Nurses' Advocacy Behaviors in End-of-Life Nursing Care

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Key words: advocacy; end-of-life nursing care; supports and barriers to advocacy practice

Nursing professionals are in key positions to support end-of-life decisions and to advocate for patients and families across all health care settings. Advocacy has been identified as the common thread of quality end-of-life nursing care. The purpose of this comparative descriptive study was to reveal acute care nurses' perceptions of advocacy behaviors in end-of-life nursing practice. The 317 participating nurses reported frequent contact with dying patients despite modest exposure to end-of-life education. This study did not confirm an overall difference in advocacy behaviors among novice, experienced and expert nurses; however, it offered insight into the supports and barriers nurses at different skill levels experienced in their practice of advocacy.

Introduction

The practice of advocacy and end-of-life care in the USA changed drastically in the twentieth century owing to the advances in medical technology and science. The leading cause of death has changed from communicable disease to chronic, degenerative illness. The care of dying people has shifted from family and the community to experts in the health professions.[1–5]

Advocacy has been identified as the common thread of quality end-of-life nursing care,[6–9] encompassing pain and symptom management, ethical decision making, competent culturally sensitive care, and caring for people through the death and dying process.[1,10–12] Nurses spend more time with people who are facing death than any other member of the health care team.[1,4,12] Throughout history, nurses have sought ways to improve quality of life for individuals, families and communities during every phase of life's journey. Nursing professionals are in key positions to support end-of-life care decisions and to advocate for patients and families across all health care settings. Congruent with the literature and for the purpose of this study, advocacy behaviors in nursing practice are simply defined as assisting patients and families to overcome barriers impeding the care path.[13]

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Statement of problem

Advocacy is embedded in nursing practice;[11,14,15] it is therefore difficult to describe. Nurse educators are challenged to prepare graduates who possess the ability to practice advocacy; however, there is little description in the literature of how nurses learn the advocacy role. Death and dying are touched on in the core curriculum of most nursing schools, but treatment is often limited to a single lecture, a brief class discussion, or a series of assigned readings.[16]

The disparity between the way people die and the way they wish to die is increasing. The majority of adults wish to be cared for at home if they are terminally ill, but the reality is that less than 29% enroll in home hospice services, leaving the majority of end-of-life care to acute and long-term care institutions.[17,18] Some institutional cultures impede good care because of their treatment and cure focus, paternalistic care, inadequate decision-making models, and inadequate policies for pain and symptom management.[1,16,18–20] When nurses advocate for patients, they may face barriers associated with health care systems[21] and professional relationships.[22–26]

Purpose of the study

The primary purpose of this study was to describe nurses' perceptions of advocacy behaviors in end-of-life nursing practice in the acute care setting.

Theoretical framework

In the novice to expert process, Benner[27] provides a framework in which nurses can move towards becoming effective patient advocates. Nursing practice skill acquisition and development suggest that movement through the levels occurs over time and with practice experience. Novice nurses rely on abstract principles, rules and concrete experience. As nurses move towards expert practice, the shift from reliance on analytical, rule-based thinking to intuition occurs. For the purpose of this study, Benner's[27] five skill levels were collapsed into three categories: novice, experienced and expert. The novice and advanced beginner stages of skill acquisition were combined to reflect the practice of first year graduate nurses in transition from students to registered nurses. The competent and proficient stages of Benner's[27] skill acquisition were combined to create experienced-level nurses.

From the nurses' skill level emerges Benner's[27] seven domains of caring practice as they relate to advocacy behaviors.[5,27,28] They relate holistically to the defining characteristics identified in the literature review of nurses' advocacy practice performed for this study. The threads of a caring and excellent practice describe in full what consequences, or desired outcomes, advocacy behaviors should produce. A conceptual map of Benner's[27] theory related to nurses' advocacy behaviors when caring for patients nearing end of life appears in Figure 1.

The first step towards integrating the behavior of advocacy is to develop a reasoning-in-transition skill. Benner's[27] description of this is transformed into moving from curative therapies to end-of-life nursing care and caring can be used to explain the trigger experience.

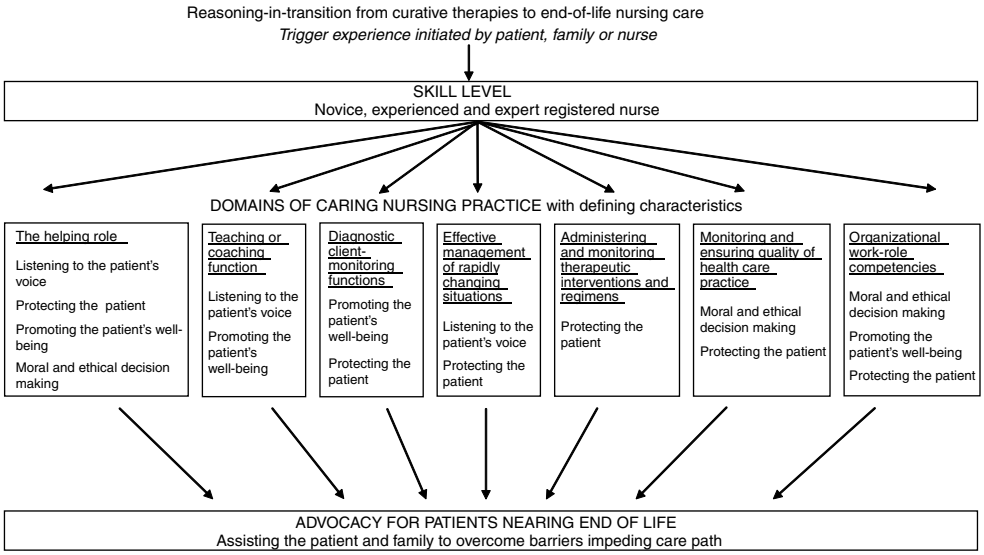

Figure 1 Conceptual model of advocacy behaviors in end-of-life nursing care

Review of the literature

Many authors[7,8,29,30] suggest that the nursing role of advocacy should enable and support autonomous clients. Patients' right to have all the information necessary to make decisions is particularly important. Thus, the act of advocacy has two parts: first, to inform and, second, to support. Nurses do not act in the place of the patient; they assist the autonomous patient and family to make decisions with representation and communication.

The foundation of advocacy is the nurse–patient relationship.[7,8,30–32] The nurse is engaged in the relationship unifying the experience and facilitating the personal meaning that the illness, suffering or dying is to have for the patient and family.[31,33,34] The nurse is in the ideal position among health care providers to experience the patient as uniquely human, with individual strengths and beliefs, and to use this position to intervene on the patient's behalf.

The person in need of advocacy has been described as vulnerable,[8,12,35,36] powerless, helpless, dependent,[6–8,28] and unable to speak, with loss of control for the person's self.[8,11] A trigger situation,[8,11] such as an illness and/or hospitalization that requires decision making and action, is necessary in order for the act of advocacy to begin.

Analysis and synthesis of the findings in the literature reveal the following defining characteristics of advocacy: (1) protecting the patient;[6,7,28,37–40] (2) listening to the patient's voice;[15,25,31,35,39,41–43] (3) moral and ethical decision making;[33,39,41,44–46] and (4) promoting patient well-being.[8,28,31,37,40,43] These four defining characteristics of the concept of advocacy from a nursing perspective appear over and over again in the literature and are rooted in the standards of professional practice.[1,9]

The patient and family outcomes that are expected to occur if advocacy is practiced by nurses during end-of-life care include: (1) safe care;[9,10,32,38,47,48] (2) improved

quality of life for the patient and family;[7,8,35,48,49] (3) patient autonomy and self-determination;[6,9,37,42] (4) patient satisfaction;[6,37,41,47] (5) dignity of life;[1,5,48] and (6) comfort and minimal suffering.[1,4,5,39,48,50] Nurse satisfaction and empowerment are additional outcomes in the practice of advocacy.[3,11,22,32,38,44,51]

Method

Design and setting

A comparative descriptive design was used to examine the differences among novice, experienced and expert nurses in the perceptions of advocacy behaviors in end-of-life nursing care in acute care settings. A naturally occurring practice setting of three regional hospitals in moderately sized urban areas of the mid-Atlantic region of the USA provided the location for this study. The hospitals ranged in size from 185 to 800 inpatient beds and have implemented professional career ladders and forms of self-governance among nursing staff. Two of the hospitals continue to sponsor diploma schools of nursing and hire many of their own graduates. One hospital has reached and another is pursuing Magnet Status.

Instrument

The Ethics Advocacy Instrument (EAI)[21] is a self-administered 38-item instrument with four subinstruments. Its purpose is to 'explore the perceptions and behaviors of nurses, identify advocacy behaviors and how the educational systems and health care infrastructures support or don't support those behaviors' (p. 89).[21] A two-stage process testing content validity, clarity and readability was conducted. In addition, a pilot study confirmed instrument reliability. The major themes identified by Wlody[21] were congruent with this study's literature review and the defining characteristics of advocacy.

Assumptions

- Advocacy is embedded in nursing practice.
- Advocacy is an inherent part of all nursing curricula.
- Novice, experienced and expert nurses advocate for patients at different levels of expertise across domains of care in every practice setting.
- Vulnerable patients are in need of an advocate (nurse or otherwise) across all practice settings.
- Novice, experienced and expert nurses provide end-of-life care.
- Barriers interfere with the practice of advocacy in nursing practice.
- The power of advocacy removes barriers to achieve the patient's desired outcomes of end-of-life care.

Data collection

After permission for human participation protection was obtained from the appropriate review boards, 1000 self-contained study packets were distributed between the three hospitals. A general invitation to all registered nurses was provided and

access to the sample was achieved through nurse managers and a research co-ordinator. A cover letter detailing the study participants' rights, the purpose of study, and instructions for anonymous return of the survey via the United States Postal Service were included in the packet.

Data analysis

Demographic data and the responses from the EAI[21] were coded and entered into the Statistical Package for Social Sciences, version 12.0,[52] by the researcher. Content analysis was performed with the self-report data obtained from the two open-ended questions on the infrastructure instrument. Drawing conclusions required consideration of what the data meant in the context of acute care practice and of what the data implied with respect to the research questions.[53,54] An expert in qualitative research provided direction and input in all phases of the data analysis and concurred with the final outcomes.

Results

Demographic description of nurse participants

There was a 33.3% return rate. The study participants' ($n = 317$) reported ages ($n = 305$) that ranged from 20 to 73 years (mean 37.6; standard deviation (SD) = 12.1). Nearly half (47.1%) reported a Diploma in Nursing as their highest level of nursing education; only 1/5 (21.2%) held a Bachelor of Science degree. The respondents' primary areas of clinical practice ($n = 314$) were medical-surgical (47.5%) and critical care units (23.9%). The majority stated their practice position as staff nurses (89%) working full time (76.9%).

Nearly 68% of the study participants reported their frequency of working with dying patients as 'daily' or 'often', while under half (41%) had participated in training seminars concerning end-of-life care in the previous three years. Seventy-six percent of all participants indicated that the concept of nursing advocacy was a part of their formal or continuing education.

One-way analysis of variance (ANOVA) revealed significant differences among the three groups in years of experience ($F = 421.9$; $df = 1$; $P = 0.001$) and age ($F = 327.1$; $df = 1$; $P = 0.001$). A chi-square test of independence revealed further significant differences in the nurses' practice positions ($\chi^2 = 12.78$; $df = 6$; $P = 0.047$). Additional significant differences among novice, experienced and expert nurses were found in advocacy education ($\chi^2 = 19.72$; $df = 2$; $P = 0.001$), area of practice ($\chi^2 = 39.42$; $df = 8$; $P = 0.001$), primary employee status ($\chi^2 = 13.02$; $df = 6$; $P = 0.043$) and educational level ($\chi^2 = 20.26$; $df = 6$; $P = 0.002$). A majority of both the experienced (88.4%) and novice (88.5%) nurses reported that the concept of advocacy had been a part of their formal or continuing education. The educational-level differences among novice, experienced and expert nurses were demonstrated by the higher percentage of diploma graduates in the expert (53.3%) and novice (50.8%) groups.

Perceptions of advocacy behaviors in end-of-life nursing care

Table 1 presents the findings for EAI score comparisons. ANOVA revealed no significant differences in the perceptions of advocacy behaviors as measured by the

Table 1 Mean Ethics Advocacy Instrument scores for perception of advocacy and advocacy behaviors among novice, experienced and expert nurses ($n = 316$)

Group	No.	Range	Mean[a]	SD
Advocacy perception scores				
Novice	61	77–108	92.66	6.86
Experienced	69	76–106	90.64	5.09
Expert	186	76–111	91.34	6.05
Advocacy behavior scores				
Novice	61	6–9	7.62	1.03
Experienced	69	5–9	7.61	1.01
Expert	186	4–9	7.54	1.10
Combined scores				
Novice	61	85–116	100.28	6.84
Experienced	69	83–113	98.25	5.28
Expert	186	83–118	98.88	6.19

[a]Differences in means not significant.
SD, standard deviation.

advocacy perception scores (APS), the advocacy behavior scores (ABS) or the combined scores among novice, experienced and expert nurses.

Supports to practicing advocacy in end-of-life nursing care

The identification of supports to practicing advocacy in end-of-life nursing care was achieved by the Hospital Structure Support subinstrument of the EAI. Table 2 displays the mean Hospital Structure Support scores among novice, experienced and expert nurse participants. Using a one-way ANOVA, no significant difference was found.

An additional open-ended question served as an opportunity for the participants to express their opinions regarding the nurse as a patient advocate when caring for patients nearing the end of life. They supplied one to several narrative statements or phrases identifying supports to their advocacy practice. Across all nurse experience categories, nurse managers and coworkers were identified most often as supports to the practice of advocacy. Additional supports included multidisciplinary teams, communication, relationships with the patient, the family, and nurses' knowledge, beliefs and compassion. The experienced and expert nurses reported with greater frequency than novice nurses on the importance of communication, relationship with the patient, nurse beliefs and compassion, and the family.

Barriers to practicing advocacy in end-of-life nursing care

A second open-ended question served as an opportunity for the study participants to express the barriers experienced in their advocacy role when providing care to patients at the end of life. The three most frequent barriers identified include the physician, the patient's family and fear. Additional categories identified were: lack of communication, lack of knowledge, lack of time, and lack of hospital support.

Table 2 Mean scores on the Hospital Structure Support subinstrument of the Ethics Advocacy Instrument among novice, experienced and expert nurse participants ($n = 316$)

Group	No.	Range	Mean[a]	SD
Novice	61	1–6	3.57	1.47
Experienced	69	0–6	3.46	1.53
Expert	186	0–6	3.78	1.30

[a]Differences in means not significant.
SD, standard deviation.

All three participant experience groups reported with great frequency the perceived barriers of physician traits and physician communication. The expert nurse group added an insight that physicians have difficulties relating to end-of-life issues. Novice nurses responded frequently that lack of communication and lack of time and/or support served as barriers to their practice. All three groups reported fear as a barrier to their end-of-life nursing care.

Auxiliary analysis

The data revealed that there were no significant differences in the perceived advocacy role measured by the total APS and ABS scores among participants holding an associate degree ($n = 92$; mean = 99.33; SD = 6.54), diploma ($n = 147$; mean = 98.50; SD = 6.11), or baccalaureate degree ($n = 66$; mean = 99.82; SD = 5.68). Significant differences among nurses participating in training seminars concerning end-of-life care in the previous three years were revealed in the perceived advocacy role measured by the total APS and ABS scores ($F = 13.46$; $df = 1$; $P = 0.001$). Forty-five percent of the experienced nurses and 42.5% of the expert nurses reported having undergone end-of-life education in the previous three years, while only 31.1% of the novice nurses reported this experience. In addition, a significant difference was found among nurses who reported the role of nursing advocacy being taught in formal or continuing education within the previous three years ($\chi^2 = 19.72$; $df = 2$; $P = 0.001$). The novice and experienced nurses reported advocacy education with greater frequency (88.5% and 88.2% respectively) than expert nurses who graduated from schools of nursing more than five years previously (66.4%).

Discussion and interpretation of the findings

The demographic characteristics of the study participants are similar to the documented demographic characteristics of the region's suburban and rural workforce.[55,56] This study is congruent with the literature[12] in that the participants' caring for dying patients was common, rather than extraordinary. The participants who received education on end-of-life nursing care scored significantly higher on the APS and ABS combined scores than those who did not; education may therefore positively influence perceived advocacy behaviors in end-of-life nursing care.

The experienced and expert nurses reported a greater frequency of end-of-life education than the novice nurses who had graduated from schools of nursing within the previous year. This finding contradicts the recent emphasis on end-of-life education in schools of nursing,[2,5,24,57] but may indicate that practicing nurses are gaining access to end-of-life education such as that provided by the End-of-Life Nursing Education Consortium.[1,24]

The literature supports the view that advocacy is an essential component of nurses' professional role;[9,14,58] however, one quarter of the study participants did not acknowledge advocacy education. The study results further support the need for this in that a significant difference between participants who reported advocacy education and those who did not was revealed in the participants' APS and ABS combined score.

The study participants' high agreement with perceived advocacy behaviors in nursing practice is consistent with nursing's professional practice acts, ethical practice statements, social policy recommendations and definitions of professional practice. The lack of significant differences among the novice, experienced and expert nurse participants may be due to the time frame of the data collection and not measuring true novice practice. In addition, novice nurses may have answered the study instrument in a theoretical way, not yet experiencing confrontations or being positioned at the centre of a dispute. Another explanation of the finding may be that the practice environment cultivates low empowerment and complacency. In contrast to Benner's[27] model, the motivation to change and 'stand up' for personal beliefs of advocacy is lowered.

The study participants scored below average on the Hospital Structure Support subinstrument; however, the mean score was higher for expert nurses than novice nurse participants. This finding may be explained in that experienced and expert nurses have the confidence, maturity and life experience to navigate interpersonal and structural systems. Access to nurse managers, interdisciplinary teams, and hospital structures and policies such as ethics committees requires the 'hybrid of practical and theoretical knowledge' (p. 294)[27] that the expert nurses would have developed. This is congruent with the theoretical process of skill acquisition outlined by Benner.

The open-ended question asking study participants to identify the greatest barrier(s) to acting as a patient advocate provided additional insight into the differences among novice, experienced and expert nurses. One possible explanation may be that novice nurses practice from theoretical knowledge[27] and need time to establish proficiency and communication patterns. Other explanations may include that expert nurses are involved in policy making for clinical practice and have established lines of communication.

The importance of the expert nurse group identifying that physicians have difficulty relating to end-of-life issues cannot be underestimated. This finding agrees with and has been documented in other studies.[1,12,20,25,26,50] All members of a health care team need additional education on the many issues surrounding end-of-life care. This study's responses by the expert nurse group supports Benner's[27] theory in that expert nurses use integrative thinking skills; they can look beyond physicians' behavior and identify their need for education.

Carpenter[29] and Gates[36] both shed possible light on why all three nurse groups frequently responded that fear was a barrier to advocacy behaviors in end-of-life

nursing care. If nurses advocate for their patients, such as by sharing information about making informed decisions, conflict may occur. The risk of disciplinary action or loss of employment may seem too high a price for nurses to bear. Patriarchal systems may serve to overrule basic patient rights, despite patients' legal and ethical right to be informed. This explains why nurses fear speaking up for patients even when they are suffering.[36]

Limitations

The major limitation of this study was the low instrument reliability measure. There is limited validity of the EAI and the reliability measurement (Cronbach's $\alpha = 0.374$) was below generally acceptable levels.[53] The reliability obtained in this study cannot be compared with previous studies using the EAI because of the unavailability of precise measurements (GS Wlody, personal communication, 14 February, 2005).

Advocacy, as well as many other phenomena studied in nursing, may involve changes in different situations and over time. If one's perception of advocacy behaviors changes, the instrument's reliability may not reflect a stable or reliable measure. The decision to use data from the EAI was based on the changing nature of advocacy and the sufficient power achieved in the study sample. Additional limitations include the convenience sample from one geographic region, uneven sample groups, and the timing of data collection, which may have interfered with the measurement of true novice nursing practice.

Conclusions

- Acute-care nurses care for dying patients on a routine basis.
- Despite the recent emphasis on end-of-life nursing education, acute-care nurses report modest exposure to end-of-life training.
- Considerable agreement was shown for perceived advocacy behaviors in end-of-life nursing practice.
- End-of-life nursing education and advocacy education positively influenced the perceived advocacy behaviors when caring for end-of-life patients as measured by the APS and ABS combined scores.
- The identified supports to the practice of advocacy center on nurse managers, coworkers and multidisciplinary services.
- Experienced and expert nurses reported with a higher frequency than novice nurses that communication, relationship with patients, nurse beliefs and compassion, and the family support the practice of advocacy.
- The major reported barriers to the practice of advocacy included the physician, the family and personal fear for all groups.
- Novice nurses reported with great regularity that a lack of communication and lack of time/support served as barriers to their practice of advocacy.
- There were no significant differences in the perceptions of advocacy behaviors among novice, experienced and expert nurses as measured by the APS and ABS combined scores.

Implications

The demand for end-of-life care will continue to increase as our elderly population grows and a burdened health care system confronts the increase in chronic and terminal illness. With the majority of nurses practicing in acute-care settings, this study's findings may serve as a baseline assessment to guide staff development education and hospital infrastructure policies.

Although there is a growing body of knowledge of the advocacy role in end-of-life issues, research in this field is still in its infancy in terms of rigorous testing and outcome measurement. The comparison of perceptions of advocacy behaviors among novice, experienced and expert nurses contributes to an understanding of the embedded practice of advocacy. This study produced similar results to previous research and is congruent with the literature in that the majority of the nurse participants agreed that they practiced advocacy behaviors, despite the reported barriers. A cross-method triangulation[53] served to strengthen internal validity by measuring the concept of advocacy from two approaches. Most studies measuring the concept of advocacy have been qualitative in nature.

Further research recommendations

Further research on this topic is recommended, including: (1) addressing the study questions using a larger sample from a wider geographic area and an instrument demonstrating acceptable reliability measures; (2) developing a quasi-experimental design using evidenced-based end-of-life nursing care with a focus on the role of advocacy; (3) expanding the sample to long-term care facilities; (4) using other qualitative methods, such as interviews or focus groups for data collection; and (5) continuing the use of experience group comparisons, but also considering the use of all of Benner's[27] five categories.

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