Patient Advocacy

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Objectives

- Define Patient Advocacy.
- Identify key components of the role of the patient advocate.
- Discuss challenges and ethical issues of the patient advocate.

Historical Overview

- The Patients’ Rights Movement influenced the emergence of the patient advocacy role of the nurse (Mahlin, 2010).
- Patient autonomy and decision making was embraced and paternalism was rejected (Mahlin, 2010).

Definitions

Examples of definitions in the nursing literature:

- A patient advocate is someone who defends the patient against ‘infringements of his or her rights’ (Winslow, 1984 as cited in Mahlin, 2010).
- ‘primary obligation is to patients – rather than to physicians or hierarchies within the hospitals’ (Bernal, 1992 as cited in Mahlin, 2010).

Non-inclusive Definition

- “the nurse to actively support patients in speaking up for their rights and choices, in helping patients to clarify their decisions, in furthering their legitimate interests, and protecting their basic rights as persons, such as privacy and autonomy in decision making" (Hamrac, 2000 as cited in Mahlin, 2010).

Patient Advocates

- Nurses
- Physicians
- Social Workers
- Dieticians
- Family Members
- Healthcare Personnel
- Clergy
Nurse Advocates

- Nurses are primary patient advocates because they spend a significant amount of time caring for their patients and families while developing holistic and therapeutic relationships.

Scope of Patient Advocacy

- Individual - patients
- Families - mediators
- Groups - vulnerable populations
- Global - healthcare disparities
- Socio-Political - resources

Key Components

- Autonomy in Decision Making
- Informed Consent
- Justice
- Advance Directives
- Ethical Issues
- Patient Bill of Rights
- Patient Self Determination Act (1991)
- Code of Ethics for Registered Nurses
- Confidentiality
- Care and Compassion

Autonomy

- Promoting and protecting patient autonomy is one of the most important roles of a patient advocate. Patients have the right and freedom to self-determination.
- Autonomy = 1: the quality or state of being self-governing; especially: the right of self-government
  2: self-directing freedom and especially moral independence
  3: a self-governing state
(Merriam-Webster Dictionary)

Threats to Autonomy

- Paternalistic attitude = “fatherly attitude.
- Patient viewed as being dependent.
- Assumptions that patient values are the same as the healthcare providers.
- Focus on technology versus caring.
(Burkhardt & Nathaniel, 2002)

Informed Consent

- Involves disclosure and understanding of essential information.
- Patient must be given a description of the health concern, treatment options and risk of benefits of intervention versus no intervention.
- The patient advocate ensures that proper protocol is followed and that the patient has been given adequate explanation.
Advance Directives

- "are instructions that indicate health care interventions to initiate or withhold, or designate someone who will act as a surrogate in making decisions in the event we lose decision-making capacity" (Burkhardt & Nathaniel, 2002, p. 213).

Examples: Informed Consents, and DNR's

Ethical Issues

What are some ethical issues you can think of that you may be involved as a patient advocate?

Principles of Ethics

- Autonomy (self-governing)
- Beneficence (promote good; prevent harm; remove evil or harm)
- Nonmaleficence (avoid causing harm to patients)
- Veracity (practice of telling the truth)
- Confidentiality (non-disclosure, HIPPA)
- Justice (fair, equitable, and appropriate)
- Fidelity (faithfulness, keeping promises) (Burkhardt & Nathaniel, 2002).

Patient Bill of Rights

Patient Advocates strive to help patients understand their rights and ensure these rights are respected.

What are the Patient Bill of Rights?

Can you give us an example?

Patient Bill of Rights

Public Health Law(PHL)2803 (4)(g)Patient's Rights, 10NYCRR, 405.7,405.7(a)(1),405.7(c)

- (1) Understand and use these rights. If for any reason you do not understand or you need help, the hospital MUST provide assistance, including an interpreter.
- (2) Receive treatment without discrimination as to race, color, religion, sex, national origin, disability, sexual orientation, source of payment, or age.
- (3) Receive considerate and respectful care in a clean and safe environment free of unnecessary restraints.
- (4) Receive emergency care if you need it.
- (5) Be informed of the name and position of the doctor who will be in charge of your care in the hospital.
Patient Bill of Rights (cont)

6. Know the names, positions and functions of any hospital staff involved in your care and refuse their treatment, examination or observation.

7. A non-smoking room.

8. Receive complete information about your diagnosis, treatment and prognosis.

9. Receive all the information that you need to give informed consent for any proposed procedure or treatment. This information shall include the possible risks and benefits of the procedure or treatment.

10. Receive all the information you need to give informed consent for an order not to resuscitate. You also have the right to designate an individual to give this consent for you if you are too ill to do so. If you would like additional information, please ask for a copy of the pamphlet “Do Not Resuscitate Orders — A Guide for Patients and Families.”

11. Refuse treatment and be told what effect this may have on your health.

12. Refuse to take part in research. In deciding whether or not to participate, you have the right to a full explanation.

13. Privacy while in the hospital and confidentiality of all information and records regarding your care.

14. Participate in all decisions about your treatment and discharge from the hospital. The hospital must provide you with a written discharge plan and written description of how you can appeal your discharge.

15. Review your medical record without charge. Obtain a copy of your medical record for which the hospital can charge a reasonable fee. You cannot be denied a copy solely because you cannot afford to pay.

16. Receive an itemized bill and explanation of all charges.

17. Complain without fear of reprisals about the care and services you are receiving and to have the hospital respond to you and, if you request it, a written response. If you are not satisfied with the hospital’s response, you can complain to the New York State Health Department. The hospital must provide you with the State Health Department telephone number.

18. Authorize those family members and other adults who will be given priority to visit consistent with your ability to receive visitors.

19. Make known your wishes in regard to anatomical gifts. You may document your wishes in your health care proxy or on a donor card, available from the hospital.

Patient Self-Determination Act (December 1991)

“Federal Law requiring health care organizations who receive Medicare and Medicaid to provide written information to their patients regarding their right to make health care decisions” (Burkhardt & Nathaniel, 2002, p. 216).

ANA states nurses play a critical role.

Nurses Code of Ethics

- Provides guidance for nurses in making ethical decisions in the care of their patients.
- Let’s discuss some ethical decisions!

Code of Ethics for Nurses

- 1. The nurse, in all professional relationships, practices with compassion and respect for the inherent dignity, worth and uniqueness of every individual, regardless of cultural, religious or ethnic background or socioeconomic status, personal attributes, or the nature of health problems.
- 2. The nurse’s primary commitment is to the patient, whether an individual, family, group, or community.
- 3. The nurse promotes, advocates for and strives to protect the health, safety and rights of the patient.
- 4. The nurse is responsible and accountable for individual nursing practice and determines the appropriate delegation of tasks consistent with the nurse’s obligation to provide optimum patient care.
- 5. The nurse obeys the same duties to self as others, including the responsibility to preserve integrity and safety, to maintain competence and to continue personal and professional growth.
Nurse Code of Ethics (cont)

- The nurse participates in establishing, maintaining and improving healthcare environments and conditions of employment conducive to the provision of quality healthcare and consistent with the values of the profession through individual and collective action.
- The nurse participates in the advancement of the profession through contributions to practice, education, administration and knowledge development.
- The nurse collaborates with other health professionals and the public in promoting community, national, and international efforts to meet health needs.
- The profession of nursing, as represented by associations and their members, is responsible for articulating nursing values, for maintaining the integrity of the profession and its practice and for shaping social policy.


Confidentiality

- Non-disclosure of private or secret information.
- HIPPA-ensures confidentiality of all patients.
- Everyone is responsible.

Patient Advocates ensure that patient confidentiality is respected.

What is Patient Advocacy?

Specifically, patient advocacy includes comprehensive support to help clients:

- clarify their diagnosis and treatment options
- assess their own values, strengths and priorities
- gain access to quality healthcare
- connect with personal and community resources
- negotiate coverage with insurers
- communicate constructively with employers
- make evidence- and value-based medical decisions
- identify necessary financing options
- partner with healthcare and other service providers

(Core Advocacy Skills)

- Building Capacity/ Empowerment
- Assessment
- Empathy
- Listening & Communicating
- Confidentiality
- Cultural Competency
- Decision Making
- Asset-based
- Creative Problem Solving Ethics
- Caring
- Collaboration
- Case Management

Patient Advocate Challenges

- Patient Advocates may face work-related repercussions for going against administration/and physicians.
- Risk termination or isolation of peers.
- Conflicts may arise among family members with patient advocate being in the middle.

How to overcome challenges

- Education.
- Know your practice guidelines.
- Be knowledgeable about current issues.
- Join professional organizations.
- Seek support from supervisors and administrators.
- Be guided by the ethical principles through care and compassion.
- Remember that you are a facilitator and patient autonomy is key.
Questions???

True or False

- Patient Advocates must be certified.
- Patient Advocates make decisions for their patients.
- Patient Advocates use ethical principles to guide their practice.
- Only nurses can be patient advocates.
- Physicians have the final say in all patient issues.

Quote by Aristotle

- “All virtue is summed up in dealing justly.”
  Aristotle

References

- Merriam-Webster’s Online Dictionary
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