

Ethical advocacy in the end-of-life nursing care: A concept analysis

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Abstract

Aim: This concept analysis was conducted to identify and define the features and functions of ethical advocacy in the end-of-life nursing care.

Background: Ethical advocacy is key to the role of the nurse in delivering quality and competent care. Despite this, the dimensions of this concept are poorly understood.

Design/Data Source: Databases such as Google Scholar, Scopus, Web of Science, Science Direct, and PubMed were searched systematically. To search these databases, the following keywords were used: “patient advocacy,” “nursing,” “ethics,” “end-of-life care,” and their combinations.

Review Methods: Walker and Avant’s method was utilized as a comprehensive review of the literature to explore how ethical advocacy in nursing can be used to improve the quality of care.

Results: The defining attributes of the concept of ethical advocacy included adhering to ethical principles of nursing, championing social justice in the provision of healthcare, safeguarding and defending patient’s rights by applying collective wisdom, and involving hospital ethics committees. Antecedents are organizational and personal power and ethical leadership. The optimal consequence of ethical advocacy can be getting the best ethical governance.

Conclusion: Based on this analysis, the concept of ethical advocacy is one of the most important roles for nurses which requires their awareness of this concept.

KEYWORDS

concept analysis, ethics, end-of-life care, nursing, patient advocacy

1 | INTRODUCTION

The International Council of Nurses emphasizes the key roles of nurses in achieving Universal Health Coverage (UHC) by 2030 illustrating the role nursing plays in the 21st century to the delivery of quality health care to meet the goals of access for all and equity in health through advocating them.¹ Nurses can be with patients from birth to death and they help patients to recover from the most difficult conditions. In the absence of family they even sit beside dying patients and comfort them in the last moments of their lives.¹ It is

within these contexts that nurses frequently have to advocate for patients’ rights.

For the purposes of this analysis it is assumed that nurses advocate on many levels—for rights, for care, and in contexts that support nurses’ ability to provide care and services.² Hence, when applying the notion of “ethical advocacy” it must be considered from a broad perspective. To this end, four commonly used ethical frameworks for decision-making, utilitarianism, duty-based reasoning, rights-based reasoning, and intuitionism (Table 1) can be useful starting points.

TABLE 1 Ethical frameworks³

Framework	Basic premise
Utilitarianism	Provide the greatest good for the greatest number of people
Duty-based reasoning	Individuals have basic inherent rights that not be interfered with
Rights-based reasoning	A study to do something or to refrain from doing something
Intuitionism	Each case weighed on a case-by-case basis to determine relative goals, duties, and rights

According to previous studies to better understand these frameworks, it is suggested to use one of the participative care models such as patient-centered care⁴ or family-centered-care.⁵ In addition, hospital ethical committees' active involvement via interprofessional collaboration in end-of-life care^{2,6,7} and Do-Not-Resuscitate (DNR) situations can be helpful to gain a comprehensive insight into ethical advocacy by nurses.

Advocacy has not always been an explicit expectation of the professional nurse; however, the early writings of Nightingale reflected her commitment to health, healing, and acting in the best interests of patients.⁸ This key concept was featured in nursing ethics debates and discussed in nursing studies since 1953 when the International Council of Nurses developed and published the Code of Ethics for Nurses.⁸ However, the concept of advocacy was not mentioned or encouraged in the early years of professional nursing. In fact, the opposite was true. Indeed nurses were expected to be obedient to physicians and other superiors.⁹ This is not to say that nurses were not practicing advocacy but the voice of the nurse advocate was often absent as nursing practice transitioned to hospital-based models of care.

Patient advocacy can be considered an ethical action in which the nurse ensures that medical decisions are congruent with the patients' wants¹⁰ and nursing professional standards to meet comprehensive care needs through collaborative interventions. The reason for advocacy in nursing is often related to ethical decisions about care and, in general, provides a means of aligning best care with the wishes of the patient.⁵ Accordingly, nurses find themselves morally bound to advocate for their patients.¹¹ In fact, patient advocacy is a moral duty for promoting patient independence.

Patient advocacy can be considered as giving voice to the patients' values, those who are unable to speak for themselves. In such circumstances, the nurse speaks with the patient's voice. This dimension of the concept of advocacy in nursing often presents the greatest moral challenge because in this case, the nurse listens, decides, speaks, and acts in the interest or goodwill of the patient.^{12,13} Therefore, it is important to use the power of knowledge and experience of nurses in complex decision-making situations in the field of patient care, which can be achieved through the use of collective wisdom, such as the involvement of hospital ethics committees.^{2,7} The idea of collective wisdom originates from Aristotle, who has been often attributed with the quote, "many heads are better than one."¹⁴ In a practical sense this can be achieved by involving multidisciplinary hospital ethics committees in the decision-making process for

vulnerable patients such as those with end-of-life choices. As the result, there is a mechanism for minimizing conflicts of interest and limiting potential biases related to disability, race, or culture, all of which may be concerns when individual physicians act as the only decision-maker.¹⁵ Additionally, intellectual, spiritual, ethical, and esthetic competencies can also contribute to acquiring intuitive rationality in addressing ethical dilemmas and can be enhanced through the collective wisdom of interprofessional collaboration.¹⁶

In the 1988, Nelson¹⁷ proposed the concept of patient advocacy in five domains of ethical, legal, political, spiritual, and substitutive from a holistic perspective.

According to the Nelson's definition, of legal advocacy, the nurse is supportive of patient's legal rights such as informed consent or the right to refuse treatment. In substitutive advocacy, if the patient is unable to express his/her opinion, the nurse should continue to respect the rights of the patient and support their prior wishes. Political advocacy includes working to change laws and policies to assure equity for all patients, groups, and society. In spiritual advocacy, the nurse assures that the patient has access to spiritual support and the care plan includes spiritual aspects of care. Ethical advocacy requires that the nurse respect the patient's values and support decisions which are consistent with those values.¹⁷⁻¹⁹ Kubsch et al.¹⁹ also have discussed these domains and indicated that ethical advocacy is used more often than the other four domains.

As a result of our inquiry and to the best of our knowledge there have been few studies that address the different domains of the advocacy. Therefore, this analysis was conducted to clarify and to obtain a comprehensive definition of the concept of ethical advocacy and its features in the case of end-of-life nursing care as an important domain of nursing duty, using the Walker and Avant's systematic approach.

2 | SUBJECTS AND METHODS

2.1 | Concept analysis approach

The Walker and Avant's approach is a simplified modification of the Wilson's 11-step classic concept analysis²⁰ procedure that has eight steps as follows: 1. Selecting a concept, 2. Determining the purpose of analysis, 3. Identifying all uses of the concept, 4. Determining all

the defining attributes of the concept, 5. Identifying a model case, 6. Identifying borderline, related, and contrary cases, 7. Identifying antecedents and consequences, and 8. Defining empirical referents.²¹

2.2 | Determining the purpose of analysis

The purpose of this concept analysis was to examine the concept of ethical advocacy in end-of-life nursing care and to define its features and functions.

2.3 | Literature search

A systematic search of a number of bibliographic databases was conducted and included Google Scholar, Scopus, Web of Science, Science Direct, and PubMed. To search these databases, the following keywords were used: "patient advocacy," "nursing," "ethics," "end-of-life care," and their combinations: "Nursing" AND ("ethics" or "patient advocacy") and ("Patient Advocacy"[Mesh]) AND "Ethics"[Mesh] AND "Nursing"[Mesh] AND "end-of-life care" [Mesh]. The search process was also completed by

using synonyms of the search terms identified in the Cambridge Dictionary and a manual library research. No time filter was applied and full-text articles available in English were retrieved. The exclusion criteria were lack of proper referencing, and duplicate articles derived from analysis of the same data.

The initial searches resulted in a total of 1270 articles. After eliminating duplicates and scanning abstracts for relevance, 102 articles were downloaded for further review. Of those 102 articles, 85 were excluded because they did not focus on ethical domains of advocacy. All articles were read for descriptions and definitions of ethical advocacy (Figure 1). A final selection of articles, based on specific application and relationship with ethical advocacy was made resulting in 18 articles whose definitions of ethical advocacy are included in Table 2.

2.3.1 | Quality assessment

A structured extraction coding sheet was constructed to gather information from the selected articles such as antecedents, attributes, or consequences of the concept. The process of extraction was done

FIGURE 1 Preferred reporting items for systematic reviews and meta-analyses flow chart [Color figure can be viewed at wileyonlinelibrary.com]

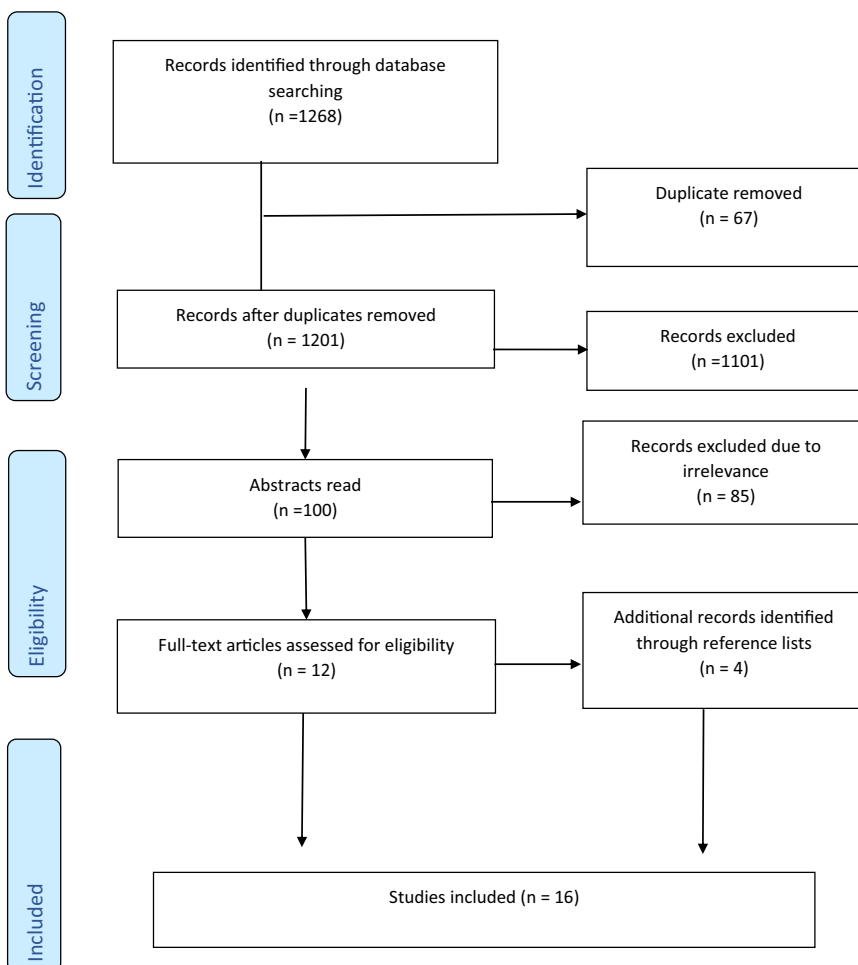


TABLE 2 Current literature related to ethical advocacy concept

First author/Year	Country	Title	Design	Antecedents	Attributes	Consequences
Abbasinia et al. ²²	Iran	Patient advocacy in nursing: a concept analysis	Concept analysis	-	Championing social justice in the provision of healthcare, Safeguarding	Nurse: experiencing a sense of being worthwhile and improving self-concept
Mason et al. ⁸	USA	Policy & politics in nursing and health care	Book	Ethical leadership	-	Negatives: of losing one's job, reputation, and professional status
Gaspar ⁴²	Brazil	Nurses defending the autonomy of the elderly at the end of life	A qualitative grounded Theory	-	Adhering to ethical principles of nursing	-
Pecanac & Schwarze ²³	USA	Conflict in the intensive care unit: nursing advocacy and surgical agency	A discourse analysis	-	Adhering to ethical principles of nursing Safeguarding defending patient's rights	Missions and responsibilities among nursing and other professions such as physicians, may result in intra-team conflicts
O'Connor ⁹	USA	Advocacy	A qualitative study	Nurses should have sufficient courage in addition to knowledge, experience, and confidence	Adhering to ethical principles of nursing	-
Smith ²⁴	USA	The ethics/advocacy connection	Not mention	-	Adhering to ethical principles of nursing	-
Shannon ²⁵	USA	The nurse as the patient's advocate: a contrarian view	Critical analysis	-	Adhering to ethical principles of nursing	-
Agom et al. ²⁶	Nigeria	Concept analysis of patients' advocacy: the nursing perspectives	Concept analysis	Ethical leadership	Safeguarding	Patient: autonomy, increased patient survival in care, empowering the patient, protecting patient rights, values and patient discomfort Nurse: job satisfaction, professional autonomy and proficiency, enhancement and improvement of public image of nursing, losing their job, professional position, roles or even have direct conflicts with other members of health team like doctors or even the employer
Ezeonwu ²⁷	USA	Community health nursing advocacy: a concept analysis	Concept analysis	Organizational and personal power	-	Improved access to equity, social justice, empowerment, and health and social reform
Kaye ²⁸	Australia		A survey	Organizational and personal power		

TABLE 2 (Continued)

First author/Year	Country	Title	Design	Antecedents	Attributes	Consequences
Bu & Jezewski ²⁹	USA	Ethical advocacy based on caring: a model for neonatal and pediatric nurses Developing a mid-range theory of patient advocacy through concept analysis	Concept analysis	-	Adhering to ethical principles of nursing Safeguarding defending patient's rights Championing social justice in the provision of healthcare, Safeguarding	Patient: protection of patients' rights, feeling of satisfaction, and increased life expectancy ethical advocacy can reduce health-care costs, that can be positive both for patients and health system
Vaartio & Leino-Kilpi ³⁰	Finland	Nursing advocacy—a review of the empirical research 1990–2003	Literature review	-	-	Nurse: increasing autonomy and self-empowerment, improved public image of the nursing profession, increased job satisfaction and self-confidence for the nurses Negative: ethically distressed and feel that they cannot do the right thing. In severe cases, their professional security may be threatened leading to legal action, ostracism, or severe disruption and havoc in their lives
Baldwin ³¹	UK	Patient advocacy: a concept analysis	Concept analysis	Nurse's should have responsibility	Adhering to ethical principles of nursing	Nurse: increasing autonomy and self-empowerment, improved public image of the nursing profession, increased job satisfaction and self-confidence for the nurses Patient: self-determination, discomfort
Falk Rafael ³²	USA	Advocacy and empowerment: dichotomous or synchronous concepts?	Not mention	Organizational and personal power	-	Nurse: satisfaction, risk
Rushton ³³	USA	The critical care nurse as patient advocate	Not mention	-	-	Negative: sometimes nurses are accused of disobedience, which may cost them their credibility, friends, and self-esteem Patient: self-determination
Gadow ¹²	USA	Clinical subjectivity. Advocacy with silent patients	Not mention	-	-	-

by two independent reviewers. Two of the authors, performed an independent reading of the selected texts and extracted elements of the concept. Then, the attributes, antecedents, and consequents of the material identified by each of the analysts were compared for agreement. A given element was considered valid if both analysts agreed. In the case of lack of agreement, input from a third researcher was sought and discussions took place until consensus was reached.

2.4 | Identifying all uses of the concept

2.4.1 | Ethical

An adjective that means "conforming to accepted standards of conduct" and was first appeared in 1573.³⁴ According to the Cambridge Dictionary, it is defined as "relating to beliefs about what is morally right and wrong."³⁵

2.4.2 | Advocacy

The Cambridge Dictionary³⁶ presents two definitions for the word advocacy: (1) "public support for an idea, plan, or way of doing something" and (2) "the work of defending people in court." The Merriam-Webster Dictionary³⁷ defines advocacy as "the act or process of supporting a cause or a proposal: the act or process of advocating." Another dictionary definition for advocacy is a pleader for the vulnerable.³⁸

2.4.3 | Ethical advocacy in nursing literature

According to the nursing literature, patient advocacy is a concept embedded in nursing ethics.³⁹ In many countries, as part of the defined scope of practice of the nurse, nurses can go beyond routine health-care practice and act as a patient advocate in all contexts and situations.⁴⁰ Within this context, if a nurse is considered an advocate who advocates for the patient's rights in all circumstances, then, they are ethically committed to their patients and in reality defend the patient's rights as a lawyer would in a court.⁴¹

3 | RESULTS

3.1 | Determining all the defining attributes of the concept

According to the results of this study, the attributes of ethical advocacy are adhering to ethical principles of nursing autonomy,⁴² beneficence, fidelity, justice,²⁵ nonmaleficence and veracity,²⁴ championing social justice in the provision of healthcare (confronting inappropriate policies or rules in the health-care system,²⁵ identifying and correcting inequalities in delivery of health services, facilitating

access to community health services, and health resources),²² safeguarding (track medical errors, protecting patients from incompetence or misconduct of coworkers, and other members of health-care team)^{22,25} and defending patient's rights²⁵ by applying collective wisdom and involving of hospital ethics committees.^{2,7}

3.2 | Identifying a model case

A frail elderly lady is in the intensive care unit on a respirator with a "No Code" sign. According to the surgeon's order, there is no need for the patient to be prepared for the Billroth II gastrojejunostomy treatment despite the patient's wishes. Her daughter had said to Sarah (her nurse) that my mother wants to continue her treatment process and all of our family are waiting for her to return back home in good health. When Sarah saw this order she spoke to the head-nurse, stating that this sign is an unethical action that disregards the patient's rights and values. After listening to her, the head-nurse went to speak with the surgeon about his order but he answered that this is not your responsibility to decide about the treatment of the patient. The head-nurse apprised the matron of this event. With the matron's following up, this issue was raised in the hospital ethics committee which consists of lawyers, the patient's surgeon, the matron, ethics consultants, physicians, the patient's daughter, her nurse, and the head of the hospital. Finally, they decided that the patient has a right to be treated like others and that this decision was in alignment with the patient's rights, values and needs.

The above example represents a case of the concept of ethical advocacy. Sarah, as her nurse based on the ethical principles of nursing identified the physician's inappropriate order and challenged it. The nurse, as the patient's advocate, was aware of the patient's right to receive treatment and the views, values and wishes of the patient and family. So, she confronted the inappropriate surgeon's order, and escalated it up through the organization to the HEC and as a result, using collective wisdom, the patients' rights were and safeguarded.

3.3 | Identifying borderline, related, and contrary cases

3.3.1 | Borderline case

During the COVID-19 pandemic, a 90 years old man was admitted to the intensive care unit on a respirator with a "No Code" sign. He is in the end stage of stomach cancer which has metastasized to his lungs, bone marrow, and liver. The doctor has said to his son that his father would die due to his situation and it is better for him to die in peace and has ordered that there is no need to continue the patient's treatment plan. The patient's son told Ahmadi (his nurse) that his father was everything that he had in the world and that he was not satisfied to discontinue his father's treatment plan. Ahmadi knows discontinuance of the patient's treatment is the opposite of the patient's wishes, and discontinuance of treatment would disregard his rights and constitute an unethical action.

He spoke with both head-nurse and matron in this regard and recommended the presentation of this issue in the HEC, but both of them said that the patient's doctor is one of the best doctors and if he says that there is no way for the patient to survive, that this is true and there is no need to elevate this case to the HEC. They said that the patient's doctor is the head of the hospital and he thinks that it's better to providing service for the young patients during this pandemic. As the result, the patient was transferred to the cancer unit despite his critical situation and the patient's wishes.

The above model represents a borderline case of ethical advocacy because it does not include all the features of this concept. In this example, Ahmadi is adhering to the ethical principles of nursing and made an effort to confront inappropriate physician order and protecting patient from this misconduct, but eventually, because of the paternalistic decision of the system, the patient transferred to the cancer unit.

3.3.2 | Contrary case

Sara is an end-stage blood cancer patient, in the ward with a "No Code" sign. Zahra is her nurse and is checking the physician's orders. Every day the patient's daughter comes to the nursing station and requests that everything possible be done, highlighting that her mother is the only person she has in her life. Every time that Zahra sees the patient's daughter, she thinks about all of the care that she provides for Sara, and feels it is futile because Sara will die as soon. One day Zahra noticed that some students are speaking about Sara... "we should improve our Intravenous Cannulation skills by trying them on this patient. She is not alert so we can try them out on her". When Zahra heard these words, verified them, and told them if you want to be a good nurse you should improve your practical skills, thus condoning the students' actions.

It can be easily understood that the above case is an unethical action and the nurse failed to play her ethical advocacy role.

3.3.3 | Related cases

Terms related to the ethical advocacy concept include the other types of advocacy such as legal, spiritual, substitutive, and political advocacy. The common point among these types is that all of them are intended to protect a patient's rights, but they are different regarding domain of care and level of activity. For example, spiritual advocacy aims to provide access to spiritual support and reassurance.¹⁹ Legal advocacy considers legal aspects of care, such as informed consent. In political advocacy, nurses actively engagement in the political process through actions such as voting, campaigning for candidates running for office, donating to a political action committee, and lobbying and educating elected officials about important issues.⁸ In political advocacy, nurses are engaged in a macro-level of advocacy.⁴³ According to our search, in substitutive advocacy, the nurse protects the interests of patients who are incapable of speaking for themselves.¹⁹ In ethical advocacy, the nurse upholds patient's

values in decision-making and its scope is more than substitutive advocacy.

3.4 | Identifying antecedents and consequences

3.4.1 | Antecedents

1. Organizational and personal power

The nurses should acquire the organizational and personal power required for advocating the patients' rights to be able to serve as patient advocates.^{9,31} Evidence suggests that nursing participation in ethical discussions about their patients such as involving in the hospital ethics committees, empowers them to discharge their advocacy role.²⁸ In other words, organizational and personal power of the nurses are important antecedents to fulfilling their role as an ethical advocate for end-of-life patients.

2. Ethical leadership

Ethical leadership is also a priori to ethical advocacy. Nurses as ethical leaders should have courage, competency, compassion, commitment, candor, consistency in applying ethical principles, and conviction of intuition to play their role as patient advocates efficiently.²⁴ They should be an integral part of training in advocacy skills,⁸ decision-making,²⁷ strong communication skills, and the ability to negotiate and provide leadership²⁸ because of the complexity of decision-making in end-of-life care of patients.

3.4.2 | Consequences

The consequences of ethical advocacy can have both positive and negative aspects for the nurse and the patient.^{26,29}

1. The patient-related consequences

All the consequences of ethical advocacy as a type of advocacy are positive for patients.³⁰ It can bring out improvement in the quality of patient care²⁸ and patient safety. It can also enhances patient empowerment³² and self-determination¹² and through applying collective wisdom it can challenge paternalism in decision-making for end-of-life patients.

2. The nurse-related consequences

The positive consequences of ethical advocacy for the nurse include increasing autonomy and self-empowerment, improving public image of the nursing profession, increasing job satisfaction and self-confidence for the nurses,^{29,30} experiencing a sense of being worthwhile, and improving self-concept.²²

The negative consequences of acting as patient advocates are that sometimes nurses are accused of disobedience, which may cost them their credibility, friends, and self-esteem.³³ They may also

become morally distressed and feel that they cannot do the right thing for their patients. In severe cases, their professional identity may be threatened leading to legal action, ostracism, or severe disruption and havoc in their lives.²⁹ There is also the risk of losing one's job, reputation, and professional status.²² Finally, differences in goals, missions, and responsibilities among nursing and other professions such as physicians, may result in intra-team conflicts.²³

3.5 | Defining empirical referents

Tools such as Protective Nursing Advocacy Scale (PNAS), Nursing Advocacy Beliefs and Practices (NABP), Patient Advocacy Scale (PAS), Patient Self-advocacy Scale (PSAS), Attitudes Towards Patient Advocacy (ATPA), The Patient Advocacy Engagement Scale (PAES), PSAS, Advocacy in Procedural Pain Care Scale (APPC), Patient-AES have examined various dimensions of advocacy in nursing. However, no independent tools for measuring the concept of ethical advocacy could be found. Only one tool, the Ethical Assertiveness Scale used by Dodd et al.⁴⁴ in 2004, appeared to be related to this concept. This tool uses 72 questions to examine the conditions in which nurses are involved in ethical decision-making. It also covers 28 ethical issues most commonly encountered according to the literature and measures the nurses' ethical performance and the acceptance of these activities by hospital. Accordingly, having examined the concept in detail and having identified the absence of a specific tool to quantify the concept it is argued that such a tool is needed if progress in measuring the degree to which nurses ethically advocate for their patients and the impact of education and other interventions to enhance their skills in this arena.

4 | CONCLUSIONS

Based on our findings, Ethical Advocacy is one of the advocacy dimensions that refers to the general concept of advocacy. This concept is one of the important aspects of nursing care specifically in end-of-life patients because of their vulnerability and inability for decision-making. Adhering to ethical principles of nursing, championing social justice in the provision of healthcare, Safeguarding and defending patient's rights by applying collective wisdom and involving of hospital ethics committees are features of this concept. By applying collective wisdom through the hospitals' ethics committees there is more chance for avoiding paternalistic decision-making which often occurs for end-of-life patients. Antecedents can be classified in two categories (organizational and personal power and ethical leadership) and its consequences can have both positive and negative aspects for the nurse and the patient. Consequently, by strengthening ethical advocacy abilities of the nurse helps ethical governance in the dimensions of the structure, process and outcome of the ethical performance of the health care team.

Like a lawyer in court that defends his/her client's rights and is committed to observe ethical principles, nurses should be able to

advocate their patients' rights against possible harms in the health-care system, consider patient's advocacy as an ethical duty, and adhere to its principles specifically in patients who are more vulnerable such as end-of-life patients. This requires the development of the political and professional power of the nurses. More studies in the field of ethical advocacy are required to understand its various aspects and how they impact quality of care.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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