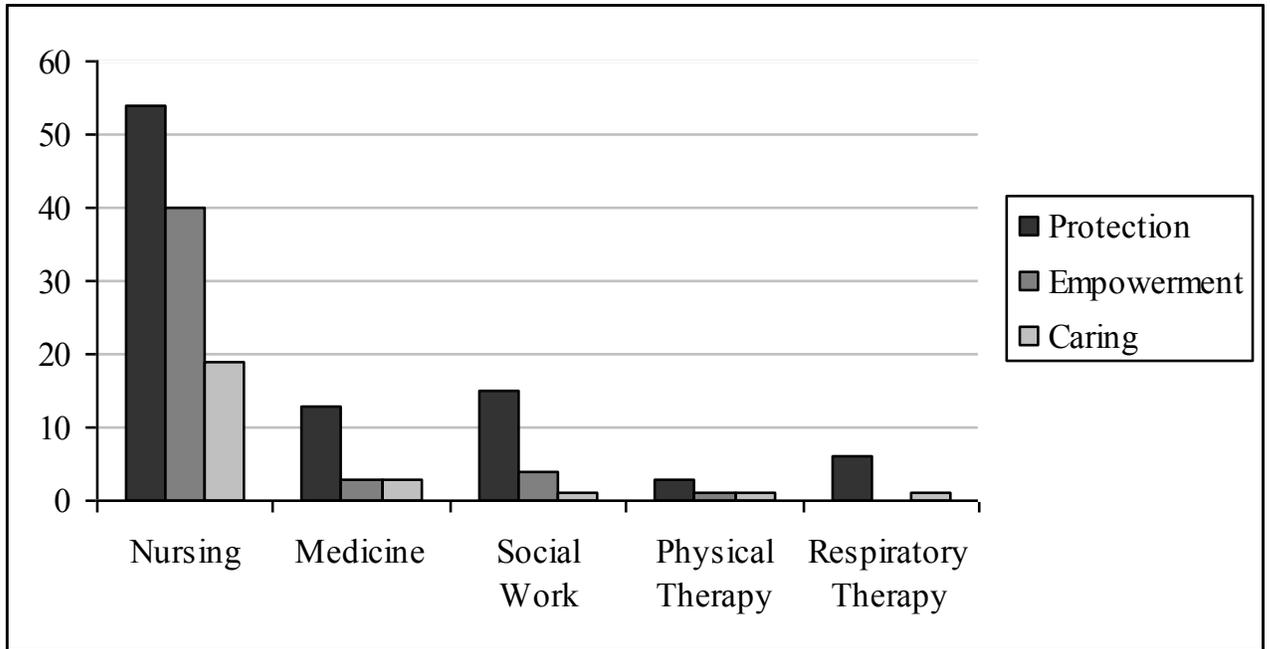
Another consideration is that work not represented in information systems cannot be accounted for, evaluated, or rewarded, and limits the data needed to make changes to improve patient satisfaction and care outcomes (Dochterman & Jones, 2003). The proposed definition of patient advocacy makes the work of patient advocacy visible, reflects the complexity of clinical practice, and promotes the development and testing of predictive models that link patient outcomes to practice contributions.

Little is known about consumers' perceptions of the patient advocacy role of their health care providers. Whether patients need or want health care professionals to act as their advocates has not been sufficiently addressed (Jugessur & Iles, 2009; Vaartio & Leino-Kilpi, 2005). In light of the inadvertent risk of paternalism associated with patient advocacy described earlier, a covenant model between nurse and patient offers a way to decrease this risk and deserves exploration (Bernal, 1992). There is also limited knowledge of how each

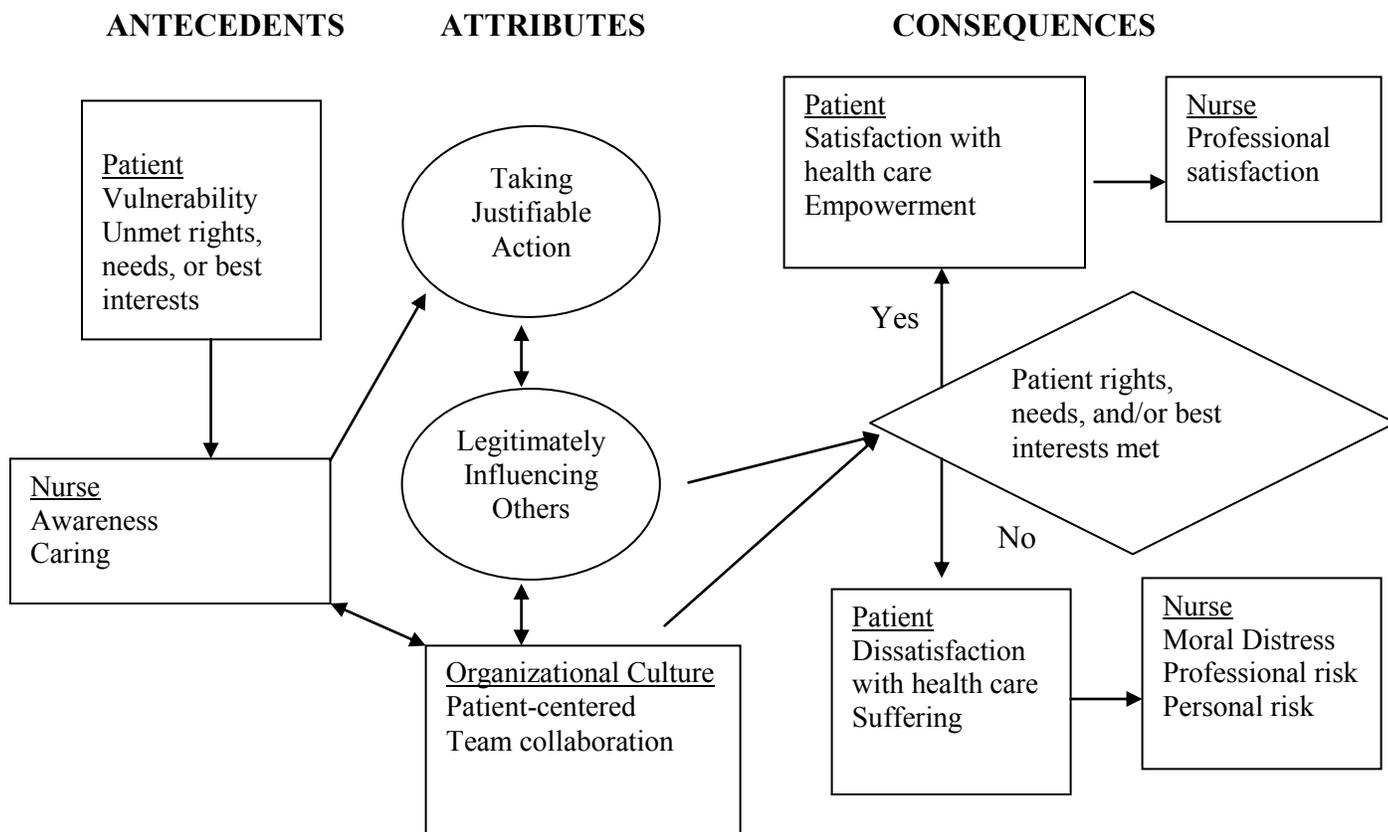
discipline educates and socializes students to the patient advocacy role, or of how these disciplinary practices can inform new competencies for interprofessional education.

### **Conclusion**

A patient advocacy model is presented that characterizes patient advocacy as a unique concept that is useful when patients' rights, needs, or best interests are not being met. The model supports the leadership role of nurses working within interprofessional teams. A conceptually clear and consensual definition of patient advocacy has the potential to improve interprofessional communication, allow for more precise measurement of the concept, and to ultimately result in increased patient satisfaction.



**Figure 1. Categorical Descriptions by Discipline**



**Figure 2. Conceptual Model of Patient Advocacy in Nursing**

## **CHAPTER III**

### **METHODS**

Chapter III begins with a preliminary pilot study and concludes with the methods section of the Dissertation Study.

## Preliminary Study

### Consumer Perspectives of Patient Advocacy: A Pilot Study

#### ABSTRACT

**Background.** Patient advocacy research in nursing is dominated by the perspectives of nurses. There is little data about what consumers want, need, or expect in terms of patient advocacy when they are hospitalized. The recipients of health care are acknowledged as bringing useful knowledge to practice settings.

**Aim.** To explore consumer perceptions and expectations of patient advocacy in the hospital setting.

**Method.** A qualitative descriptive approach was used for this pilot study (n = 6). Semi-structured interviews were used to discover the perspectives of patients (n = 4) and their family members (n = 2) on the medical-surgical unit of an acute care hospital. Data were analyzed using qualitative content analysis.

**Findings.** Categories identified were *Support*, *Unmet needs*, *Potential advocates*, *Teamwork*, and *Time*. Consumers believed that advocacy requires knowing about the patient, that anyone involved in patient care is a potential advocate, and that teamwork enhances patient advocacy. Some participants believed that patient advocacy was only necessary if their care needs were not met. Time and interpersonal skills were barriers to patient advocacy.

**Conclusion.** Findings support a multidisciplinary perspective of patient advocacy.

Influencing the multidisciplinary team based on patients' needs and nursing values has the potential to advance patient advocacy to higher level theory, and may allow more meaningful expressions for clinical intervention. A larger study is warranted.

**Keywords:** patient, consumer, perspectives, advocacy, hospital, acute care, research

## **Consumer Perspectives of Patient Advocacy: A Pilot Study**

### **Introduction**

There are continuing concerns in the nursing literature about the meaning of patient advocacy in clinical practice. Endorsed as a core principle in nursing (American Nurses Association, 2001, 2010; International Council of Nurses, 2005, 2012), there is not a consensual definition of patient advocacy after more than 30 years of discussion (Abrams, 1978; Spence, 2011). Moreover, there are constraints and potential risks for nurses acting as patient advocates in health care systems characterized by competing values and divided loyalties (Black, 2011).

Characterizations of patient advocacy in the nursing literature represent dyadic and triadic perspectives. Dyadic patient advocacy is comprised of two people, the nurse and the patient, and is defined in terms of developing and maintaining a therapeutic nurse-patient relationship in order to know patients' beliefs and values, help patients find meaning (Curtin, 1979; Gadow, 1980) and provide information so that patients can make informed decisions in support of autonomy (Kohnke, 1980). Triadic perspectives involve a third-party or factor, and are focused on protecting patient rights by acting to change decisions which are against the interests or wishes of patients (Mallick, 1997). Many characterizations of patient advocacy are a mix of dyadic and triadic perspectives (Boyle, 2005; McDonald, 2006; McSteen & Peden-McAlpine, 2006; Monterosso et al., 2005; Seal, 2007; Vaartio, Leino-Kilpi, Suominen, & Puukka, 2009).

A primary concern about the varying definitions of patient advocacy is the lack of differentiation from other concepts, such as caring (Sellin, 1995), empowerment (O'Conner & Kelly, 2005), accountability, trust, dignity (Ambler et al., 1999), ethical comportment

(Breeding & Turner, 2002), and fidelity (Long, 2002, as cited in Vaartio & Leino-Kilpi, 2005). A report that nurses have trouble describing patient advocacy because “it is so embedded in nursing practice that it becomes invisible” (Foley, Minick, & Kee, 2002, p. 182) exemplifies the conceptual vagueness of this concept.

Patient advocacy research has been predominantly focused on nurses’ perceptions and experiences of their role as a patient advocate in clinical practice. There is little data, however, about what patients or their families want, need, or expect from nurses in terms of advocacy during hospitalization (Mallick, 1997; O’Connor & Kelly, 2005; Vaartio & Leino-Kilpi, 2005). A professionally dominated view of excellence prevents patients and families from bringing useful knowledge to health care encounters (Berwick, 2009; Institute of Medicine, 2011).

### **Purpose of the Study**

The purpose of this pilot study was to gain insight into the dimensions and variables associated with patient advocacy from consumer perspectives. Conducting a pilot study was determined to be appropriate since it was not known to what extent patients would be able to articulate their views about patient advocacy. The research question for the study was, “What are the perspectives of patients, their families, and/or their significant others concerning patient advocacy in the hospital setting?”

### **Literature Review**

A literature search was conducted using the electronic databases of Medline and the Cumulative Index to Nursing and Allied Health Literature (CINAHL). The search was not restricted with respect to dates. The search terms were: patient, consumer, perspectives, advocacy, hospital, acute care, and research. The search resulted in 218 articles from Medline

and 306 articles from CINAHL, and was therefore limited to key words in the abstract. This resulted in 76 articles from Medline and 48 articles from CINAHL. After the abstracts were reviewed, two research studies were found that described patient views of advocacy in the hospital setting. Studies that briefly mentioned patient advocacy, but were not specifically concerned with patients' perceptions of this concept were not included.

The first study used a qualitative design to explore how patients (n = 22) and nurses (n = 21) on medical-surgical units defined and experienced patient advocacy in the context of procedural pain care (Vaartio, Leino-Kilpi, Salanterä, & Suominen, 2006). Patients described advocacy as “exceptional care”, “something that nurses do for their patients on account of their personal and/or professional commitment to help”, “continuous care”, involving such actions as receiving medication when needed and receiving assistance around the clock (p. 285), and “individual care” when nurses acknowledge patients' unique situations (p. 288).

The second study used a mixed methods design to examine the preferences of women with newly diagnosed breast cancer (n = 103) for an “advocacy” model, described as “promoting a better understanding of treatment options”, “increasing patients' sense of composure and involvement”, and “providing emotional support”, to a “conventional” model of care (Ambler et al, p. 447). Qualitative data supported a preference for the advocacy model.

In other studies, the concept of empowerment was used to describe some of the qualities ascribed to dyadic patient advocacy. For example, patients described giving information, showing an interest in patients, encouraging patients, and giving patients opportunities to exercise self-determination as empowerment, and not as patient advocacy. (Charalambous, Papadopoulos, & Beadsmore, 2008; Pitkanen, Hatonen, Kuosmanen, &

Valimaki, 2007) In another study, the concept of ethical care rather than patient advocacy was used to describe respecting patients as persons, being sensitive to individual differences, and realizing patients' vulnerability (Randers, Olson, & Mattiasson, 2002).

### **Philosophical Framework**

Philosophical frameworks provide the justification for the choice of research design and the validity of knowledge that comes from the study (Crotty, 2003). Since little is known about consumer perceptions of patient advocacy, a qualitative methodology was chosen to explore these perceptions. Qualitative methods are appropriate for describing and explaining phenomena about which little is known, and are particularly useful when exploring attitudes and beliefs from the perspective of those experiencing the phenomena of interest (Morse & Field, 1995).

The study is guided by a constructionist perspective. Understanding the meaning that people make of social situations, reflects a constructionist epistemology in which truth comes into existence from "engagement with the realities in our world" (Crotty, 2003, p. 8). The opposite view comes from the positivist perspective in which meaning is believed to exist independently of consciousness (Crotty, 2003). According to constructionism, meaning is "constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context" (p. 42).

### **Methodology**

The methodology chosen for the proposed study is qualitative description as described by Sandelowski (2000). Sandelowski (2010) supports a "naturalistic" perspective in the reporting of data (p. 77). Naturalist inquiry commits to studying phenomena in the natural state to the highest extent possible, avoiding the manipulation of research with a

priori assumptions (Lincoln & Guba, 1985). Axioms of the naturalistic paradigm include that 1) there are multiple constructed realities, 2) the knower and the known are inseparable, 3) knowledge exists in the form of working hypotheses, 4) it is not possible to distinguish causes from effects, and, 5) inquiries are value-bound and influenced by the choice of paradigm that guides the investigation (p. 37).

Qualitative research can be used to describe events and perceptions from the perspective of others, and it can also be used to develop theoretical constructs from these descriptions (Morse & Field, 1995). Although all description carries, to some extent more than others, the interpretation of the researcher (Denzin & Lincoln, 2005), descriptive studies are less interpretive than studies in which data is transformed to more abstract and theoretical levels (Sandelowski, 2010). Sandelowski (2000) argues that qualitative descriptive studies can stand on their own merit. Artinian (1982), on the other hand, suggests that qualitative descriptive studies are an “entry point” to other types of qualitative studies, such as grounded theory (as cited in Sandelowski, 2000, p. 335).

The choice of which method to use depends on the purpose of the research (Morse & Field, 1995). The “low inference” descriptions of qualitative descriptive studies provide a summary of events that Sandelowski (2000) believes is “likely to result in easier consensus among researchers” (p. 335). Because there is little data about patient advocacy from the perspective of consumers, a description of participant responses is considered useful for a beginning study, and in particular, for a pilot study.

## **Methods**

### **Ethical Considerations**

The study proposal was reviewed and authorized by the University of Hawaii Committee on Human Studies, and consent was received from the hospital's Chief Nurse Executive. Oral and written informed consent was obtained from the participants, and included the purpose of the study, authorization to tape the interviews, that participation was on a voluntary basis, that any and all personally identifiable information would remain confidential, that codes will be used to identify the interviews, and that participants could withdraw from the study at any time. Data was stored on a password protected computer. Transcripts and interview tapes were stored in a locked file cabinet behind a locked door.

### **Setting and Sample**

Purposive sampling strategies are appropriate for qualitative descriptive studies (Patton, 1990, as cited in Sandelowski, 2000, p. 337). The purposive sample for the current study ( $n = 6$ ) was comprised of four adult patients admitted to a medical surgical unit of an acute care hospital, the daughter of a patient, and the husband of a patient. Inclusion criteria were that participants must be able to speak English and be willing and able to discuss their perceptions and experiences of patient advocacy with the researcher. An information sheet explaining the nature of the inquiry and the role of the researcher was given to patients by their primary nurses. Patients circled either a "yes" or "no" preference to participate and submitted the preference to the nurse.

### **Data Collection**

Data collection in qualitative descriptive studies is focused on discovering the "who, what, and where" of events and experiences, typically including interviews, focus groups,

and observation (Sandelowski, 2000, p. 338). Semi-structured interviews were conducted by the researcher in June of 2011. Each patient's primary nurse was consulted to ensure that care would not be delayed or interrupted. The interviews were conducted at the bedside and lasted approximately 30-45 minutes. A digital tape recorder was used to record the interviews and notes were made by the researcher. The following questions guided the interviews:

- 1) How would you define or describe a patient advocate?
- 2) Do you believe people who are in the hospital need an advocate?
- 3) Who do you believe should advocate for hospitalized patients?
- 4) Do you have the expectation that nurses will advocate for you when you are in the hospital?
- 5) Can you describe a situation where someone has advocated for you or for a family member?
- 6) Can you describe a situation where someone failed to advocate for you or someone you know?

### **Data Analysis**

Data were analyzed after each interview using content analysis of the text, described by Sandelowski (2000) as the strategy of choice for qualitative descriptive studies. Because Sandelowski (2000) does not explicate specific analytic strategies, the content analysis method of Morse and Field (1995) was used to guide the analysis. The interviews were transcribed verbatim and read several times in order to become familiar with the data. Each interview was segmented by categories, which are descriptive labels for each group of data. Categories were developed through a coding process in which similarities and differences of words and phrases were identified within the data.

Computer software was used to assist in managing the coding process. Interviews were loaded into NVivo 9 software to assist with finding patterns in the data. Text units, or codes that reflected similar participant comments, were identified and filed accordingly. The codes were analyzed and used to identify categories. It is important to note that while the computer program facilitated coding, it was the researcher who located and recognized the significance of the data and inserted the codes (Morse & Field, 1995).

DeSantis & Ugarriza (2000) explain that the thematic analysis of data to the level of abstractness supports behavior across multiple situations. Thematic analysis was not undertaken in this study since the methodology was descriptive, and pilot studies by their nature do not sufficiently reflect behavior across multiple situations.

### **Evaluation of Quality**

There are multiple ways of judging the quality of qualitative research (Morse & Field, 1995). The following criteria of rigor and validity explicated by Russell and Gregory (2003) were used to guide the study: 1) the research question was clear and adequately substantiated, 2) the design was appropriate for the research question, 3) the method of sampling was appropriate for the research question and design, 4) the data were collected and managed systematically, 5) the data were analyzed appropriated according to the method, 6) the findings were meaningful and relevant, 7) the study helps to understand the context of practice, and 8) the study enhances knowledge about practice (p. 36).

### **Findings**

Five categories were identified from content analysis of the data: 1) Support, 2) Unmet needs, 3) Potential Advocates, 4) Teamwork, and 5) Time.

## **Support**

Patients identified patient advocacy as support from others in both dyadic and triadic terms. Dyadic refers to interactions between two people, while triadic refers to a third party that interferes with a patient's rights, needs, or best interests (Mallick, 1997). Descriptions of support are summarized as 1) knowing patients as individuals, 2) giving information, 3) ensuring quality care, and 4) upholding wishes when patients are unable to do so independently. Specific participant descriptions were:

*"Someone who can help the patient, or the family, on different levels, the medical level, the financial level, and the emotional level" (P1).*

*"Someone who can speak for you if you are not able to speak, say, from unconsciousness or not speaking English, someone who directs your wishes" (P2).*

*"Having a connection with the patient, between the patient and nurse, or some other person helping you, so they know what's happening with you" (P3).*

*"Someone who helps you get things done when they aren't being done" (P4).*

*"Someone who helps you understand what is going on" (P5).*

*"Getting you information when it is not readily available" (P6).*

## **Unmet Needs**

Patient advocacy was described by some participants as only needed when care needs are not being met, a view that is shared by a number of authors (Bird, 1994; Chafey, Rhea, Shannon, & Spencer, 1998; Schwartz, 2002). In this view, if a patient's needs were being met, there was no need for a patient advocate. Participant responses that support this view were:

*“In this day in age, with all the patient rights, people might or might not need advocacy, it depends on the situation. It depends, I mean, if you are getting good care you probably won’t need advocacy” (P3).*

*“If you have good care, you won’t need an advocate” (P5).*

*“If you are in a really good hospital, one that is run properly, especially with enough staff, well then, you don’t need an advocate” (P6).*

### **Potential Advocates**

Participants considered family, friends, health care professionals, and essentially anyone involved in their care as potential patient advocates depending on the situation. Nurses, doctors, social workers, physical therapists, respiratory therapists, family members, and staff from the business office were identified as advocates evidenced by the following descriptions:

*“A lady from the business office came in and gave the doctors information about what my insurance covers. I was grateful for that because my insurance is not good” (P1).*

*“Potentially a lot of people could be your advocate in the hospital. It depends on what they know and if they are providing any kind of services for you” (P2).*

*“The nurse took my blood pressure on my left arm, even though I had a mastectomy. I told another nurse about it, and she took care of it” (P3).*

*“My doctors went to bat for me by pursuing the medical battle I had to endure to finally get disability because of my injuries” (P5).*

*“The respiratory therapist kept telling my nurse the treatments weren’t working, until the nurse finally called the doctor” (P5).*

*“The physical therapist helped me out more than anybody. He told us what to expect and report, and when I might get to go home according to the doctor’s notes” (P6).*

*“The social worker noticed that mom was qualified to get a discount on her medications, and she even called for us” (P5).*

*“My wife was scheduled for an EGD and they tried to feed her lunch. I had to step up and put a stop to that. It’s a good thing I was there” (P6).*

### **Teamwork**

Participants believed that patient advocacy was not the sole responsibility of any one person in the hospital. The role was viewed as a shared responsibility among the interdisciplinary team. The following responses reflect teamwork among practitioners as a key factor in patient advocacy:

*“There are competing interests, and it takes a team - providers, patients, the insurance company, employers, the government, and each of these can be further subdivided. Administration, doctors, and people who see the patient would get together and decide how to make clients happy. I’m sure that the patient load, as number of patient fill up the hospital, adds more burden onto one person. That is why it has to be a team” (P1).*

*“The key to connect the levels is communication; it has to be good communication from all of the levels. If the communication is good, your care will be good” (P2).*

*“It’s really about teamwork. A lot of different kinds of people involved in your care might need to advocate for you if you need something done within that particular line of work” (P3).*

*“There are so many people that service a single patient, and there are different shifts. It’s about keeping the communication where everybody is on the same page for that patient” (P4).*

*“Sharing patient information with all the people involved” (P5).*

*“Patients need someone who knows about the system, someone who can assist a patient, and not necessarily individually, but as a group” (P5).*

One participant was perceptive of how the larger organizational system can affect a patient’s care. The response showed an awareness of the value of information systems in supporting teamwork:

*“If you can’t figure out how to make it easier for people on a one-to-one basis, then you need a system of information accessible to everyone taking care of the patient. (P3).*

## **Time**

The lack of time was identified as constraint to patient advocacy, particularly for nursing. This finding is consistent with time as a major constraint to patient advocacy in the nursing literature (Hanks, 2007; Ware et al., 2011). Specific responses were:

*“Really, when I am in the hospital I probably more think of the nurse first, even before the doctor because the nurse is usually the most available person, well that is, if the staffing is good. Nurses are quite busy with their work, and I think most patients know that” (P2).*

*“I don’t think, from what I saw, that the nurses have time. And the doctors are only there for 5-10 minutes a day” (P5).*

*“A lot of people could be your advocate, but it depends on how busy they are” (P3).*

*“Yes, in this case, the nurse had time. You don’t always see that” (P6).*

*“Those nurses were running all day long. I felt sorry for them sometimes. One person can only do so much” (P4).*

*“The aging population is making everything harder. The problem is that hospitals, and whoever, are in financial difficulty. To a large degree, it’s about how much is available and how much can be done” (P1).*

### **Limitations**

The purpose of this pilot study was to determine if the methods were appropriate to answer the research question. Data saturation was not achieved, and a larger sample is needed for credibility of the results. Additionally, the study was conducted on only one unit of the hospital.

### **Discussion**

The methodology and methods showed sufficient potential to answer the research question. As well, the participant’s knowledge of patient advocacy and ability to articulate their perspectives and experiences support using a methodology focused on higher level theoretical interpretation of the data. Discovering more about the actual process of patient advocacy may be useful for practitioners. Some research methodologies, such as grounded theory, specifically focus on process (Morse & Field, 1995).

Some participants viewed patient advocacy as necessary only if care needs were not being met. This finding is not congruent with patient advocacy characterized as the philosophical foundation of nursing practice (Gadow, 1980). Schwartz (2002) argues that patient advocacy is not needed when care needs are being met, and Taylor (1998)

recommends changing systems that make patient advocacy necessary. These views illustrate the chasm between dyadic, proactive patient advocacy and triadic, reactive patient advocacy.

All people who provide patient care services were considered potential patient advocates. This finding has particular salience for nursing practice. The potential for a variety of persons to serve as a patient advocate supports an imperative to critically consider the meaning and boundaries of this concept, particularly in multidisciplinary settings where other professionals subscribe to the patient advocacy role (Day, 2006).

An exclusive claim to the role of the patient's advocate is considered by some authors to be adversarial and unrealistic in multidisciplinary settings (Bernal, 1992; Day, 2006; Mallick, 1998). However, close proximity to patients and comprehensive understanding of care processes allow nurses a unique ability to function within multidisciplinary teams (Institute of Medicine [IOM], 2011). Using the logic that conceptually clear concepts support effective communication and decision making across disciplines (Berwick, 2009), the success of a leadership role in promoting the best interests of patients in complex organizational systems will necessarily require conceptual clarity of key concepts.

All of the participants except one identified the lack of time as a barrier to patient advocacy, particularly for nurses. Research correlates adequate staffing, which gives practitioners more time with patients, with improved patient outcomes (Aiken et al., 2010; Dumpel, 2010). Patient advocacy may influence patient satisfaction outcomes; however, there is currently little empirical evidence to support this premise.

Advocating for patients individually and within multidisciplinary teams requires effective interpersonal skills (MacDonald, 2006). One participant response shed light on the need for relational skills by identifying personality as a factor in whether or not nurses or

other care providers would advocate for patients: *“Well, I’ll tell you, it’s like the doctor, the nurses who are helping you, or whoever, it’s their personality. Some people are very people oriented, and some people are family oriented, and some are just into their academia and knowledge, and they’re not people persons, do you know what I mean? (P3).* A consumer in the study by McGrath et al. (2006) expressed a similar view in saying, *“And personalities come into it a bit. I mean, some nursing staff are very easy to talk to, and some are very business-like”* (p.399).

One argument in favor of the dyadic interpretation of patient advocacy is that it is proactive, and thus preventative in nature (Snowball, 1996). When patients’ needs are known and addressed, there is less potential for needs to be unmet (Vaartio et al., 2006). The question remains, however, of whether these dyadic activities constitute patient advocacy or whether they are sufficiently represented by other concepts, such as caring, empowerment, dignity, respect, and fidelity.

The difficulty with depicting patient advocacy as an umbrella term for good nursing care is that attention is not given to the specific skills needed to resolve the more challenging situations that are present when care needs are not met. Some of the skills required in such situations are ethical sensitivity (Weaver, Morse, & Mitcham, 2008) and conflict resolution (Schlairet, 2009). Moreover, it is essential to be able to define, measure, and evaluate the quality of health care (Dochterman & Jones, 2003). Inconsistent definitions of the structure and process of nursing limits progress in research (Clarke & Donaldson, 2008). Without differentiation from other concepts, patient advocacy will likely continue to be defined in various ways, making meaningful measurement of this concept difficult, and even impossible. Recommendations for further research are to 1) develop a consensual meaning of

patient advocacy for clinical nursing practice, 2) explore how other health care professionals view and enact patient advocacy in the practice setting, and 3) conduct a larger study of consumer perceptions and expectations of patient advocacy.

### **Conclusion**

Nurses are considered indispensable in the provision of high quality health care (Hughes, 2008), and are envisioned as leaders of interprofessional teams in the delivery of patient-centered care (IOM, 2011). Given that the patients in this study considered any person who provides any aspect of patient care as a potential advocate, and given that various other health care professionals also subscribe to patient advocacy (Day, 2006; Grace, 2001), the nurse's role of patient advocate in multidisciplinary settings has important implications for nursing practice, education, and research.

Interpreting the patient advocacy role of nurses as influencing interprofessional team decisions based on patients' perspectives and nursing values takes loyalty to patients to a higher level. Because health care organizations often have other agendas in addition to understanding and promoting the needs of patients (Kagan & Chinn, 2010), the positive influence of interprofessional teams in advancing patients' interests (Chafey et al., 1998; Day, 2006), and in changing bureaucratic systems (Snowball, 1996) is a valuable tool for improving patient outcomes. As nursing advances into new roles, conceptual clarity of key concepts is imperative. The minimum requirements for such a nursing role are a consensual definition of patient advocacy, an awareness of how other professional disciplines view their role as the patient advocate, and a continual understanding of what consumers expect from health care providers.

## **Dissertation Study**

### **Methods**

#### **Consumer Perspectives of Patient Advocacy: A Grounded Theory**

### **Research Question**

The research question for the proposed study was, “Under what circumstances, and to what extent, do consumers want or need nurses or others to act as their advocates when they are hospitalized?”

### **Methodology**

The research methodology for the dissertation study was the qualitative grounded theory method of Corbin & Strauss (2008). Grounded theory is a systematic methodology for generating explanatory models of human behavior that are grounded in empirical data (Morse & Field, 1995). Originally developed by Glaser and Strauss (1967), grounded theory has undergone methodological and epistemological revisions, most notably by Strauss & Corbin (1990). The aim of the study was to develop theory at the substantive level. Substantive theories address a specific area of inquiry, such as patient care, and provide a strategic link in the development of formal theory, which operates at a higher level of generalization (Glaser & Strauss, 1967).

### **Theoretical Perspective**

The theoretical perspective of a research study is the philosophical stance that justifies the methodology and the results (Crotty, 2003). Corbin (2008) endorses the feminist social justice perspective of Olesen (1998), in which social change can be realized through the “physical, emotional, and moral problems” that are found in people’s stories” (Corbin &

Strauss, 2008, p. 11). Olesen (1998) states that feminist researchers “reveal how societal and institutional forces mesh with human activity” (as cited in Denzin & Lincoln, 1998, p. 217).

Interactionism and pragmatism, are highlighted by Corbin & Strauss (2008) as informing the epistemology of their method of grounded theory. Crotty (2003) explains that symbolic interactionism was developed from pragmatism through the work of philosopher George Herbert Mead (1863-1931). The basic tenets of symbolic interactionism described by Blumer (1969), a student of Mead, are:

- Human beings act towards things on the basis of the meaning that these things have for them;
- The meaning of such things is derived from, and arises out of, the social interaction one has with one’s fellows;
- These meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he encounters (as cited in Crotty, 2003, p. 72).

Pragmatism is concerned with process, as evidenced by Dewey’s (1929) view that, “The test of ideas, of thinking generally, is found in the consequences of the acts to which the ideas lead, that is, in the new arrangement of things which are brought to existence” (as cited in Corbin & Strauss, 2008, p. 3). This practical philosophy is a good fit with the intention of the proposed study, which is to provide nurses with a conceptual framework for recognizing and predicting situations that require patient advocacy. The connections between interactionism in valuing peoples’ experience, of pragmatism in promoting informed changes in actions, and feminist social justice theory in exposing domination and oppression (Oleson,

1998) meet the needs of the study to better understand a conceptually ambiguous concept within the social setting of the hospital.

Patients bring their unique perspectives to the culture of health care organizations. This mixing of cultures is a key factor, as shown by Jezewski's (1993) grounded theory of "culture brokering", in explaining one aspect of patient advocacy from nurses' perspectives (p. 80). It is not known, however, under what conditions patients actually want or need nurses or others to act as their advocates.

## **Methods**

### **Literature Review**

Corbin and Strauss (2008) acknowledge the value of experience, previous knowledge, and a review of the literature to assist in formulating questions for the initial interview in order to increase theoretical sensitivity. McCann and Clark (2003) point out Glaser's argument that the research questions should emerge from the study (Glaser & Strauss, 1967), establishing a key difference between these two grounded theory methods. For the proposed study, the gap concerning patients' perspectives in the literature may not have been recognized without a comprehensive literature review. This does not mean, however, that the emerging theory should be influenced by preconceived ideas. The literature in this study was used in identifying the problem, developing the initial interview questions, and discussing the study findings. In addition, findings from a pilot study (n = 6) and from two studies of patient perceptions of patient advocacy, one concerning pain care (Vaartio et al., 2006) and the other concerning breast cancer (Ambler, et al., 1999), were used as comparative data, but did not result in any modifications to the current study findings.

## **Setting and Sample**

The research setting was an approximately 200-bed medical and surgical hospital accredited by The Joint Commission and located in the state of Hawaii. The hospital places importance on the training of health care professionals, and offers both inpatient and outpatient services that include adult heart surgery, cancer care, dialysis, psychiatric care, physical rehabilitation, and wound management. The specific units involved in the study were two medical surgical units, the emergency department, and the intensive care unit.

Authorization to conduct the study was received from the University of Hawaii Internal Review Board and the review board of the hospital where the study took place. The Chief Nursing Officer of the hospital arranged for an introduction of the study during a monthly unit manager meeting. The purpose and nature of the study were explained, questions were answered, and unit managers expressed support for the study.

The sample for the current study consisted of 22 patients and their family members. Inclusion criteria were that participants could speak English, were willing and able to engage in an interview about patient advocacy, and were at least 18 years of age. Age range, gender, race, ethnicity, and severity of illness were collected. Participant demographics spanned a range of ages from 24 years to 73 years and included various races and ethnicities. The basic categories used by the United States Office of Management and Budget (OMB) (Ver Ploeg & Perrin, 2004) were used for identifying race and ethnicity. Demographic data is shown in Appendix I.

## **Data Collection**

Participants who were medically stable enough to participate were identified by primary nurse referral. Potential participants were then given an introductory flyer by the

nurse with two boxes at the bottom, one for “Yes” to participate, and one for “No” to decline participation (Appendix II).

Confidentiality was maintained by using codes and demographic ranges for each participant rather than any personally identifiable information. Oral and written informed consent was obtained from each participant, and included the purpose of the study, authorization to tape the interviews, that participation was voluntary, that any and all personally identifiable information would remain confidential using codes to identify the interviews, and that participants could withdraw from the study at any time and for any reason. A consent form (Appendix III) was signed and a copy of the signed consent was given to each participant. Data was stored on a password protected computer. Transcripts and interview tapes were stored in a locked file cabinet behind a locked door.

Semi-structured interviews with patients and family members were conducted at the bedside, or in two cases in an adjacent room to ensure privacy, and varied in length from 15-60 minutes. In two instances, spouses were interviewed due to the limited ability of the patients to participate. Three interviews included the patient and his brother, the patient and her sister, and the patient and his son. Four interviews included both the patient and spouse. Acuity of illness ranged from moderate to high. Questions for the first interviews provided entry into the discussion of patient advocacy. Findings from a previous qualitative descriptive pilot study showed that patients and families were able to articulate their views when given an entry into the topic. Questions used to begin the dialogue were:

- 1) What does patient advocacy mean to you?
- 2) Can you tell me if someone advocated for you during this or any hospitalization?
- 3) Can you tell me about a time when you needed an advocate, but did not have one?

Prompt questions to keep the data flowing from the participant's perspectives (Morse, 1995) were:

- 1) Can you tell me more about that?
- 2) What was that like for you?

Analysis of the first interviews lead to the identification of initial concepts. The newly identified concepts informed the next round of data collection, following the strategy of theoretical sampling (Corbin & Strauss, 2008). This circular method of sampling, analysis, and data collection continued until the key concepts and their properties and dimensions were saturated, meaning that all of the concepts were “well defined and explained, and no new or significant data was forthcoming” (p. 145).

### **Data Analysis**

In grounded theory research, the first data provide a foundation for further data collection and analysis (Corbin & Strauss, 2008; Strauss & Corbin, 1998). Cues and relevant issues are incorporated into subsequent interviews, which mean that, through the process of theoretical sampling, the research process guides the discovery of possibilities (Corbin & Strauss, 2008). Concepts merit their way into theory by being repeatedly present in the data (Glaser & Strauss, 1967).

First, the interviews were read several times through. Next, blocks of data were identified by naming like phenomenon with the same conceptual term in an open coding process to identify concepts (Strauss & Corbin, 1998). These concepts were continually evaluated for similarities and differences in a process of “constant comparison” (Corbin & Strauss, 2008, p. 73). Conceptually similar data was then grouped together into higher level theoretical concepts that were relevant across the interviews. As with all data, these higher

level concepts were continually compared and validated through constant comparative analysis. Axial coding was then used to identify relationships and link concepts (Corbin & Strauss, 2008). Participant examples and descriptions provided specific dimensions and properties of concepts to assist with linking concepts. Dimensions “give specificity and range to concepts”, while properties are “characteristics that define and describe concepts” (p. 159).

In addition to theoretical sampling and the constant comparison of data, Corbin and Strauss (2008) recommend a variety of other analytical tools that can be useful in probing the data and stimulating the analysis. The first additional analytical tool used in this study was the use of questioning. Questions of “who, what, when, where, how, and why”, were used as a framework to order concepts according to their general properties and dimensions (p. 55). Conceptual ordering using this strategy was documented through “memos”, which are written accounts of the analytic process (p. 117). Examples of memos are shown in Appendix IV.

The second additional tool used in this study was to carefully examine the language used by participants. Various meanings can be uncovered by examining the temporal aspects of words and having sensitivity to emotions and feelings embedded in participant responses. Some participants conceptualized events so expressively that the words themselves were used as “in-vivo” codes, which indicates that the concept came verbatim from the data (p. 82).

The analytical process continued until the data were saturated and a core concept was identified. The product of a grounded theory consists of a central or core concept that “appears to have the greatest explanatory relevance and highest potential for linking all of the other categories together” (p. 104). Said another way, the core concept is a conceptual idea

that is “larger than the sum of its individual parts, under which all of the other concepts of the theory can be subsumed” (p. 105). Three interrelated concepts were identified that explain and are subsumed under the core concept. Together, these concepts represent a theory of patient advocacy from the perspective of the health care consumers in this sample.

## Appendix I. Participant Demographic Data (N = 22)

Patients	14
Spouses	5
Brothers	1
Sisters	1
Children	1
<u>Age Range</u>	
18-30 = 2	2
30-45 = 2	2
45-60 = 7	8
60-75 = 10	9
75-90 = 1	1
> 90	0
<u>Gender</u>	
Female	9
Male	13
<u>Ethnicity</u>	
Hispanic or Latino	4
Not Hispanic or Latino	18
<u>Race</u>	
Asian	6
American Indian or Native Alaskan	
Black or African American	
Native Hawaiian or Other Pacific Islander	10
White	6
<u>Severity of illness</u>	
Mild	3
Moderate	16
Severe	3

## **Appendix II. Participant Preference Sheet**

Aloha,

I am a PhD nursing student who is studying patient advocacy in the hospital setting. The goal of my research is to interview 15-25 patients about their experiences with advocacy during this, or any other hospitalization. If you would be willing to talk with me in private about your beliefs and experiences with advocacy, please check YES below. If you would prefer not to, check NO. Thank you for your time.

\_\_\_\_\_ YES, I would be willing to participate

\_\_\_\_\_ NO, I choose not to participate at this time

## **Appendix III. Participant Consent Form**

### **Agreement to Participate in a Research Study: “Consumer Perspectives of Patient Advocacy”**

#### Information for Participants

This is a nursing research study. The goal of the study is to improve patient care by understanding consumer experiences with advocacy when they are in the hospital. I have been a registered nurse for over 25 years, and am currently a doctoral student at the University of Hawaii at Manoa. This research is a partial fulfillment for a PhD in nursing. I am asking 15-25 patients to share their experiences with advocacy. You will be given a copy of this signed consent.

#### Research Procedures

Participants will meet with the student researcher for a private interview. The interview will last approximately 15-60 minutes. A family member or significant other can be present. The interview will be recorded, transcribed, and analyzed by the student researcher.

#### Possible Risks

You may encounter discomfort in remembering past events. You have the right not to answer any questions that make you uncomfortable. Your participation is completely voluntary. You will be able to ask questions. You can withdraw your consent to participate at any time.

#### Confidentiality

The results from this research may be published. You will not be identified in any way. The interview transcripts will not have your name on them. Random numbers will be used to identify the interview data. All data will be stored in a locked file. A password-protected computer accessible only to the researcher will be used. The data will be destroyed after the research project is finished. Information will be confidential to the extent allowed by law. Agencies with research oversight, such as the University of Hawaii Committee on Human Studies, have the authority to review research records.

#### Personal Benefit

While there are no immediate personal benefits for participating in this research, information gained from the research has the potential to improve patient satisfaction in the future.

#### Consent to Participate

I am aware of the possible risks involved in this project. I have been given satisfactory answers to my questions. I understand that I am free to withdraw my consent to participate at any time and for any reason without prejudice. I know that the interviews will be recorded, and that the student researcher will take notes. I am aware that copies of the questions and answers will be kept on file. I understand that I will not be identified on either the notes or the interview transcripts. Publication of this research may include what I have said, however, my name and any other personal information will not be shared.

I hereby give my consent to participate in this study. I understand that consent does not waive my legal rights. My consent does not release the student researcher or any employee or agent thereof from liability for negligence.

Signed \_\_\_\_\_

Date \_\_\_\_\_

CC: Signed copy to participant

If you have any questions about the study, please contact me or my advisor at the contact information below.

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University of Hawaii at Manoa  
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Research Instructor  
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School of Nursing & Dental Hygiene  
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Honolulu, HI 96822  
808-956-0532

If you cannot obtain satisfactory answers to your questions or have comments or complaints about your treatment in the study contact: Committee on Human Studies, University of Hawaii, and 1960 East-West Road, Honolulu, Hawaii, 96822. Phone: (808) 956-5007.

## Chapter IV

### Findings

In this chapter the findings of the qualitative study, “Consumer Perspectives of Patient Advocacy: A Grounded Theory” are reported. The grounded theory methodology of Corbin and Strauss (2008) was used to guide the study. The research question was, “Under what circumstances, and to what extent, do consumers want or need nurses or others to act as their advocates when they are hospitalized?” The research question was developed in response to the lack of consumer perspectives in the patient advocacy literature.

The results of grounded theories can help nurses predict processes and patterns of behavior that improve the quality of patient care (Nathaniel & Andrews, 2007). While much research has been done regarding nurse views of patient advocacy, the consumer perspective is largely missing. Described as conceptually ambiguous in nursing for more than three decades (Abrams, 1978; Spence, 2011), consumer beliefs and expectations may assist in an improved understanding of patient advocacy. Berwick (2009) contends that a professionally dominated view of excellence prevents patients and families from bringing useful knowledge to health care encounters.

The concepts that represent patient advocacy in the acute care setting from participant perspectives are *Being heard*, *Receiving information*, and *Participating*. These concepts reflect the needs and expectations that participants identified as important during hospitalization, but that unfortunately do not always occur. Patient advocates were described as necessary to provide and assure that these aspects of care occur. Failure to achieve these care expectations was associated with hospital organizational systems and the characteristics of health care workers. Participants believed that there is a real risk that hospitals may fall

short of meeting these important aspects of their care, which lead to the identification of the core concept of *Falling through the cracks of the system*.

Although Asian and Native Hawaiian or Other Pacific Islander cultures had a higher representation, responses did not show differences that could be linked to differing demographics. Concepts and their dimensions and properties are displayed in Table 4. A conceptual model of the theory is exhibited in Figure 3.

### **Core Category: Falling Through the Cracks of the System**

The core concept of *Falling through the cracks of the system* is an “in-vivo” code, which means that the concept came directly from participant responses (Corbin & Strauss, 2008, p. 65). Metaphors that participants used to describe *Falling through the cracks of the system* had strong emotional overtones, described as feeling “road-blocked,” “feeling lost,” “feeling shunned,” “feeling like a number or a chart,” “being put on the back burner,” and having to endure “red tape” and “passing the buck.” Conversely, when the aspects of care described as patient advocacy were met, participant responses included, “it felt like we were somebody,” “being alone but not feeling alone,” “so much support it felt like my family was already there,” “being kept in the loop,” “feeling honored,” and “feeling special.”

Because participants believed that hospitals exist to meet patients’ needs, *Falling through the cracks of the system* represents the unintentional unmet needs of patients during hospitalization. Cracks symbolize weak areas in the hospital system.

*“It’s such a big wheel of bureaucracy, big spokes and things can fall through the cracks. So, I think of a patient advocate as a nice safety net. Or at least a liaison, someone you can call if you feel like your needs are not being met” (Participant 4).*

*“I think this is falling through a crack, that is what it feels like” (Participant 10).*

## Phase 1: Being Heard

The first theoretical concept identified from participant responses is *Being heard*, a second in-vivo code, which represents the first phase of the proposed theory. Being heard occurs at the beginning and throughout the health care encounter. This concept has two dimensions. One dimension is 1) having a voice, which is actualized by a type listening that results in achieving a connection through knowing what patients and families mean by what they say. Properties of this dimension include attitude, attention, compassion, sincerity, and patience, all of which participants believed increased the chances of *Being heard*.

The second dimension involves 2) communicating information and preferences important to a patient care to others in the team, which includes speaking for patients when appropriate. Properties of the second dimension are accuracy and diplomacy. Participants desired that their situations and needs be shared with others accurately and respectfully in order to maintain cohesiveness within the health care team.

The first dimension of *Being heard*, having a voice, was explicitly described as patient advocacy:

*“Patient advocacy, to me, means that I have a voice” (Participant 11).*

*“My idea of patient advocacy is to make sure that patients’ voices are heard when they are at their weakest” (Participant 4).*

In this case, a daughter was disturbed that no one was listening to her grandfather:

*“He was trying to get through to them, but they wouldn’t listen. If you know him, and lots of nurses do now, he isn’t trying to be difficult, but he does have his opinions and knows about medicine and all, you know, because of his profession. He gets so mad when people don’t listen to him, my Grandma included” (Participant 22).*

This participant did not expect her healthcare providers to know everything about her, but she did expect them to listen in a way that she felt heard:

*“But, as long as they know me, are listening to me, and hear what I am saying, I don’t really care that they don’t know every little thing about me, but, I want them to know me, and what my issues are” (Participant 20).*

Communication and attention resulted in feeling connected:

*“Communication and attention are the foundation of being able to connect with the patient. This makes you feel comfortable. Sometimes you don’t feel that connection” (Participant 9).*

Not all nurses were perceived as having the patience or compassion to connect with patients through listening:

*“They have to be compassionate because they are talking with people that a lot of times the surgery went wrong, or something went wrong, that needs somebody to have compassion and be a good listener and feel with their heart, not just talk from their mouth, let’s put it that way. So, in other words, not every nurse could be an advocate. A lot of the nurses, they are so burnt out, they just don’t have the patience. You need a connection” (Participant 6).*

Being heard was influenced by whether or not nurses were genuine in responding to patients’ communication:

*“You can tell when nurses are being real. That, to me, is the best way to care for someone.”*

*“Is that advocacy?”*

*“It is. It’s like they pull patients in, they listen and engage you, and you feel like you are not just a chart or a number. You can hear it in their voice, in their intonation; you can see it in their face, in their eyes.”*

*“Why do you consider that advocacy?”*

*“Because it doesn’t always happen, and I’ve been in the hospital a lot” (Participant 16).*

In the following two examples, participants described the level of support from *Being heard* being similar to the support of their own families. After waking up after surgery with a new and unwanted colostomy, this patient expressed the power of listening and attitude:

*“As a patient in the hospital, what does patient advocacy mean to you”?*

*“Overall, the thing that has made it easier for me is that everybody has been listening to me and laughing at my old jokes, and they are just comfortable to be around. And, they are happy. They act like they are enjoying what they are doing, and, it’s just the attitude, the atmosphere. It is almost like, well, my daughter is coming down to help me, but it’s almost like she is already here in another body because they are helping me that much. I am completely comfortable. I haven’t had one person make me feel uncomfortable, unwanted, or a problem” (Participant 15).*

In the second example, even after losing her baby, this participant described the feeling of unparalleled support, like that you would receive from a family member:

*“It is the same kind of attention you would get from a loved one who knows you, who spends time with you, who really listens to you, that is what it felt like. Maybe they have the ability to connect, or they have more emotion and connect more. The experience doesn’t happen to everybody, so to get that experience you feel honored*

*and you feel special. It really feels like you have a family member with you. I was scared in the labor room, but I felt like I had family in there. It was like I had such a great support system and stuff, that I didn't feel alone. To be alone, and to not feel alone, that's pretty special. It is extraordinary"* (Participant 8).

This spouse expressed the need to "fight" to be heard:

*"Could you be a patient advocate for your husband?"*

*"Oh, yes, I am. I fight for everything he gets. We have to fight to save our family's life.*

*"Can you tell me more about the things you are fighting for?"*

*"I fight for better care, for better ears to listen to what we say. We don't have a degree, but we know the patient. And voicing for us. I don't want to fight all the time, it would be nice if somebody would say, 'Let me take over,' and ask, 'What do you need'?"* (Participant 6).

The second dimension of *Being heard* is speaking for patients:

*"Patient advocacy is when you need to have someone to speak for you, or help you speak"* (Participant 2).

*"Bottom line, advocacy is being the voice for someone else. Even if we could do it ourselves, an advocate would know more about the system and could get things done. You don't know, there is a lot of red tape and passing the buck"* (Participant 6).

Speaking for patients so that the team is aware of important patient information was viewed as affecting quality of care:

*"And I know patient advocacy is to make sure that patients' voices are heard, so that they have people speaking up for them and with them. I think that balance of*

*communication is key to the teamwork aspect of it. And, if you've lost the teamwork you've lost a lot, I think anyway, in the overall care" (Participant 4).*

A property of speaking for patients is representing patient opinions accurately:

*"Yes, speaking for a patient is advocacy, but you have to understand what the patient wants" (Participant 3).*

This participant included both dimensions of *Being heard*, having a voice and speaking for another, as well as the property of accurate representation in her response:

*"To me, advocacy means that we are representing an opinion of a person that is a patient, and to always be represented correctly. Most people, when it comes to this type of a conversation, they don't listen to the patient, and that is the first step. I find that nurses and doctors hear words but they don't understand what is being said" (Participant 21).*

When patients are unable to express their views, for instance in the case of unconsciousness, participants expected that their voice would be heard through family members and those listed in their Advance Directives:

*"What if a patient was unconscious and a care need was not being met, or a decision needed to be made. Who would you expect to step in?"*

*"There is a list of people on the Advance Directive that should make decisions. The nurse should call those people. If there isn't a directive, then someone needs to find someone who knows the patient, someone who isn't from the hospital would be the best" (Participant 13).*

How patients' needs and desires were communicated to the rest of the health care team was considered a crucial factor in maintaining team cohesiveness:

*“And you know, the advocacy thing, I think, can potentially make people defensive if they see something improper being done and call it out. You know what it is, in order to keep the balance of communication; they need to be the bulldog that doesn’t bite. It is important to make health care more cohesive, not more fractured” (Participant 4).*

A benefit of creating and maintaining team cohesiveness as a tool for change in large organizations was articulated by this patient:

*“I think the way care is organized and set up is very important, and the hospital administration has a part in that. I think building a strong ideology with different disciplines, presenting it to the bureaucracies that be, then, boy, it will build a strong base” (Participant 4).*

Teamwork and communication were so important that advocacy would not be needed for this patient if these aspects of care were in place:

*“Good communication and teamwork is how to make sure you don’t need a patient advocate” (Participant 17).*

## **Phase 2: Receiving Information**

The second theoretical concept identified in the data is *Receiving information*. This concept represents the second phase of the theory. Receiving information is influenced by *Being heard*. This is not a static process, the relationship between *Being heard* and *Receiving information* is ongoing and reciprocal. Each concept influences the other throughout the care encounter. When their voices were heard, participants felt that it was increasingly possible to know the type and level of information that they needed and wanted. *Receiving information* has two dimensions. One dimension is 1) comprehending what is going on, including what is

being planned. The second dimension is 2) obtaining answers to questions. A property of both dimensions is speaking in language that patients and families understand.

The concepts of *Receiving information* and *Being heard* were so important that this participant felt an advocate would not be needed if these conditions were met:

*“The hospital staff needs the patient rights, so they will listen to patients and answer their questions. You don’t need an advocate if you have that” (Participant 9).*

This couple expressed feeling like they were “being put on the back burner” after not being given information:

*“Nobody explained anything to us about why the procedure was being cancelled over and over again. I felt like we were being put on the back burner” (Participant 8).*

Participants felt that information should be given in language that patients understand:

*“You have to understand what the patient wants, but also the doctors and nurses can use language that we don’t understand, so I have to have them break the language down” (Participant 2).*

This participant describes needing an advocate to ask patients if they have any questions:

*“Communication is the key, and the patient is more at ease and more calm. It is frustrating not knowing. I think each patient needs an advocate to ask if you have any questions or concerns” (Participant 6).*

A lack of communication was devastating because it could result in a loss of identity:

*“I know people who are critical, like really sick, need more attention. But, that doesn’t mean that the other people don’t need attention. Can you tell us something? We are just a number, just a chart” (Participant 10).*

*“I woke up in the ICU, and I looked around, and I wondered if I was going to be just another number” (Participant 11).*

The sister of a patient felt “road-blocked” after failed attempts to obtain answers to her questions:

*“I spoke to the doctor about my insurance and he said, ‘That’s not my job.’ And well, I understand that it isn’t his job. And then, the attendant came through and took her for some tests. I said, ‘Um, have you any idea when she will be back’? He said, ‘That’s not my job.’ You just feel road-blocked.” (Participant 20).*

The effects of not knowing caused stress between this wife and her husband:

*“If all of your questions are answered, then you are relieved and relaxed. But if you are not given anything, it is frustrating. And then I take it out on him” (Participant 6).*

Bad news was considered to be better than not knowing:

*“I had to talk my husband into staying here many times in the past few days. I had to give him an ultimatum, and that’s not good for our relationship. Even if they tell you bad news, it is worse not knowing” (Participant 10).*

Alternatively, knowing what is going on had the effect of raising this couple’s self-esteem:

*“They treated me like it was okay that I knew things. They have a communication bond. They do, it is so wonderful. I want to go where I am treated like I mean something. I am not a number, I am a person. And that is how they treat you there. Their system works. I think it is a big example of patient advocacy. Everything was coordinated. All we did was have to get there. It felt like we were somebody” (Participant 6).*

### **Phase 3: Participating**

The first and second theoretical concepts of *Being heard* and *Receiving information* create the conditions for *Participating*, which is the third phase in the theory. *Participating* has two dimensions. The first dimension is that 1) patients and/or families may want to be involved in care activities, such as making decisions and taking part in the physical aspects of care, and the second involves the 2) engagement of others in patient care activities, including friends, family members, and health care providers. Participants believed that encouragement and motivation increased their ability for *Participating* in their care.

This patient describes both dimensions of *Participating*. His ability to be engaged in his care was dependent on the engagement of others:

*“And for you, that feels like advocacy?”*

*“ Yes, you know I can't do these things, I mean I get here and I am sick, okay, I am sick, and somebody has to take over and lead me towards, or take me to, or surround me by what is supposed to be done, and what I need to do. And not only to be medically done in the way that you do what's right, but to do it in such a way that it is mentally healing as well as physically healing” (Participant 15).*

*“There were a couple of times when I was difficult because I didn't want to have a colostomy, but I had to have it, so I just was very upset. The first day that my nurse came to talk to me, I realized that she was trying to make it easy for me, make this thing that I don't want a lot easier to handle. She was advocating for me.”*

*(Participant 7)*

A spouse spoke about the power of motivation and encouragement in increasing her husband's participation in his care:

*"How did you advocate for your husband?"*

*"I had gone to the nurse and explained why I wanted to take him outside. I got him in the wheelchair and took him downstairs to get some fresh air. When I got him outside he asked why I brought him there. I told him because I thought he needed fresh air to think. And when I did that for him, it motivated him to start physical therapy, to get out of the bed, and learn to sit up, stand, and walk" (Participant 3).*

This patient explained how *Being heard* and *Receiving information* helped him to participate in his own care:

*"The advocacy part is not only speaking to the doctor, but someone who speaks to you as a personal friend and counselor that can help you understand what your goals are and what you have to do, instead of just feeling sorry for yourself" (Participant 2).*

Alternatively, the sister of a patient recounted an experience when her husband was not effectively or realistically encouraged to participate in his own care:

*"But, I noticed a difference in his care, because he couldn't shave, and his beard grew in white. His care level went down so bad, that I told him he had to shave, he had to. But he said he couldn't because he couldn't stand up. They told him to go in and take a shower, and yet he couldn't stand up. Really, the more gray hair he got, the worse they treated him" (Participant 21).*

Lacking the preceding concepts of *Being heard* and *Receiving information* led to this patient's failed attempt to participate in her own care:

*"This male nurse took my blood pressure on my arm and it was high. I told him this was not the right way when you have had a double mastectomy, you should use the leg, and I asked him why he was going to do it that way, but he didn't listen to me. He came back with a medicine and said I had to take it for my high blood pressure. I ended up taking it, even though my blood pressure was high because of dealing with him. But it wasn't right, you know. Nurses tend to think they have the answer to your problems. I don't even know, to this day, what I took"* (Participant 20).

What patients want was acknowledged as not always being the best choice. How health care providers addressed this issue made a difference in this patient's motivation to participate:

*"Because there are things that you want to do that are not in your best interest, they can help you see that. But, they don't bully you; they help you see why it is necessary.*

*"Is this patient advocacy?"*

*"Well, for me, in this situation, definitely. I needed a lot of help to get on board with the program"* (Participant 7).

A patient's wife compared advocacy in law with advocacy in health care. For her, needing a lawyer in the courtroom was similar to needing health care professionals to help participate in the medical system:

*"We are lost. And, I feel that because we don't have a say, we need an advocate. For instance, we can't go to court by ourselves, I mean, well, we can but it's not a good idea. The lawyers know the rules, they know how to talk to the judge, they have the license, you know, they have everything in their power to advocate for you. That is*

*how I feel in the medical sense. The doctor and the nurses and the therapists, and whatever, they have the power to help you, to help you with what you need to do, so they advocate for you to help you, because you don't know, and so you can't help yourself" (Participant 10).*

### **Who, What, When, Where, and How**

Any theory would be incomplete without the features of “who, what, when, where, and how” (Corbin & Strauss, 2008, p. 55). The features of “what “and “how” are reflected in the key concepts of *Being heard*, *Receiving information*, and *Participating*. “Where” is identified as the acute care hospital. “When” is represented by both the provision of care, and when patients experience *Falling through the cracks of the system*, but more precise explanation is needed for “who” can, or should be, a patient advocate.

Some participants viewed everyone involved in patient care as a potential advocate, while others held a firm belief that a patient advocate could only be someone who was not affiliated with the hospital due to a potential conflict of interest. Additionally, further explication of differences regarding “when” patient advocacy is required, as well participant views of the barriers to patient advocacy, are presented.

Family, friends, health care professionals, and essentially anyone involved in a patient's care were potential patient advocates for these participants:

*"Do you think that all people who work in a hospital can be a patient advocate?"*

*"Yes. Each person does a certain, special part of the care" (Participant 8).*

*"I would say the closest one to be an advocate is the nurses because they are constantly with you. Really, whoever is with you, like the therapists and the aides and everybody in the whole facility, really" (Participant 3).*

On the other hand, other participants identified patient advocates as having a specialized role:

*"I don't think this hospital has an advocate, because as much as we've been through, I haven't seen or heard of one" (Participant 22).*

*"Who can be a patient advocate?"*

*"A titled person, like, their title would be patient advocate. I say this because people in hospitals have a lot to do. They care, they advocate in the sense that we're all here for the purpose of healing, but sometimes things fall through the cracks" (Participant 4).*

Many participants saw patient advocacy as a team effort:

*"As a family member, when you have a loved one in the hospital, do you think that a patient advocate could or should be one of the members of the healthcare team?"*

*"Yes, I do."*

*"Is there anyone in specific?"*

*"No, I think it should be a team - the whole team" (Participant 13).*

This participant describes how patient advocacy should be a team effort in a hierarchical organizational structure:

*"Well, if say, a floor nurse sees something and goes directly to the person that is doing the wrong thing, there is a good chance that nothing is going to get done. But, if she goes to the person above, and that person goes to the person above them, then they are all advocates. They are working as a team" (Participant 7).*

Specific training and experience were believed to be necessary to be a patient advocate:

*“I think of an advocate as a special person trained to listen, to research, you know there is research involved when we have a question. Someone who doesn’t pass the buck, which is usually what we get” (Participant 6).*

*I think training and experience are important to be an advocate. I’ve been in and out of hospitals for various reasons, and have had a fair amount of experience with nurses. And, I have observed a fair amount of difference in their knowledge. Nurses need specialized training, I think, to be patient advocates” (Participant 1).*

A major constraint to the role was perceived to be a lack of time:

*“Could nurses or physicians be patient advocates?”*

*“No, because I think they have too much on their plate. There should be someone who has a special job as the advocate. Someone who can listen and follow-through with what has been done, and is to be done. Like dietary, you can tell them everything and write it down and what comes up is totally different. Some days, it feels like people are just not paying attention, there is no follow-through” (Participant 6).*

*“Tell me about nurses being patient advocates.”*

*“That doesn’t work. They are short staffed, and they have all these traveling nurses that have to learn different things. There’s no blame there, but that is just how it is” (Participant 5).*

*“But, it is not fathomable for a nurse to be an advocate for us because she has so many duties. And we never see the case manager. I don’t even know what they do” (Participant 12).*

This patient held the hospital management responsible for the lack of time:

*“Would someone who is really busy possibly not have time to advocate?”*

*“I think that if that’s the case, that it is the fault of the supervisor, or really, the hospital” (Participant 7).*

In addition to a time constraint, mention was made about nurses’ lack of influence:

*“The nurses should have more influence it seems. I really think they are the backbone, like I said before. They should definitely have more power than they do” (Participant 10).*

The lack of authority was believed to be related to the hierarchical power structure of hospital systems

*“Could the nurse who takes daily care of you in the hospital be your advocate?”*

*“Not really. But, I would expect them to do a good job.”*

*“Is there a difference between doing a good job and advocating?”*

*“Yeah, I think there is a difference, because nurses have to answer to somebody else. Floor nurses and such don’t usually have the authority to make something right. I look at advocacy as a person that is in charge, that advocates for all the patients, makes sure that the people underneath them do their jobs. They have the power to do something about things” (Participant 7.)*

This next participant articulated the difficulty of changing the system:

*“When you felt too weak to get up, did you consider calling your nurse?”*

*“Oh yeah. My nurse was terrific.”*

*“Did you call her?”*

*“Yes, I did call. And I was told that ‘it was on the schedule’.”*

*“Do you feel that the nurse failed to advocate for you?”*

*“ Oh, no. You cannot blame the nurse. She wasn't offered a choice, and she didn't have the authority. It would better if they did. But, basically, it's in the system already. The system will not change” (Participant 11).*

For this participant, no one in the health care system could be a patient advocate due to loyalty to the hospital:

*“If the advocate is an independent person, sure. The person would have to be independent for that to work, to keep it on the up and up. If you've worked somewhere your whole life, you'll do what the system says to keep your job” (Participant 14).*

In this next view, patient advocacy was different than providing appropriate care, even in a case of reporting incompetence:

*“So, are you saying that even in a case of incompetence, where one person is not following the standard of care, correcting that situation is not advocacy, it is part of the job?”*

*“Yes, they are doing their job. That, to me, is not advocacy”.*

*“Let me recap what you have shared with me: If you are hired to care for patients, you are not their advocate, all of your actions fall under the job description. On the other hand, if you are not hired by an organization and you take action to meet a patient need, you are advocating for that patient?”*

*“Yes, that is what I think, that is how I think it works” (Participant 12).*

Patient advocacy was believed to be different from the “regular job” of healthcare workers, particularly in light of how busy health care workers are:

*“Are there qualifications to be a patient advocate?”*

*“I think that the requirements would be that they would have to be not too busy with their regular job to really pay attention” (Participant 4).*

The wife of a patient believed that a patient advocate is only needed if there is a problem, which should not occur if health care workers do their jobs:

*“Are you saying that if hospital employees do their jobs well, patients don’t need an advocate?”*

*“Exactly. That is exactly what I am saying” (Participant 13.)*

Another patient agreed that good care prevents the need for advocacy:

*“When patients are cared for properly, there is no reason to advocate for them.*

*Providing good care isn’t advocacy, it prevents the need for advocacy” (Participant 21).*

A health care professional visiting a family member expressed a similar belief that patient advocacy in the hospital should not be necessary:

*“I think the word ‘advocacy’ in the hospital is a misnomer. It shouldn’t be needed. It suggests an inherent conflict, that you are up against an inscrutable system. It is sad that people see it as part of patient care at all. It is a commentary on the state of health care” (Participant 17).*

Likewise, this patient believed that advocacy was not necessary if care needs were met:

*“I think that I would call on a patient advocate when I observed something that I didn’t approve of in a hospital, when I saw the need for additional training in some*

*area, when the accommodations were not suitable, for whatever reason, the attitude of the staff, the nurses towards the patients, whether tasks were completed”.*

*“Are you saying that you wouldn’t need an advocate if everything went well?”*

*“Well, yes, that is what I am saying” (Participant 1).*

### **Summary**

This chapter presented the findings of a grounded theory study that resulted in a substantive-level theory of patient advocacy developed from consumer perspectives. The aspects of care that the participants described as patient advocacy were *Being heard*, *Receiving information*, and *Participating*. These concepts showed a pattern of stages that reflect a process. *Being heard* leads to *Receiving information*, which results in a greater capacity for *Participating*. This process is not static; it is reciprocal and continuous throughout the care encounter. The in-vivo core concept of *Falling through the cracks of the system* indicates that these aspects of care are not always met within a system that exists to meet those needs.

A patient advocate was perceived to be someone who could take action to meet these needs, either proactively in the delivery of care, or reactively after recognizing these unmet needs and expectations. Some participants felt that anyone involved in the care of a patient could be a patient advocate, while other participants believed that only persons not affiliated with the hospital could be a patient advocate. Notably, nurses were frequently viewed as too busy to be patient advocates.

## Appendix IV. Memo Examples

1) Memo 1 illustrates open coding of the data after the first interview. A table was used to order concepts using the parameters of who, what, when, where, how, and why.

This participant describes triadic (third party involvement) patient advocacy and feels that patient advocacy is not needed if care is good. Training and experience are important to prevent care from being altered in the “wrong way” or causing “trouble.” This patient states that he has observed differences in nurses’ knowledge, and describes an unfortunate example. A topic for theoretical sampling is if participants believe that patient advocacy is needed only when care needs are not being met.

Who	What	When	Where	How	Why
Personal physician Nurses with training Hospital ombudsman Not just anyone	Being a go-between patient & MD or head nurse	When there is trouble Accommodations not suitable Poor staff attitudes Care is not timely	Hospital	Checking things out first Not altering a patient’s care in the wrong way Being available Listening	To meet patient’s needs

Memo 4 is an example of the analytical thinking involved in considering the concepts involved in the theory.

Participants talked about competent care mostly in terms of listening, letting patients knowing what is going on, and being a part of the care process. This seems clear, but there may be differences in how consumers evaluate the actions of different people in the hospital. For example, one patient told a care provider that he didn't feel strong enough to get up. The patient then told the nurse the same thing, who told him that it "was already scheduled" and in the system. Remarkably, this patient recounted his evaluation of this situation very differently for the nurse and the other professional. While he was adamant that the first provider didn't listen to him, he said the nurse was not at fault for not listening to him because she was acting under the power constraints of the system. Participants give nurses a lot of credit for what they do, and most seem to also rationalize that nurses are legitimately too busy or don't have the authority to be patient advocates. Why did he treat these practitioners differently? Was this a gender issue, or is his difference in evaluation because of a different connection with nurses due to their continuous presence throughout the hospitalization? Another incidence was when a patient experienced a severe loss of body fluid during dialysis, despite his attempts to explain his usual "dry weight" to the nurse. Rather than describe these incidences as incompetent care, both participants attributed the event as the result of not being listened to. Partnering with patients in these examples is a safety issue.

Memo 5 is an example of the analytical thinking involved in identifying the theoretical concept of "*Being heard*."

Is "listening" better expressed under the larger concept of "connecting"? The concept of connecting would also encompass obtaining information and understanding what is going on. Connecting could also be an outcome of effective listening, and was described as such by a participant. What does effective listening mean, and how is it ensured? Being heard is a much more specific description than "listening" or of "connecting, and seems to be a more accurate backdrop for the emotions embedded in the examples that were recounted. Can you listen without hearing?

Memo 6 depicts an example of the analysis of the second dimension of “*Being heard.*”

Surprisingly, participants are extremely sensitive of the value of the team to patients’ care and an advocate’s role in promoting and preserving the optimal functioning of the team. They realize that how the team functions affects the quality of their care. The views seem to add another dimension to listening, that of the team knowing what is going on with patients and families. Is this a cue to change the concept? Or is this a dimension of “being heard?” In describing how advocates should communicate patient’s concerns, a patient uses the “bull dog that doesn’t bite” as a metaphor. Bull dogs keep a watch out and take action when they sense something is wrong. What are bulldogs like? They are not passive. They keep an acute awareness about them. They are protective. They are persistent. They are loyal. Not ‘biting’ means to be tactful and preserve relationships, a strategy that other participants also felt benefitted their care. She says that alienating team members “fractures the team” which disadvantages patients. If the advocate is perceived as ‘attacking’ others and causes trouble for the team, that negativity overflows to the patient. How a patient advocate delivers the message is a property of the second dimension of “Being heard”, that is, apprising team members of information important to patient care. Accuracy and diplomacy are important when speaking for others.

It is amazing to see this participant’s high level of awareness and insight into the constraints of bureaucratic structures in an impromptu conversation, when she says, “I think building a strong ideology with different disciplines, presenting it to the bureaucracies that be, then, boy, it will build a strong base. That is why communication to me is the most important thing” (Participant 4).

Who	What	When	Where	How	Why
Family Friends Titled Position Someone who has time Nurses don’t have time	Making sure patients voices are heard Speaking for Speaking with Being a liaison	When patients cannot self- advocate When needs are not met When patients “fall through the cracks” of the system	Hospital	Communicating Preserving relationships Influencing the plan of care Being the “bulldog that doesn’t bite” Provide a safety net	To meet the needs of patients Fair & equal treatment Making situations the best they can be

Memo 7 is an example of how a more precise identification of the concept of “*Receiving information*” progressed:

Is “understanding” the most accurate representation of how participant’s described knowing what is going on? How do patients come to “understand?” What about “knowing?” Is this a more accurate portrayal? Is comprehending a better description of what participants are saying? Both understanding and knowing involve more than being aware of. What participants are actually saying is more like being aware of and comprehending enough to understand. To understand and to know infer a complete comprehension, a wide parameter which is not what consumers described. Participants have concerns that information needs to be understandable to those who don’t know medical terminology, “in language that we can understand.” This being the case, neither “understanding” nor “knowing” are totally accurate portrayals of what participants are expressing, whereas, comprehension can be delimited to the situation, which is more what participants seem to be saying. Comprehending what is going on and what is being planned comes from, is an outcome of receiving information. This seems to be closest to what participants are expressing in their examples. What are the dimensions and properties of receiving information? Having their questions answered was an important concern for most participants. That means that receiving information encompasses both comprehension of what is going on and obtaining answers to specific questions.

Memo 10 is an example of the questions asked of the data in developing the concepts, some of which resulted in the need to theoretically sample the data.

Which concept comes first? So far, participants want to be heard from the beginning, from the first encounter. Those consumers who saw any person involved in their care as potential advocates provided examples of these early encounters, including that the administrative staff was sensitive to concerns about insurance coverage during admission and checked insurance coverage, and ambulance personnel answered questions about what was going on and what was being planned. When participants’ voices were heard, they felt they were able to receive answers to their questions and concerns. This is important because patients differed in the amount and type of information they wanted. These participants, however, are all alert and oriented. If someone was unconscious, how could they be heard? This is a topic to sample. How does ‘being heard’ apply to unconscious patients?”

Memo 11 is an example of internal discussions of inductive versus deductive approaches, and how these two different methods of inquiry influenced theory development.

Participating in care was described as being involved in making decisions and being involved in the tasks of care. What indicators in the response show where this concept fits? Deductive logic says it fits after being heard and understanding information, but the theory needs to be inductive to fit grounded theory principles. Application of the theory to nursing, however, will be a deductive process. It is necessary to identify where participating fits in the theory using participant responses. Why does *Participating* require *Being heard* and *Receiving information*? Also, not everybody wants to participate.

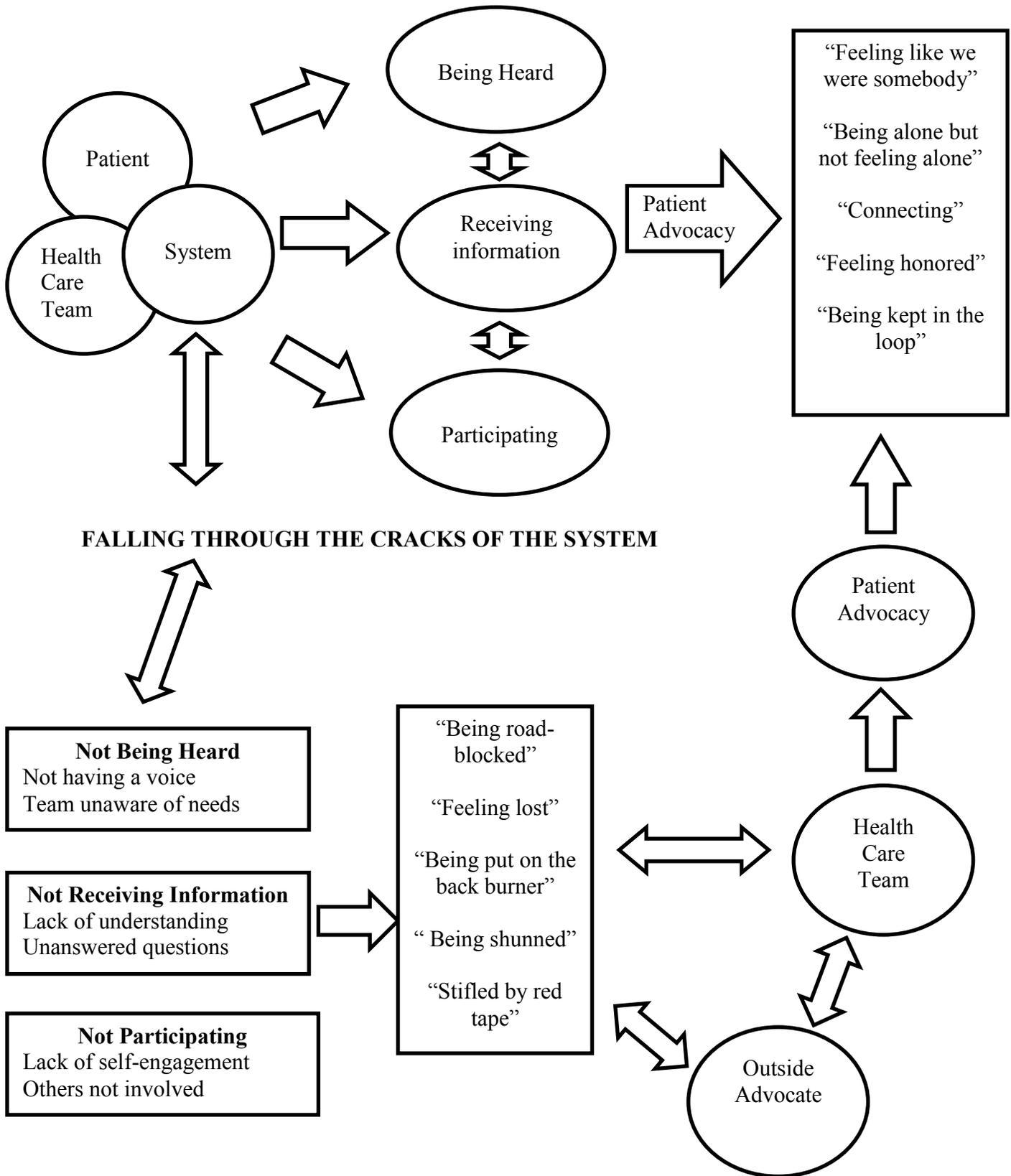
Memo 12 is an example of the analytic dialogue concerning implications of the results of the study for nursing.

Does what consumers describe as patient advocacy necessarily mean that is what advocacy means for health care professionals? If a nurse listens to a patient, does that mean he or she is advocating? When considering the practice guidelines and competencies that define nursing practice, it seems that there may be a difference between the meaning of patient advocacy for consumers and the meaning for nurses. It will be important to ask participants why they interpret patient advocacy in this way.

**Table 4. Theoretical Concepts**

<b>Concepts</b>	<b>Dimensions</b>	<b>Properties</b>
Core Concept: Falling Through the Cracks of the System	Lack of: Being heard Receiving information Participating	Practitioner characteristics  System factors
Being Heard	Having a voice  Sharing information with the team	Attitude, attention, compassion, sincerity, patience  Accuracy, diplomacy
Receiving Information	Comprehending what is going on & what is being planned  Obtaining answers to questions	Speaking in language that patients and families understand
Participating	Patient and family involvement  Engagement of others in care	Encouragement Motivation

**Figure 3. Conceptual Model of Patient Advocacy from the Consumer Perspective**



## Chapter V

### Summary of Findings

The grounded theory method of Corbin and Strauss (2008) guided this qualitative study of consumer perspectives of patient advocacy to the level of substantive theory. Twenty-two hospitalized patients and their families participated in the study. Hospital units included two medical-surgical units, an emergency department, and an intensive care unit. Data were collected using theoretical sampling and analyzed using a constant comparative process facilitated by the use of written memos (Corbin & Strauss, 2008).

Identification and development of a core category and three associated concepts that reflect consumer descriptions of patient advocacy resulted from the study. The core concept of *Falling through the cracks of the system* indicates that one or more of the processes of *Being heard*, *Receiving information*, and *Participating* are expected, but are not experienced during the care encounter. “Cracks” symbolize weak areas in the structure and function of the hospital system, and occur when these aspects of care are missing or lacking. A conceptual diagram of the theory is presented in Figure 3.

A previous qualitative descriptive pilot study showed that patients and their families were willing and able to discuss the topic of patient advocacy. Findings from the pilot study, as well as from two other studies of patients’ views of patient advocacy found in the literature served as a comparison data, but did not result in modifications to the concepts identified in this study.

The reason that participants gave for describing the identified aspects of care as patient advocacy was because, from their current and past experiences, one or more of these expected aspects of care was either missing or lacking. Acknowledging that hospitals strive

to meet patients' needs, participants also believed there is a real risk that their needs may not be met. The complexity of health care systems and the differing characteristics of health care professionals were reasons why patient needs could escape attention or notice. Who could be a patient advocate differed among participants, ranging from family, friends, and everyone involved in a patient's care, to only an outside advocate who carried no risk of divided loyalty between the patient and the hospital. Nurses were highly regarded for the work they do, but were considered by most participants as too busy to be patient advocates.

### **Discussion**

There are two crucial points in the findings. The first is that the components of *Being heard*, *Receiving information*, and *Participating* were described as examples of patient advocacy by participants because these aspects of care were not always present, although they were expected. The second point is that the aspects of care described by the participants are expectations of the role of professional nurses (American Nurses Association [ANA], 2001, 2010; International Council of Nurses [ICN], 2005, 2012). After a discussion of the nature and details of *Being heard*, *Receiving information*, and *Participating*, these points will be discussed in terms of implications for practice, education, and research.

#### **Phase 1: Being Heard**

The in-vivo code of *Being heard* is the first theoretical concept and the first phase of the theory. *Being heard* occurs at the beginning of the health care encounter and is a continuing and influencing aspect of the patient care experience. This concept includes the two dimensions of interpersonal communication and interdisciplinary communication. Participants expected that their views and feelings would be heard, meaning that others would know what they meant by what they said. They desired to have a voice, even if it

meant that someone else spoke for them. Participants expected that their unique situations and perspectives be accurately interpreted and represented to the team of health care workers responsible for their care. These expectations, however, did not always occur.

Listening to patients seems like a simple request, but the science of listening and research findings show that this is not the case. Shotter (2009) points out that we usually listen for opportunities to express or contrast our own point of view, a style of listening that often results in not truly understanding what people mean by what they say. Emphasizing that listening to another results in a new reality co-created by both parties, Goffman (1967) explains why understanding what others mean is an ethical concern:

If a second person feels the first to be pursuing an agenda of his or her own, then not only will that second person feel ethically offended at the first person's lack of respect for them, they will also feel ethically offended at that person's lack of respect for their joint endeavors. (as cited in Shotter, 2009, p. 24)

A different type of listening, one that is more likely to result in the feeling of being heard, is characterized by responsively replying to what others say (Shotter, 2009). In this style of listening, each party is changed by the expressions of the other, creating a "living connection" that ultimately results in a relationship of trust (p. 22). Thomas and Pollio (2002) contend that "Only if we make the effort to understand does it become possible for language to connect rather than separate us from our patients" (p. 48).

Research has shown that nurses and other health care providers need to improve their listening skills. Moran, Scott, and Darbyshire (2009) found that concentrating on technical aspects of care prevented development of the supportive relationships that patients wanted with nurses. A lack of communication by nurses was found to be a primary theme in patient

experiences in a study by McCabe (2004). Barriers to communication with nurses were described by Park & Song (2005) as: the use of medical language, working without a sincere attitude, having an authoritative attitude, changing the subject frequently, and being unfriendly.

*The Initiative on the Future of Nursing* (2009) reports that the information gathered by nurses in their interactions with patients is critical to reducing medical errors and improving patient outcomes (Shalala & Bolten, 2009). The importance of listening is clearly captured by Chinn (1993):

Medicine focuses on surgical and pharmacological interventions, with interpersonal interactions being an adjunct to these interventions. In contrast, technical interventions are viewed in nursing as being secondary to primary interpersonal interactions. (as cited in Thomas & Pollio, 2002, p. 8)

Listening to patients and their families is an essential element of current health care reform efforts to create a more patient-centered care environment (Berwick, 2009). A lack of time due to the busy work load of health care workers was mentioned by participants in this study as a primary reason why they did not receive as much attention as they expected. Berwick (2009) explains that what is most important is the return on time and energy spent. He sheds light on the worthwhile return of investing time and energy by being more responsive to patients in saying:

....the moats we dig between patients and clinicians can drain spirit from both. When in a caring relationship we deny what we could with free hearts give, we both suffer from the denial; one loses the help, the other loses the joy of helping. (p. 562)

The second dimension of *Being heard* signifies that participants expected the entire team of health care workers to be aware of their situations and views, although this also did not always occur. Other studies have described the frustration that patients express when their condition and plan of care were not communicated among their caregivers, which they believed resulted in compromising the quality of care that they received (Frampton et al., 2008).

The value of teamwork to patient care was consistently acknowledged by participants, and they were sensitive about how information was relayed in order to preserve team cohesiveness. The metaphor expressed by this participant, as being “the bulldog that doesn’t bite” exemplifies this:

*“What do you think are the qualities that a person has to have to be a patient advocate?”*

*“You know what it is, in order to keep the balance of communication, they need to be the bulldog that doesn’t bite. It is important to make health care more cohesive, not more fractured. I see it as everyone contributing to that” (Participant 4).*

In two difficult patient care situations, Quallich (2010), a nurse, describes being the recipient of “misguided attempts from nurses to act as patient advocates”, recommending that the nursing profession take a more critical look at the implications of this role (p. 216).

## **Phase 2: Receiving Information**

The second theoretical concept is *Receiving information*, which represents the second phase of the theory. *Receiving information* is influenced by *Being heard*. When participants’ voices were heard, it became increasingly possible to know the type and level of information that they needed and wanted. Hawkins-Walsh (2000) contends that “only by listening to a

patient will we become aware of the need for more information” (p. 24). *Receiving information* has two dimensions. The first dimension is comprehending what is going on, including what is being planned. The second dimension is obtaining answers to questions. This is not a static process, the relationship between *Being heard* and *Receiving information* is ongoing and reciprocal. Each concept influences the other throughout the care encounter.

A key property of *Receiving information* is that information be given in language that makes sense to patients and their families. The confusing language of health care can cause feelings of stress and anxiety. Frampton et al. (2008) examined the far reaching effects of inadequate information, stating that, “If patients do not understand the instructions given to them for taking care of themselves, they will be far less able to ask informed questions, and ultimately will be less likely to adhere to their treatment regimen” (p. 115). Sources of conflict in health care, including the lack of information, inconsistent information, inaccurate information, misunderstood information, and gaps in information (Schlairet, 2009), highlight potential difficulties associated with *Receiving information*.

As a legal doctrine, informed consent is based on the ethical principle of autonomy, and means that patients conditionally have the right to make their own decisions about their health care options (Burkhardt & Nathaniel, 2008). In order to make informed decisions, it is vital that patients receive and understand information (ANA, 2010). The importance of *Receiving information* is underscored by the World Health Organization (2008) report that, “One of the most common sources of patient dissatisfaction is not being properly informed about and involved in their treatment” (Coulter, Parsons, and Askham, 2008, p. 3). The nurse’s role in informed consent for medical procedures is to assure that the patient understands the information, and to contact the provider performing the procedure if this is

not the case (ANA, 2010). Informed consent for nursing care is also acknowledged in nursing practice guidelines (ANA, 2001). Yet, despite this expectation, Aveyard (2005) found that nursing care was often performed with minimal or no information given to patients.

Seeking information is an important coping strategy in the psychosocial response to illness (Lambert & Loiselle, 2007). The participants in this study not only expected to have their questions answered, they also wanted to be asked if they had any questions. These expectations of care are addressed in the ANA (2001) directive that nurses continually assess the patient's comprehension of information. This can become complex when caring for patients with varying levels of capacity, differences in culture and language, and challenging family dynamics (Johnstone, 2011).

In a qualitative study involving patients from multiple cultures, Garrett, Dickson, Young, Whelan, & Forero (2008) found that patients, across the board, valued information and involvement. Negotiating family involvement was found to be important in their study because while many patients were reliant on family due to language difficulties and culture preferences, other patients desired more control. Due to the highly variable range of influences that patients bring to health care encounters, Garrett et al. (2008) recommend that cultural competence can be best achieved through consistent renegotiation. Comprehensive resources for making health care practices more culturally and linguistically accessible can be found in the National Standards on Culturally and Linguistically Appropriate Services (2001) (U.S. Department of Health and Human Services Office of Minority Health, 2007).

The skills involved in delivering information to patients, assessing comprehension of this information, and answering questions were highly valued by the participants in this study because, based on their experiences, these are aspects of care that do not always occur.

### **Phase 3: Participating**

*Being heard* and *Receiving information* lead to the third theoretical concept of *Participating*, the third phase of the theory. *Participating* reflects that patients and their families may want to be engaged and involved in the delivery of care. The experiences of *Being heard* and *Receiving information* offer a greater likelihood for *Participating*. There are times, however, when patients may not wish to participate in their own care due to the debilitating effects of illness, or because it is their personal preference. *Participating* has two dimensions. The first dimension of *Participating* concerns 1) patients being involved in care activities. The second dimension recognizes 2) the involvement of important others in a patient's care, including friends, family members, and health care providers. Encouragement and motivation were properties that participants believed increased *Participating*.

Eldh, Ekman & Ehnfors (2006) found that patient participation was influenced by being listened to and being considered as a knowledgeable resource of information. Similarly, Eldh, Ekman, and Ehnfors (2010) found that being informed was an essential attribute of participation. This participant expressed how *Being heard* and *Receiving information* helped him participate in his care:

*"I think it helps when you know, like when people get older and they don't want to do anything, you've been in the hospital for so long, and you need to know what is going on and what you can do help yourself, how to improve yourself so you can get better. Sometimes when you try and ask questions they don't know how to explain to you. But then another person comes in and listens to you, maybe makes you laugh, and talks to you like they care about you, then it is easier for the patient to communicate back and to do what needs to be done to get better"* (Participant 2).

Patient participation is considered an essential component of medical treatment and nursing care (ANA, 2010). Most research about patient participation is from the perspective of health care professional and relates to decision making (Eldh, Ekman, & Ehnfors, 2010). While the participants in this current study identified shared decision making as *Participating*, they also described other aspects of care, such as performing recommendations for progressive ambulation and learning wound and colostomy care.

The involvement of important others in a patient's care was described by the participants in this study as increasing the ability to participate. However, engagement in care can decrease participation when others attempt to influence patients in a paternalistic way. In a qualitative study of hindrances to patient participation in care, Sahlsten, Larrson, Plos, and Lindencrona (2005) reported that support of patients' wishes and opinions was undermined by the lack of professional assessment of patient resources and unmet needs. Despite the value of *Participating*, patients in this study and in other studies have experienced deficits in this aspect of care (Frampton et al., 2008). As with *Being heard* and *Receiving information*, *Participating* was identified as patient advocacy because this aspect of care did not always occur.

### **Implications for Practice**

*Being heard*, *Receiving information*, and *Participating* were identified as patient advocacy because, from participant experiences, these aspects of care did not always exist, although they were expected and needed. Since these aspects of care are professional competencies and expectations of professional nurses, the implications for nursing practice gained from the study are informed by an interpretation of patient advocacy that addresses these unmet needs in the context of professional practice standards.

How participants defined patient advocacy is congruent with the principles found in Gadow's theory of existential advocacy (1980), which highlights the "shared humanity between nurses and patients" (p. 83) and is a major influence in the patient advocacy literature (Vaartio & Leino-Kilpi, 2005). Gadow's theory is a "dyadic" interpretation of patient advocacy that reflects information giving and counseling approaches in helping patients make decisions about their health (Mallick, 1997, p. 310). Both Gadow (1980) and Curtin (1979) proposed that nursing be defined by a philosophy of patient advocacy, and not by tasks, in response to a statement in the literature that others could perform nursing tasks. Rand (1982), however, argues that philosophies are best chosen by "rational and disciplined processes of thought and scrupulously logical deliberation" (as cited in Burkhardt & Nathaniel, 2008, p. 28). Testimony to the lack of serious consideration of patient advocacy as the philosophy of nursing practice is found in the nature of metaphors.

The capacity of metaphors to focus on some aspects of reality while obscuring others (Lakoff & Johnson, 1980) is pointed out by Wurzbach (1999), who suggests that patient advocacy as a metaphor in nursing has concealed the potential conflicts inherent in the role. Metaphors convey meaning by describing one thing in terms of another (Milton, 2009), which is the case when patient advocacy represents a myriad of other concepts. Becker (1993) observes that "using a metaphor is a serious theoretical exercise", a view echoed by Nisbet (1976) and Richardson (1994) (as cited in Sandelowski, 1998, p. 378). Envisioning patient advocacy as a metaphor, and not as a unique concept, obscures the specialized skills needed to consistently and effectively assist patients when their legal or human rights are jeopardized. Moreover, measurement of the outcomes of health care requires clearly defined variables (Hudon, Fortin, Haggerty, Lambert, & Poitras, 2011).

From a historical perspective, it is easy to see the value of this early theory of the nurse's role as patient advocate in a health care system that had only recently acknowledged patient rights (Annas & Healy, 1974). Yet, such a dyadic interpretation exemplifies standards of nursing practice (ANA, 2010), and not necessarily advocacy. Also missing in the literature is how this interpretation of patient advocacy differs from other concepts reported to embody similar principles, such as caring (Sellin, 1995; Watson, 1985) and empowerment (Bird, 1994; Falk-Rafael, 1995).

In light of the current goal for nurses to become leaders in a health care system that meets patients' needs (Institute of Medicine [IOM], 2011), a dyadic interpretation may risk obscuring an important function of patient advocacy in meeting the unmet needs of patients in complex organizations, such as hospitals. Kohnke (1980) describes patient advocacy as helping patients understand information and supporting patients' decisions in spite of barriers that may prevent patients' autonomous decision-making. This interpretation includes a real or risk of a potential conflict with another party or parties, and is described in the literature as "triadic" patient advocacy (Mallick, 1997, p. 310). Triadic patient advocacy affords unique attributes to the concept of patient advocacy. The ANA (2001) Code of Ethics does not make ambiguous statements concerning patient advocacy, clearly stating a triadic view that:

As an advocate for the patient, the nurse should be alert to and take appropriate action regarding any instances of incompetent, unethical, illegal or impaired practice by any member of the health care team or the health care system or any action on the part of others that places the rights or best interests of the patient in jeopardy. (3.5)

The Code also provides guidelines for enacting the role of the patient's advocate that are highlighted by interpersonal communication, interprofessional collaboration, and use of

the organizational chain of command as appropriate. A critical aspect of patient advocacy is that this expected role has legal implications. Burkhardt and Nathaniel (2008) forewarn that courts recognize and rule against nurses who follow questionable orders or fail to alert the chain of command when problems arise. As well, patient experiences affect quality and safety, with patient-driven metrics such as the publically reported *Hospital Consumer Assessment of Healthcare Providers and Systems* (HCAP) carrying a financial impact for hospitals (Institute for Healthcare Improvement [IHI], 2012).

Because institutional and hierarchical constraints limit nurses' autonomy concerning triadic patient advocacy, Mallick (1997) concludes that the role becomes a choice rather than an obligation. Bernal (1992) answers the argument that patient advocacy is contingent on autonomous nursing practice by pointing out that an "idealized version of autonomy" is something that "no one working in hospital actually possesses", arguing that "what is needed is not greater individuation for nurses, but greater cooperation among all professionals who provide health care in a hospital setting" (p. 21). Currently, the unmet needs of patients are recognized as a system problem (IOM, 2011). Taking system dynamics in consideration when advocating for patients involves different skills than those required for dyadic interpretations of patient advocacy.

Despite similarities in how patients and nurses have characterized patient advocacy, there are major contextual differences between patients and nurses. The choice of a grounded theory methodology uncovers these differences. Glaser (1967) explains that "The goal of grounded theory is to generate a theory that accounts for a pattern of behavior which is relevant and problematic for those involved (p. 93). Although both patients and nurses are surrounded by the same local context of the physical hospital structure, there are professional

responsibilities of nurses and situational factors of patients that influence the definition of patient advocacy.

Patients, unlike nurses, generally have limited knowledge of medical conditions or the hospital system, and are vulnerable due to effects of illness (Schlairet, 2009). Nurses are charged with delivering care that is based on professional practice standards, which include the aspects of care described as patient advocacy by the participants in this study (ANA, 2010). These are clearly two very different contexts. Distinguishing patient advocacy as performing expected nursing competencies, such as listening, giving information, and helping patients participate in their own care appears to have contributed to the confusion surrounding this concept in nursing. Schwartz (2002) agrees with this view in arguing that, “the salutary values advocacy embodies are already part of good professional health care” (p. 37). If assuring that patients have the information they need to make informed health care choices is patient advocacy and not empowerment or shared decision-making, one can begin to see why patient advocacy in nursing continues to be conceptually ambiguous. The response of one participant with a background in health care captured the essence of this confusion:

*“I think the word “advocacy” in the hospital is a misnomer. It shouldn’t be needed. It suggests an inherent conflict that you are up against an inscrutable system. It is sad that people see it as part of patient care at all. It is a commentary on the state of health care” (Participant 17).*

Meleis (2012) argues that, “Theory development in nursing has not kept pace with the expanding roles of nursing and does not support nursing actions” (p. 448). In the previous example, providing information requires different skills than does taking action to uphold

informed consent when it is lacking. In other words, advocacy *for* informed consent is different than defining patient advocacy *as* informed consent. Adding to the confusion is that patient advocacy as a nursing diagnosis, intervention, or outcome of care is not found in nursing taxonomies. It is important to maximize nursing's contribution to health care, and to make the "invisible" work of nursing visible (Spilsbury & Meyer, 2001, p. 6)

The way that practitioners perceive advocacy for hospitalized patients has compelling implications for nursing practice. For example, Day (2006) maintains that patient advocacy interpreted as protecting patients from harm can result in blaming others without a full understanding of the circumstances. Agency that is realized "as part of a collaborative, multidisciplinary, team-oriented approach to care" results in a more complete understanding of situations (p. 428). Said another way, hospitals are social settings, and in achieving goals practitioners cannot "abstract themselves from the social obligations, relationships, and contingencies that characterize social settings" (Bernal, 1992, p. 22). Contemporary authors agree that nurses need to find common ground with other health care professionals as collaborative practice gains momentum (Crigger & Godfrey, 2010; Benner, Sutphen, Leonard, & Day, 2010). Participants believed team cohesiveness to be highly beneficial to the care they received. A spouse describes the powerful effects of team cohesiveness:

*"They were all connected. They treated me like it was okay that I knew things. They have a communication bond. They do, it is so wonderful. I want to go where I am treated like I mean something. I am not a number, I am a person. And that is how they treat you there. Their system works. I think it is a big example of patient advocacy. Everything was coordinated. All we did was have to get there. It felt like we were somebody" (Participant 6)*

Who should be a patient advocate provoked differing responses. Many consumers felt that everyone involved in the care of patients could be a patient advocate, while others believed that employees of the hospital had conflicting interests and should not be patient advocates. Nurses were consistently described in positive terms for their contribution to patient care, but there was a perception that nurses are too busy to be patient advocates. Most participants believed that patient advocacy should be a team effort. Team involvement in care meant there was a greater likelihood of *Being heard*, *Receiving information*, and *Participating*, in other words, of not *Falling through the cracks of the system*.

### **Implications for Education**

Patient advocacy that is characterized by team involvement has implications not only for nursing practice, but also for nursing education and nursing research. The specific skills and techniques required for nurses to be influential members of health care teams require identification, practice, and evaluation (Apker, Propp, Ford & Hofmeister, 2006). *The Future of Nursing: Leading Change, Advancing Health* (IOM, 2011) publication calls for “nursing education that is transformed in a number of ways to prepare nursing graduates to work collaboratively and effectively with other health professionals in a complex and evolving health care system” (p. 164).

If patient advocacy is an umbrella term for the work that nurses do (Allmark & Klarzynski, 1992; Foley, Minick, & Kee, 2002), then no special or additional training is needed for the role. However, if patient advocacy is a unique concept for the purpose of meeting the unmet or at-risk needs of patients, then the skill set differs. Teaching students to listen and reply responsively to patients is an essential focus of nursing education, and granted, is a competency that has been described as difficult to teach (Hawkins-Walsh

(2000). However, taking action to restore *Being heard* when this aspect of care is lacking or inadequate requires a different skill set, one that involves dealing with the various factors involved in the deficiency. The same holds true for *Receiving information* and *Participating*. Interpreting patient advocacy as meeting the unmet needs of patients necessarily requires specific skills. Important to this discussion is that in suggesting that nurses could fulfill the new role of the patient advocate in upholding patient rights in the hospital, Annas and Healy (1974) cautioned that specialized training would be necessary. Woodrow (1997) and Hamric (2000) argue that advocacy as a moral ideal in nursing has not been translated for students into a practical reality.

Meeting the needs of patients is an ethical issue (Roper, 2008). The nurse's role in preventing and resolving ethical conflict has been described by Taylor (1995) as a form of patient advocacy. Burkhardt and Keegan (2009) point out that nurses have long used ethical principles grounded in respect for individuals, such as autonomy, beneficence, nonmaleficence, and distributive justice. Nonetheless, there are many situational factors and contingencies that complicate ethical situations and issues. One of these factors concerns the education of health care workers. Mitchell, Uehlinger, and Owen (1996) found that nurses often feel incapable of initiating ethical discussions due to the lack of an adequate theoretical background in ethics. As well, the everyday aspects of care were reported to be largely neglected in the ethics literature (Robertson, 1996). Knowledge of ethics and ethical decision-making models are necessary topics for nursing education in order to prepare nurses to engage in ethical discussions and to influence outcomes with nursing values (ANA, 2001; Weaver, Morse, & Mitcham, 2008).

An example of the complexity involved in advocacy viewed as defending patient decisions is that some decisions may be detrimental to the patient's well-being, or may infringe on the moral code of others (Bird, 1994). In this case, the ethical principles of beneficence, autonomy, and paternalism must be weighed, resulting in what Zomorodi & Foley, 2009 call clarifying the "thin line" between advocacy and paternalism (p. 1746). Such situations require not only knowledge of ethics and ethical decision-making strategies, but also well-developed communication skills in order to most effectively interact with patients and all involved parties (Schlairet, 2009).

The greatest need for change in the delivery of health care is argued to be at the hospital bedside (Viney, Batcheller, Houston, & Belcik, 2006). Based on the professional obligation to advocate for patients, Schlairet (2009) maintains that nurses should be leaders in bioethics mediation in order to promote care that is driven by individual patient circumstances. Recommendations for undergraduate education that support the development of leadership skills, necessary for nurses to act as patient advocates, are outlined by the American Association of Colleges of Nursing (AACN) in *The Essentials of Baccalaureate Education for Professional Nursing Practice* (2008). Essential topics for education include ethics, communication, knowledge of human diversity, and an understanding of health care systems. Schlairet (2009) recommends additional competencies for the "mediation advocacy" skill set of advanced practice nurses, including preparation for initiating change, facilitating communication, systems theory, management skills, and policy development (p. 190). The importance of developing effective communication skills in nursing education is underscored by the potential that communication has for creating conflict. Scott (2004) points out that

many problems encountered at the bedside are communication problems (as cited in Schlairet, 2009).

The concepts of *Being heard*, *Receiving information*, and *Participating* are identified in the literature as important components of patient centered care, a major focus of current health care reform (IOM, 2011). According to the World Health Organization (WHO) (2008), “People who are more informed and engaged tend to use fewer health care resources, and make more appropriate choices, leading to better health outcomes” (Coulter, Parsons, & Askham, 2008, p. 1). The difficulty of providing patient centered care, however, continues to be challenging, and new strategies are continually being developed to strengthen patient engagement (Frampton et al., 2008). Educating nurses about these challenges, strategies and tools can make a positive difference in patients’ experiences, and can assist nurses to role-model patient engagement behaviors. Through role-modeling, nurses can expand their credibility to influence systems that fail to meet patients’ needs.

*Falling through the cracks of the system* emphasizes knowledge of the system as an important factor in meeting patients’ needs. There are few accounts of hospital policies that guide nurses through the process of patient advocacy found in the literature, which means that nurses may be faced with figuring out how to carry out this role on their own within the various structures of health care organizations. In light of the personal risks when nurses attempt to meet unmet patient needs on their own in unresponsive systems (Black, 2011), teaching nurses how to influence interdisciplinary teams using evidence-based practices, nursing values, and patient needs offers a far less threatening strategy to take action as a patient advocate. Both Snowball (1996) and Chafey, Rea, Shannon, and Spencer (1998)

emphasize the potential of collectively uniting to improve patient experiences within the constraints of bureaucratic hospital environments.

McGrath, Holewa, and McGrath (2006) found that differing disciplinary perspectives can make decision-making difficult. Knowledge of the roles and priorities of other disciplines is foundational for effective collaboration (Crigger & Godfrey, 2010). One promising educational strategy is simulation. Researchers report that simulation enhances interdisciplinary learning and has widespread utility for interprofessional application (Moule, Wilford, Sales, & Lockyer, 2008). Ultimately, Bird (1994) concludes that, “If the multidisciplinary team exercise their responsibility and accountability in acting in the best interest of patients in carrying out their duty to care to avoid harm, then ‘advocates’ are unnecessary” (p. 153).

### **Implications for Research**

The research implications from this study concern meeting patients’ needs in the hospital and advancing the concept of patient advocacy in nursing. Focusing on establishing a consensual definition of patient advocacy in nursing practice is a priority research recommendation. More than a decade ago, Breeding and Turner (2002) argued for a consistent understanding of patient advocacy in order to explore this concept in a more meaningful way. Research concerning patient advocacy is predominated by qualitative studies asking nurses about their beliefs and experiences. It is important to consider that these accounts are influenced by nursing education that has also faced the problem of conceptual ambiguity concerning patient advocacy found in the literature. Paley (2001) argues that an “elusive concept” occurs when attempts at definition are made by compiling “things said”, which only results in a constant repetition of associations and resemblances (p. 196). Clear

conceptual definitions are needed to measure the work that nursing does on behalf of consumers (Hudon et al., 2011).

Another relevant area of research concerns how the structures and processes of interdisciplinary teams influence the patient advocacy role of nurses. Interprofessional education (IPE) is a recommended strategy to improve interprofessional collaboration that has been linked to improved patient outcomes (IOM, 2011). However, in a review of IPE research, Reeves et al. (2009) concluded that “it is difficult to be certain about the effect of IPE and to understand the key features of IPE to train health and social care professionals to work together effectively” (p. 2).

The differing perspectives of health workers can be beneficial in identifying priorities and choices for most effectively solving problems (IOM, 2011). Pederson (2012) argues that such a “distributed cognitive system” improves patient safety and promotes professional practice that is healthy and caring (p. 541). Research that 1) critically examines use of the concept of patient advocacy in nursing and in other professions, 2) evaluates the utility associated with various interpretations, and that 3) identifies optimal conditions for the resolution of problems is needed to increase understanding of how teams from various disciplines can use patient advocacy as a tool to best realize patients’ needs and expectations.

In a recent literature review of IPE, Dufrene (2012) reports that nursing students lack confidence in speaking with other members of the health care team because of limited opportunities to experience collaboration in practice. Identifying and overcoming the obstacles involved in why some nurses do not “speak up” with information may make a difference in ensuring the best patient outcome (Sayre, McNeese-Smith, Phillips, & Leach, 2012, p. 458). Simulation can begin to provide the practice needed to develop this skill.

Identifying, developing, and evaluating skill sets that help nurses interact easily and effectively with other professionals is a priority to provide evidence based practices for the expanding role of nurses.

Further validation of the propositions and hypotheses generated by grounded theories can be empirically verified in subsequent studies (Glaser & Strauss, 1967). As well, structural equation modeling (SEM) includes a variety of different statistical models to evaluate the validity of a proposed model (Lei & Wu, 2007). Proposed graphical theoretical models that are generated by grounded theories can be applied to the graphical interface of SEM software to evaluate the “fit” of the proposed models based on data results (p. 285).

### **Evaluation of Quality**

Corbin and Strauss (2008) use the term “credibility” to indicate that findings from qualitative research are “trustworthy and believable” (p. 302). The following criteria are evaluated for this particular method of grounded theory: 1) fit, 2) applicability, 3) concepts, 4) contextualization, 5) logic, 6) depth, 7) variation, 8) creativity, 9) sensitivity, and 10) evidence of memos (p. 306):

1) Fit: “Do the findings resonate/fit with the experience of the participants and the professionals for whom the research was intended?”

The developing concepts of the theory were validated by participants during the interviews by repeatedly asking participants if they agreed with the interpretation of their responses. Examples of this strategy are included with participant responses. The strategy not only helped to validate the concepts, but was valuable in eliciting the dimensions and properties of concepts as participants clarified and expanded on their perceptions. It is not yet known whether application of the theory to nursing practice will resonate with nurses. In

considering the risks associated with triadic patient advocacy described in the literature, the utility of patient advocacy viewed as a collaborative practice endeavor may be appealing.

2) Applicability: “Can the findings be used to develop policy, change practice and add to the knowledge base of the profession?”

Since the study resulted in a substantive theory and not a formal theory, more evidence will be required to change practice and develop policy. The results, however, do increase the knowledge base of the profession by providing the perspectives of one sample of consumers in advancing the dialogue of patient advocacy towards greater clarity.

Professional disciplines must be able to “clearly articulate a coherent view of the discipline, its values, goals, and areas for future development” (Meleis, 2012, p. 354).

3) Concepts: “Are the findings organized around concepts, and are concepts developed in terms of their properties and dimensions so that there is density and variation?”

Each conceptual phase in the theory is accompanied by various dimensions and properties. Concepts and their properties and dimensions are shown in Table 4.

4) Context: “Is there sufficient “contextualization of concepts” so that the reader can fully understand why events occurred, why certain meanings and not others are ascribed to events, or why experiences were one and not another?”

As would be expected when interviewing participants whose needs have not been met, the examples given were often specific, explicit, and filled with passion, allowing for the inclusion of several in-vivo concepts in the development of the theory. Examples of questions asked of the participants are included with their responses, which increases meaning and context.

5) Logic: “Do the findings make sense? Are methodological decisions made clear so that the reader can judge their appropriateness for gathering data and doing analysis?”

Glaser & Strauss (1967) maintain that the adequacy of a theory cannot be separated from the process of creating it. In addition to specific questions and participant responses, examples of memos written during the analysis are provided in Appendix IV to help readers judge the appropriateness of methodological decisions. Numerous descriptions were provided that support the identification of concepts.

6) Depth: “Do descriptive details add richness, variation, and lift the findings out of the realm of the ordinary?”

Some participant responses, such as the metaphors that they offered to describe the feelings that accompanied their experiences, were so moving that they were used verbatim in the theory. Each concept has several dimensions and multiple properties that show the importance of what patients value.

7) Variation: “Are there examples of cases that don’t fit the pattern or that show differences along certain dimensions or properties?”

Areas of differences concerned 1) when a patient advocate was needed, and 2) who could be a patient advocate. Some participants believed that if their needs were met, there was no need for a patient advocate, while others felt that meeting patient needs was evidence of patient advocacy. While most participants believed that anyone involved in their care was a potential advocate, some participants felt that no one in the health care system could or should be a patient advocate due to the potential for a conflict of loyalty. These differences are reflected in the conceptual model of the theory shown in Figure 3.

8) Creativity: “Does the research say something new, or put old ideas together in new ways?”

Grounded theories consist of tentative hypotheses about problems that explain patterns of behavior and apply new understanding to processes (Nathaniel & Andrews, 2007). The research proposes a substantive theory informed by consumer expectations. Application of the theory to nursing practice provides a new perspective by drawing on nursing practice guidelines in differentiating between consumer perceptions and nursing responsibilities for patient advocacy.

9) Sensitivity: “Did the analysis drive the research, or was the research driven by some preconceived ideas or assumptions that were imposed on the data?”

The theoretical concepts and their dimensions were developed inductively from the responses of the participants, which can be appreciated by the many examples given for each of the theoretical concepts. The discussion and application of the results to nursing practice, however, were identified deductively through comparisons made with the nursing literature and nursing standards of practice.

10) Evidence of Memos: “Is there evidence or discussion of memos in the final report?” (Strauss and Corbin, 2008, p. 302).

Examples of memos are provided in Appendix IV.

### **Limitations**

Data from this study were obtained from only one hospital, although various units within the hospital were sampled. Because of this, and because there are few accounts of consumer perspectives of patient advocacy during the hospital experience, only a substantive theory could be developed. Substantive theories are limited, while formal theories can be applied across a wide range of context (Corbin & Strauss, 2008; Glaser & Strauss, 1967).

Since formal theory requires the analysis of a number of substantive theories, more research is needed to provide a higher level of guidance and predictive value regarding the patient advocacy role in practice. Although participants provided powerful positive and negative emotional effects of having or not having their needs met, there are other complex ethical issues that patients face, such as futile treatment, withdrawal of treatment, end-of-life decisions, and family conflicts (Schlairet, 2009) that were not captured in this study.

### **Conclusion**

The purpose of this grounded theory of consumer perspectives about patient advocacy in the hospital setting was to advance the concept of patient advocacy in nursing. The theory encompasses the continuous and reciprocal processes of *Being heard*, *Receiving information*, and *Participating*. *Being heard* leads to *Receiving information*, which results in a greater capacity for *Participating*. Participants explained that describing patient advocacy in these terms reflects the reality that these aspects of care are often lacking or missing, which lead to the core concept of the theory: *Falling through the cracks of the system*. A patient advocate provides these expected aspects of care and takes action to make certain that they are provided when they are missing or lacking.

The theory is applied to nursing through the lens of nursing standards of practice. Aspects of care identified by consumers as patient advocacy mirror competencies and standards of professional nursing practice. If patient advocacy in nursing is interpreted as a metaphor for these competencies, then no additional training is needed for the role. However, if patient advocacy is a unique concept for the purpose of meeting the unmet needs of patients, then the skill set differs due to the potential for a variety of factors to contribute to the deficiency in care. Care delivery models in which nurses influence interprofessional

teams with nursing values, consumer needs, and evidence-based practices highlight patient advocacy as a tool for change when patient's needs are not met. The health care consumers in this study were very much aware of the cohesiveness of the team of health care practitioners and the impact of teamwork on the quality of care that they receive.

An area of difference was who could be a patient advocate. Some consumers viewed anyone involved in their care as a potential advocate, while others felt only persons not affiliated with the hospital could be a patient advocate due to a potential conflict of loyalty. Many participants believed nurses were too busy to be patient advocates.

Findings from the study offer a framework for developing nursing interventions that enhance the delivery of quality patient care and that make the work of nurses enacting the role of patient advocate visible and measureable. As nursing practice evolves into expanded roles of interacting with other professionals in shared leadership frameworks, an interpretation of patient advocacy that guides nurses to effectively influence teams of health care professionals with patients' needs, nursing values, and evidence based practices has much to offer.

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