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Informed refusal: A patient's right?

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Abstract: This article discusses the principles of informed consent and informed refusal (IR) in the context of patient-centered care and evidence-based practice, the right of patients to refuse care when properly informed, and the implications of IR for nursing practice.

Keywords: informed consent, informed refusal, evidence-based practice, patient-centered care, patient refusal

Case study

An 83-year-old woman visits a new primary care physician (PCP) for an initial consultation. She has a history of multiple orthopedic surgeries including bilateral total hip arthroplasty, a total knee arthroplasty, laminectomy for lumbar spinal stenosis, and severe osteoarthritis. She required a wheelchair because of significant functional impairment. When asked about scheduling a colonoscopy, she said that she had one that was normal a decade before and she would prefer not to have another since she had no risk factors for colorectal cancer. Also, her lack of mobility would make bowel prep very difficult. Getting into the position for this procedure would also be very painful for her. In addition, if she were to be diagnosed with colorectal cancer, she would want palliative care only. The PCP responded: "Well, do you want cancer then?" The patient, who had full capacity to refuse, felt that she was being attacked for her decision not to schedule the colonoscopy.

Do patients have the right to decline healthcare procedures? Informed refusal (IR) applies the concepts of informed consent to refusal of care.[1] According to Selde et al.,[1] patients have the right to refuse care as long as they understand their current medical situation and the possible outcomes of refusing care. With today's increasing focus on patient-centered care and the public's easy access to medical information online, patients are taking active roles in their healthcare, including refusal of care. To provide patient-centered care, providers are charged with offering patients adequate information so that they can make informed decisions about their health that best fits their values and preferences.[2] This article discusses the principles of informed consent and IR in the context of patient-centered care and evidence-based practice, the right of patients to refuse care when properly informed, and the implications of IR for nursing practice.

Patient-centered care and evidence-based practice

"Patient-centered care" became a buzzword in 2001 when the National Academy of Medicine (formerly the Institute of Medicine [IOM]), Quality and Safety Education for Nurses (QSEN), The Joint Commission, and many other organizations shifted the focus away from provider-centered to patient-centered care.[3] Patient-centered healthcare includes respect for patients' values, preferences, and expressed needs; coordination and integration of care; information, communication, and education; physical comfort; emotional support and relieving fear and anxiety; and involvement of family and friends.[3]

During the COVID-19 pandemic, many aspects of patient-centered care have not been met, such as not allowing family members to be with a hospitalized patient or accompany a patient to a provider outpatient visit.[4] The use of telemedicine for outpatient provider visits could bridge that gap.[4]

Shared decision-making is a key component of patient-centered healthcare. This is the process by which patients and their providers collaborate to make decisions about needed assessments, interventions, and plans of care.[5]

Shared decision-making includes three components: the patient must meet the clinical criteria for the test or procedure; a decision aid, a tool developed to assist in the decision-making process through clarification with a detailed focus on options and outcomes, should be used; and preference-sensitive conditions should be conveyed by the provider openly without a discernable preference for any option.[6] Empathy, skilled communication, and acceptance of vulnerability are also helpful in achieving shared decision-making.[6]

According to the 2001 IOM report, the term "patient-centered care" encompassed qualities of compassion, empathy, and responsiveness to the needs, values, and expressed preferences of the individual patient while addressing technical care and interpersonal interactions within a healing relationship.[3] These qualities of patient-centered care along with shared decision-making will assist in the discussion and decision that may lead to informed refusal.

Evidence-based practice (EBP) is another concept that was reinforced by the National Academy of Medicine, QSEN, The Joint Commission, and many other organizations. EBP may involve making clinical decisions based on clinical judgment, patient preferences, and the best-available evidence that usually comes from disciplined research.[7] Providers need to ensure that they are using EBP as they interact with their patients and families to deliver the best treatment and care. Some providers do not actively use EBP strategies because of a lack of time, buy-in, or understanding.[8] Strategies that are not evidence-based may cause distrust in the shared decision-making process, leading to refusal of care.

Principles for informed consent

Five principles serve as the foundation for informed consent:

- The patient must have sufficient information about their medical condition.
- The patient must understand the risks and benefits of available options, including the option to not act.
- The patient must have the ability to use the clinical information to make a decision in keeping with their values.
- The patient must be able to communicate their choices.
- The patient must have the freedom of will to act without undue influence from other parties including family and friends.[9]

These principles of informed consent, inherent in the communication between a healthcare provider and patient when a patient is treated for a medical condition or undergoes a specific medical intervention, may be applied to IR of care.

Informed refusal of care

A patient's right to refuse care is based on the ethical principle of autonomy. According to this principle, every person has the right to make their own decisions about their healthcare.[10] Providers need to ensure that the patient is informed, that all aspects of treatment have been explained, risks and benefits discussed fully, and that the potential outcomes of a lack of treatment are also discussed and understood. If a patient refuses care after being fully informed of the consequences, the

Ethical principles that guide healthcare[10]

Principle	Definition
Autonomy	Self-determination: Every person has the right to make informed decisions about their healthcare.
Beneficence	Doing good: Actions taken by HCPs for the benefit of the patient.
Nonmaleficence	Do no harm: HCPs must take steps to ensure that patients and society are not harmed by their actions.
Justice	Fairness: Benefits and risks associated with healthcare are distributed equally among the population without bias.

provider must not impose their own beliefs or decisions.[10]

Providers must consider the cultural practices and beliefs of the patient when considering informed consent or IR. While the predominant culture in the US values autonomy, individual autonomy may not be valued in other cultures.[11]

Capacity to refuse care

When a patient refuses care, healthcare professionals (HCPs) must first determine the patient's capacity to refuse.[10] HCPs must assess if the patient can express understanding about the situation, the decision to refuse care, and the risks and benefits of refusing care; if the patient has expressed a clear, consistent choice to refuse care without changing their mind; if the patient can discuss the outcome of the refusal on how it affects their own life; and if the patient can discuss the consequences of their decision and explain why they want to refuse care.[11]

There are times when a patient cannot decide to refuse care such as intoxication, the presence of a mental illness, dementia, or when they are at the end of life when a person's cognition may be impaired by the disease process. Validated tools are available to assist healthcare team members with assessing patients' decision-making capacity, such as the MacArthur Competence Assessment Tool for Treatment and the Assessment of Capacity for Everyday Decision-making.[11]

Dignity of risk

The term "dignity of risk" (DOR) has been used for many years by people who care for or work with patients with psychiatric, physical, or developmental disabilities and represents respect for persons' self-determination and minimizing paternalism.[12] Some additional questions to ask when there is a refusal of treatment are:

- Is the refusal of care a low-, moderate-, or high-risk one?
- Does the patient have the capacity to make this decision?
- Is the patient being coerced or under duress?

If the patient has the required capacity to make this decision and understands the benefits and risks of the IR, the refusal can be documented.[12] DOR also allows a patient to change their mind after refusing treatment.[12] IR should be considered a process, where there is time for the patient to rethink and reconsider the decision they have made, even if it requires readmission or treatment in the future.[13] Ensure that the IR is not a result of doubt, misconstrued information, or being frightened or anxious.[13]

One framework for making ethical decisions relies on the principles of autonomy, beneficence, nonmaleficence, and justice (see *Ethical principles that guide healthcare*).[10,14] It encourages HCPs to examine situations through factors such as medical indications, patient preferences, quality of life, and contextual features like social, legal, and administrative. Salient, specific items can be placed in each of the four quadrants or boxes to clarify all aspects of an ethical dilemma. Providers could use a version adapted specifically for instances where patients refuse care after being informed about all aspects of treatment (see *The Four-box method*).[15,16]

Examples of IR in clinical care

Pregnancy

Pregnant women may decline care that is supported by evidence, such as an oral glucose tolerance test to screen for gestational diabetes. The process of shared decision-making while supporting the woman's autonomy will ensure that coercion is not used when a pregnant woman refuses treatment.[6] In a study that investigated women's experiences of declining procedures in maternity care where one form of engaged patient behavior may be to decline certain procedures, women who attained a graduate education had higher odds of declining care when compared with those with a high school diploma; older women had lower odds of declining care compared with women between 18 and 24 years; and first-time mothers had higher odds of declining care when compared with mothers who had already delivered a baby.[2] However, information on what type of care was refused was not collected.[2]

It is important to remember that pregnant women and fetuses are considered vulnerable groups and have additional ethical standards when involved in research studies. As a result, research on these populations is lacking. The COVID-19 pandemic further highlighted the lack of pregnant and breastfeeding women in medical research.[17] The FDA began focusing on a global initiative to expand research on these populations safely and ethically in 2018.[17] Because of the lack of clear evidence in the obstetric field, there may be uncertainty about some of the evidence used to make recommendations. IR may be a logical decision for pregnant mothers based on the uncertainty of benefits due to a lack of sound studies in this population.

Vaccinations

Shared decision-making is a key component of patient-centered healthcare. More decisions are being recommended as shared clinical decision-making, such as the current recommendation for the 13-valent pneumococcal conjugate vaccine (PCV13) in those older than 65 years. Until 2014, PCV13 has been recommended only for children and adults in high-risk groups, such as those who are immunocompromised.[18] The Advisory Committee on Immunization Practices (ACIP) expanded its recommendation to include patients older than 65 years to further reduce pneumococcal disease in older adults.[18] Despite nearly 50% of patients with Medicare over 65 years receiving this vaccine between 2014 and 2018, pneumococcal disease, pneumococcal pneumonia, and mortality from these have not decreased.[19] As a result, the ACIP approved a change in their recommendations for the vaccine from age-based recommendations to a shared clinical decision-making process.[20] Some suggest first clarifying that the vaccine is safe and effective, taking into account risk factors the patient may have, the community in which they live, and then applying such considerations to the patient's preferences and views toward vaccines.[19] Shared clinical decision-making should be the standard of care when there are uncertain risks and benefits.

Discharge from the ED

Discharge against medical advice accounts for 0.1% to 2.7% of all ED discharges.[21] Decisional capacity is essential to evaluate patients in the ED who wish to leave without being evaluated or treated.[22] A variety of assessment tools may be used to determine decisional capacity, such as the Mini-Mental State Examination, the MacArthur Competence

The Four-Box method[15,16]

CLINICAL ISSUES **The principles of beneficence and nonmaleficence**	**PATIENT PREFERENCES** **The principle of respect for autonomy**
• What is the patient's medical history/diagnosis/prognosis? • Is the problem acute, chronic, critical, emergent, or reversible? • What are the goals of treatment? • What are the probabilities of success? • What are the plans in case of therapeutic failure? • How can the patient be benefited by medical, nursing, or other care, and harm avoided?	• What has the patient expressed about preferences for treatment? • Has the patient been informed of benefits and risks, understood, and given consent? • Is the patient mentally and legally competent? What is the evidence of incapacity? • If incapacitated, who is the appropriate surrogate? Is the surrogate using appropriate standards? • Is the patient unwilling or unable to co-operate with treatment? If so, why? • In sum, is the patient's right to choose being respected to the extent possible in ethics and law?
QUALITY OF LIFE/DEATH **The principles of beneficence and nonmaleficence and respect for autonomy**	**CONTEXTUAL FEATURES** **The principles of loyalty and fairness**
• What are the prospects of returning to normal life with and without treatment? • Are there biases that prejudice providers' evaluation of patients' quality of life? • What physical, mental, and social deficits is the patient likely to experience if treatment succeeds? • Is the patient's present or future condition such that continued life might be judged undesirable by the patient? • Are there any plans and rationale to forego treatment? • What are the plans for comfort and palliative care?	• What chapter is this in the patient's life? • Are there family/cultural issues that affect treatment decisions? • Are there HCP issues (MD, RN) that might influence treatment decisions? • Are their cultural or religious issues? • Is there any justification to breach confidentiality? • Are there resource allocation problems? • Are there legal implications? • Is there an influence of clinical research or teaching involved?

Assessment Tool for Treatment as mentioned previously, and the Hopkins Competency Assessment Test. When patients refuse medical treatment in an ED, providers should communicate to the patient information about their diagnosis, recommended treatment, risks, benefits, and alternatives to the proposed interventions.[22] Providers must adequately document when treatment is refused and should include an assessment of the patient's decisional capacity, how the information was delivered, why the treatment or procedure was refused, and the patient's autonomous choice.

Nursing implications

Patients should be active partners in making decisions about their healthcare. Nurses need to continue to apply the principles of informed consent and IR to all aspects of patient care. HCPs need to continue to inform patients and their families of the advantages and disadvantages of a particular treatment including any risks associated with having or not having that treatment. Informing the patient of options or alternatives to treatment and their pros and cons is also important. Information needs to be presented in a way that the patient and their family members understand, without medical jargon. Patients may need time to think about treatments and their alternatives before making a decision. Most important, HCPs must respect the patient's decision about consenting to or refusing that treatment, as much as the HCP may not agree with the patient's decision.

The way information about treatment is communicated is important. As mentioned earlier, coercion is not appropriate when a patient refuses treatment. HCPs must ensure that patients have the information that is needed to make an informed decision. Nurses may be able to fill in gaps in knowledge or clarify the risks related to a procedure that were not fully explained or that the patient did not understand in the original discussion of informed consent.

Ask questions to evaluate patient understanding, such as:

- “Can you please tell me what you know about what's happening right now?”
- “What do you think is causing your symptoms?”
- “Do you have any questions about what we have discussed?”[10]

When patients refuse treatment, they are often considered noncompliant since they are not following everything the healthcare provider suggests. In fact, “noncompliance” was an approved NANDA International nursing diagnosis for many years and was retired in 2017.[23] Though not an approved NANDA nursing diagnosis, “nonadherence” is suggested.[24] It is defined as “being unable or unwilling to follow treatments and recommendations to promote personal health and well-being.”[24] Again, the word “nonadherence” carries a negative connotation and suggests that the patient is not doing something that has been suggested by an HCP. Nurses need to avoid considering a patient who is refusing care to be an adversary. It is still the primary responsibility of HCPs to ensure that a patient receives the best possible care, even when refusing certain treatments.[10]

Reasons for refusal

Patients may refuse treatment due to the cost of care or treatment, because of the inability to travel, the inconvenience of the time that this treatment may take, or the expected pain and suffering that the treatment may cause. Nurses may uncover such reasons in a full sociocultural assessment and make referrals as needed.

Conclusion

In the past 20 years, healthcare has undergone a shift from relying on advice from more experienced colleagues, intuition, or what was learned as a student, to using EBP to make clinical decisions, which includes patient preferences. Healthcare has also experienced a swing from being provider-centered to being patient-centered. Providing patients and their families with comprehensive information about informed consent and IR is crucial to ensuring patient-centered care. Ultimately, HCPs need to respect the decisions of patients and their families. ■

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