




The Ethics of Self-Determination in Medical Settings

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1



Learning Objectives

- Identify key ethical concepts and considerations in medical self determination.
- Analyze self determination ethical dilemmas in case studies.
- Review and summarize social work code of ethics values, principles and standards.

2

Opening Vignette

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An otherwise healthy 44-year-old woman recently diagnosed with aggressive Leukemia has been inpatient for several weeks receiving chemotherapy treatment. On the way back from testing in the hospital, the patient trips over her IV pole and falls to the ground. The patient is not injured in the fall.

One of the patient's treating oncologists comes to the patient's room right after the fall and tells the patient that she will need be put on fall risk status. The physician explains that when a blood cancer patient has a fall, they are immediately put on fall risk due to low blood counts, which can cause heavy bleeding if a fall occurs. The physician states that the patient will have to remain on 24-hour bed rest with an alarm for the remainder of her hospital stay, which will be at least a few more weeks. The patient will have to buzz a nurse to get out of bed, use the restroom, get dressed, etc.

After the physician leaves, the patient is stunned. She feels well and is concerned about the implications of being in bed 24 hours a day and losing many aspects of independence.

The patient is very physically active in the hospital; she does yoga in her room and walks 1-2 miles a day on the hospital floor. The patient begins to fear being bedridden for weeks and losing the ability to move independently and exercise. For the next few days, the patient is frustrated, depressed, and despondent.

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When a different oncologist comes to visit the patient 48 hours later, the patient decides to advocate for herself.

- She acknowledges the risks of falling but clarifies that the fall was not due to dizziness or fainting, but instead due to tripping over the IV pole.
- The patient also stresses the significant emotional and mental toll that being bedbound for weeks will cause her.
- Finally, the patient expresses a strong desire to continue to exercise, citing that cancer patients who remain active do better in treatment.
- The patient requests that the oncologist consider removing her from fall risk status and allowing her to regain her independence.

The oncologist agrees to lift the fall risk status After two successful vitals readings that day, the patient is removed from fall risk status. The patient is elated and feels understood and respected by her provider.

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What is self-determination?

Self-Determination Theory

Human beings have three basic needs:

<p>Competence</p> <p>People need to gain mastery and control of their own lives & their environment. Essential to wellness</p>	<p>Autonomy</p> <p>People need to feel in control of their own life, behaviours and goals. This is about choice.</p>	<p>Relatedness</p> <p>People need to experience a sense of belonging and connection with other people. <i>Feeling cared for by others & to care for others.</i></p>
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Based on the work of Richard Ryan and Edward Deci.

Client self-determination means the right of the client to determine the appropriate level, if any, of medical intervention AND the right for clients to change their wishes about their treatment as their condition changes over time or during the course of their illness.

Self-determination assumes that the client is mentally competent.

Image source: <https://images.squarespace-cdn.com/content/v1/54909c71e4603b726738b1fc/1410483521017-0119HW46S4DRWPYR6UGJ/self-determinationstheory.png>

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Defining an ethical dilemma

"An ethical dilemma is a situation in which professional duties and obligations, rooted in core values, clash" (Reamer, 1999).

"A given situation has ethical content when an action freely performed or not performed has the potential to harm or benefit others" (Robichaux, 2012, p. 69.).

- Ethical dilemmas are not a matter of "right" vs. "wrong".
- In ethical decision making, a value or standard is compromised (not upheld) due to another standard carrying more weight

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NASW Code of Ethics

1.02 Self-Determination

- ▶ Social workers respect and promote the right of clients to self-determination and assist clients in their efforts to identify and clarify their goals.
- ▶ Social workers may limit clients' right to self-determination when, in the social worker's professional judgment, client's actions or potential actions pose a serious, foreseeable, and imminent risk to themselves or others.

Value: Dignity and Worth of the Person

- ▶ Ethical Principle: Social workers respect the inherent dignity and worth of the person.
- ▶ Social workers treat each person in a caring and respectful fashion, mindful of individual differences and cultural and ethnic diversity. Social workers promote clients' socially responsible self-determination.

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Necessary Skills for Social Workers

1. Ethical Assessment
 1. Including knowledge of profession's COE, bioethics, agency policies, laws and regulations, religious and cultural values
2. Process/Problem-solving Approach
 1. Reflective, responsive vs. reactive
 2. Effective interaction with key decision makers
 3. Facilitation of fair and structured meetings
3. Interpersonal Abilities
 1. Listening and communicating with respect, support, and empathy
 2. Management of ambiguity, differing opinions, values and beliefs

8

9 **General Ethical Decision-Making Model**

HANDOUT:
Ethical Dilemma
Guidance
Questions

1. Assess situation completely from a medical and social work perspective.
2. Determine issues that present the ethical problem.
3. Consider alternatives available for implementation, weighing positives and negatives of each.
4. Consult with professional colleagues and/or experts with knowledge about this or similar situations
5. Review alternatives with patient and family – document accordingly.
6. Implement the best alternative, given the circumstances and environment.
7. Monitor, evaluate and document the decision.
8. Review as necessary and be open to changing course if needed.

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10 **The 4 Box Method**

HANDOUT:
Paradigm
(4 boxes)

- ▶ Introduced by a philosopher, a physician and an attorney (Jonsen, Siegler, & Winslade respectively)
- ▶ Takes into consideration:
 - ▶ Medical indications
 - ▶ Patient preferences – is the patient decisional?
 - ▶ Quality of life
 - ▶ Contextual features – legal issues, cost to society

10

11 **Autonomy**

The personal rule of the self that is free from both controlling interferences by others and from personal limitations that prevent meaningful choice.

- ▶ In the U.S., respect for autonomy is a key principle of medical ethics
- ▶ Ideally, a patient should make their own health care decisions
- ▶ When a person cannot make their own decisions, stakeholders (i.e., surrogate decision makers, medical team) must rely on other means of deciding.

- ▶ Autonomous individuals act intentionally, with understanding, and without controlling influences.
- ▶ Examples of promoting autonomous actions:
 - ▶ presenting all treatment options to a patient
 - ▶ explaining risks in terms that a patient understands
 - ▶ ensuring that a patient understands the risks and benefits
 - ▶ Allowing someone to defer to another person to make their decisions

11

12 **Beneficence**

The action that is done for the benefit of others. Beneficent actions can be taken to help prevent or remove harms or to simply improve the situation of others.

- ▶ An obligation to:
 - ▶ prevent and remove harms
 - ▶ weigh and balance possible benefits against possible risks of an action.
- ▶ Can also include protecting and defending the rights of others, rescuing persons who are in danger, and helping individuals with disabilities.
- ▶ Examples of beneficent actions:
 - ▶ STD education
 - ▶ Duty to warn
 - ▶ Assuming consent (i.e., a person arrives at the ER unconscious and the doctors assume that the patient wants to be treated)

12

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Case Example: Autonomy and Beneficence?

A 49-year-old businesswoman, well-known in the community, was hospitalized and in a coma as a result of closed head trauma. Her family set up a journal on the hospital's sponsored website, like carepages.com, caringbridge.org, or mylifeline.org. Posts, including posts by celebrities, flooded the journal.

The patient's sister gave a nurse permission to share information about the patient's status in the journal. The nurse shared specific details about the patient's status, identified herself as the patient's nurse, and invited questions about the patient and her condition.

Some of the information the nurse revealed led to an investor withdrawing from a business venture because of uncertainty about the patient's prognosis. Though the patient later recovered fully and resumed her career, the information that the nurse shared had an adverse effect on a significant business opportunity.

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Case Reflections

Some questions to consider considering ethical principles:

Autonomy:

Did the sister's permission respect the patient's autonomy? Would the patient have wished this information to be shared if she were able to speak for herself?

Non-maleficence and Beneficence:

Though the many postings to the website may have provided comfort and support to the patient's family, does that balance her business loss and compromised privacy?

Justice:

How did the patient's prominence in the community influence the sharing of information? Might a lesser-known individual have received greater protection of privacy?

14

15 **Decision Capacity vs. Competence**

HANDOUT:
Decision-Making
Capacity

Decision Capacity

A specific decision that is confronting the patient

More global ability of a patient to make decisions

Competence

Assessing Decision Making Capacity

- Mental status exam (MSE)
- Patient's orientation
- Short-term memory
- Attention to the interviewer
- Comprehension of detailed information
- Ability to follow directions

15

16 **Temporary Impairment to Decision-making Capacity**

Mr. Benton was in surgery when the Employee Health Service was notified that one of the health care workers had been exposed to the patient's blood during the surgery. The hospital policy required that the patient be tested for HIV to be sure the health care worker could be treated quickly in the event there was a positive finding. It was late on a Friday afternoon and the health service wanted to begin the testing procedure and needed his consent to do so. Since he was anesthetized, he was unable to consent, and the health service nurse asked the social worker to find the patient's wife so that her consent as his surrogate could be obtained.

16

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Case Reflections

- This choice presented a dilemma for the social worker.
- The patient had been able to consent prior to the surgery and there was no reason to expect that he would not be able to do so afterwards.
- The nurse was anxious to initiate testing and hoped that consent could be obtained right away.
- Nevertheless, the social worker advised the health service nurse to wait for the patient to recover from anesthesia.
 - It was important to allow the patient to consent for himself and urgency was not required as obtaining consent that evening or the next day would meet the hospital's requirement.

17

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Cultural Influences

Cultural Considerations

- There are cultural differences with regard to health care decisions
- The Western model of bioethics is not accepted by everyone living in the United States
 - Based on White, middle-class philosophies and laws
 - Model requires that difficult information be shared with patients (informed consent)
 - Some people are reluctant to share what is wrong, or what needs to be done
 - Health literacy is shown to be a more important factor than the race of the patient in decision making.

Paternalism

Taking away a patient's right to autonomy.

- More of a possibility due to:
 - Decision-making capacity
 - Consent
 - Mental illness
 - Neurological defects or injuries
 - Cultural or religious differences

18

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Paternalism & Cultural Implications: The Spirit Catches You and You Fall Down

Let's look at this case study...feel free to follow along in your handout packet.

HANDOUT:
Book Summary



Image source:
<https://chancellor.apostate.edu/newsletter/id/spirit-catches-you>

19

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Culture Case Example

An Asian patient named Mrs. Nguyen was in intensive care unable to communicate and her husband was making decisions for her. However, after a few days she regained consciousness, and it appeared her decisional capacity had returned. Although she had improved, her husband continued to make her decisions.

The medical team became concerned and wanted to meet directly with Mrs. Nguyen to obtain consent for a procedure, but her husband was opposed to this. The social worker was alert to the possibility that the family dynamics in which her husband maintained a high degree of control over her, could prevent her from making her own decisions.

The team decided it would be prudent to explore the wishes of the patient regarding her medical decision making. They met privately with Mrs. Nguyen, and she reassured them that her husband was acting in her best interests.

When they asked her if she wanted to make her own decisions or continue having her husband make them for her, she chose her husband and the physicians acceded to her wishes and worked with him. The team was satisfied that he understood her wishes and would make decisions substituting her wishes for his preferences.

20

911 Lone Star: Ethics, Laws, & Values in Conflict



Paramedics respond to a 911 call from a woman who says her sister is not responding to phone calls or door knocks at her home. She tells the paramedics that her sister has Stage 4 cancer. The police and paramedics make entry into the home, where they find the woman unresponsive on the floor.

The paramedics begin lifesaving efforts, with one of the paramedics pausing slightly before beginning. The woman is revived in the home but is not happy. She pulls up her sleeve and shows the paramedics her DNR bracelet. She states that her sister is aware of her DNR but refuses to accept it.

Later in the episode, one of the paramedics admits to her supervisor that she saw the DNR bracelet on the woman's wrist but proceeded anyway. The cancer patient sues the paramedics for failing to take reasonable measures to check for a DNR, stating that she did not wish to be revived. The patient dies shortly thereafter, and her sister reports that the lawsuit will be dropped against the paramedics.

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21

22 Minors and Self-Determination

Mature Minor Doctrine (U.S. Law)

- A minor who is deemed able to understand short-and long-term consequences is considered to be "mature" and thus able to provide informed consent/refusal for medical treatment.
- This "maturity" authorizes the minor to make decisions regarding his or her medical treatment.
- It does not, however, provide carte blanche permission for minors to make decisions regarding medical treatment without parental consent.

- Circumstances in which the mature minor doctrine permits minors to consent to treatment are the following:

1. The minor is an older adolescent (14 years or older).
2. The minor is capable of giving informed consent.
3. The treatment will benefit the minor.
4. The treatment does not present a great risk to the minor.
5. The treatment is within established medical protocols.

22

23 **Minor's Status and Service**

Make sure to check state law!

- Status
 - a. a pregnant minor (for medical care and surgery)
 - b. a married minor
 - c. a minor in the armed services
 - d. a minor with a child (for medical and dental care, or surgery for the child)
 - e. a minor living apart from parents and financially self-reliant
 - f. a victim of sexual assault or abuse may consent to medical care or counseling.
- Service that is sought
 - a. venereal disease treatment or HIV testing
 - b. contraception, prenatal care, or abortion
 - c. mental health treatment
 - d. emergency care
 - e. alcohol or drug abuse (after age 12 years).

23

24 **Putting it all Together**

HANDOUT:
Ethics Case Studies

- Start by asking the clients what they want for themselves. Ask open-ended questions and see where it goes.
- Help them clarify their goals and set concrete hopes. Make sure they are the client's goals – not what you think they should work on.
- Be cautious of having an agenda. There might be things you want to cover in a session, but the client should determine where the conversation goes.
- Ask yourself – Is this what the client wants or is it me who thinks this is a good idea?
- Consider whether what the client plans to do put them or someone else at imminent risk for harm.
- Consult with other social workers to get different perspectives.
- Remind yourself that your client's reactions and their situation is not about you.
- Ask yourself – Is there a really sound reason I am taking away this person's right of choice?

24

25

A Deeper Dive: Clinical Resources

- NASW Standards for Palliative Care: <https://www.socialworkers.org/LinkClick.aspx?fileticket=xBMd58VwEhk%3D&portalid=0>
- Living and Dying: A Love Story documentary: <https://vimeo.com/257939456>
- Self-determination article (Reamer): https://www.socialworktoday.com/news/eoe_0803.shtml
- PCC4U Modules (Principles of palliative care): <https://pcc4u.org.au/learning/modules/>
- Get Palliative Care: <https://getpalliativecare.org/resources/>
- NASW ethics resources: <https://www.socialworkers.org/About/Ethics/Ethics-Education-and-Resources>
- Zur Institute SW ethics resources: <https://www.zurinstitute.com/resources/social-work-ethics/>
- End of Life video toolkits: <https://www.eldac.com.au/tabid/5940/Default.aspx>

25

26

😊 THANK YOU 😊
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graph TD
    A[What did you learn?] --> C((Your Experience))
    B[What will inform your practice?] --> C
    D[What do you need to explore further?] --> C
  
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26