The Ethics of Advocating For Your Patient

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Objectives
1) Define the social work role as patient advocate for persons receiving hospice services.
2) Discuss NASW Values in the Social Work Code of Ethics and established values in medical ethics.
3) Discuss common areas of ethical conflict in hospice and palliative care.
4) Learn about the Collaborative Ethical Decision-making Framework.
5) Discuss beneficence versus respect for autonomy as it applies to the social work role of advocate for patients and families in hospice care.
6) Explore the influence of professional and personal boundaries on the role of patient and family advocate.
7) Discuss how the culture of Hospice can create potential for ethical conflict.

NASW Values in the Code of Ethics
• Service
• Social Justice
• Dignity and Worth of the Person
• Importance of Human Relationships
• Integrity
• Competence

Tasks of Social Workers in Hospice
Sherri Brickle, LMSW (Crossroads Hospice)
• Evaluate
• Educate
• Advocate
• Participate

Values of Medical Ethics
• Autonomy
• Beneficence
• Nonmaleficence
• Justice
• Dignity
• Fidelity
Where can conflict occur?

- Transitions
- End of life planning
- Symptom management
- Patient's and Family's Behaviors
- Culture
- Communication
- Existing Family conflict
- The Others

Collaborative Ethical Decision-Making Framework

Step 1: **Assess** situation completely from a social work perspective (clinical, physical, legal, cultural, and systemic issues)

Step 2: **Determine** issues that present the ethical problem

Step 3: **Consider** alternatives for implementation (weighs the pros and cons)

Step 4: **Consult** with professional colleagues and/or experts

Step 5: **Review** alternatives with patient and family and document

Step 6: **Implement** the best alternative given the circumstances and the environment

Step 7: **Monitor, Evaluate,** and **Document** the decision!

Modified 4-Step Model

- Autonomy
- Beneficence
- Nonmaleficence
- Justice
Beneficence versus Respect for Autonomy

What is the Social Work Role in the Ethical Decision Making Process?

- Framing "refuse" to "decline"
- Practice cultural humility
- Recognize personhood
- Allow client to grieve own death
- Honor limitations to client's wishes and goals
- Allow hope to be present and persistent
- Listen with intention
- Build relationships that are open to advocacy
- Model effective communication

Navigating personal & professional boundaries with clients

Case Vignette #1

Sheila is a 59 year old African American female who had a heart transplant in her late 40's. Since the transplant, she has had numerous health problems, and has often been non-compliant with her medication treatment and plan of care. She has a family history of heart problems, with her mother and older sister both dying from heart attacks in their early fifties. At her most recent appointment, her physician stated that her heart was failing again, and she would need to make some end-of-life decisions. He has recommended the option of hospice care for her either in the hospital or at home, which Sheila accepted. Sheila's husband and adult children are devastated by this news and have expressed to the physician and the social worker that they want "any and all" possible treatments to prolong her life. They also want more tests and second opinions. Sheila however has stated she does not want to undergo any further treatment and would prefer hospice care. She has expressed to you several times that her family does not consider her wishes and that they often make health decisions without her involvement. She describes the past several years as unbearable. She has been treated for depression in the past year. Her husband, Alan, states to you, "Sheila doesn't know what's best for her when it comes to thinking about her health. Her depression causes her to be so sad and upset." Her family wants to take legal steps to make all future healthcare decisions for her and remove her from hospice care.

(S.R. Wilson, PhD, LCSW, L.K. Jennings, PhD, LCSW: Approaches to social work ethical decision making in end of life care, May 2011)
Case Vignette #2

Grecia and Marco are an older Hispanic couple who have been married for 35 years with one adult daughter, Mira, who lives nearby. Marco has had multiple admissions to the hospital for complications related to COPD and diabetes. He is also suffering from kidney failure and unable to participate in discussions with his medical team due to his condition and pain control medications. Clearly, he is declining in health and approaching death. The nephrologist gently raises the possibility of foregoing dialysis, accepting Marco's inevitable decline, and instead pursuing hospice care at home, which the couple accept. During your first home visit, their daughter, Mira, comes by. She becomes very angry when learning that her father is now under hospice care. As the social worker, you attempt to convey to Mira that hospice can provide excellent care and support to Marco as well as the entire family. Hospice also can provide Marco’s medications and other medical needs to ease that burden. During the conversation, Grecia does not speak or make eye contact with you. Mira, however, abruptly and angrily bursts out that her father is not dying and that God will provide a miracle. She also insists that they are perfectly able to care for his needs as a family and that the medical team should not talk about “hospice” and the end of his life when they should be focused on her father’s recovery. She insists that dialysis be initiated immediately and that a kidney transplant be pursued no matter what. Grecia states she does not have the energy to go against her daughter’s wishes.

Case Vignette #3

Diana Taylor is a 95-year-old patient at a nursing home facility. She has been a hospice patient for 18 months. She has two durable powers of attorney, which share responsibility for decision making. Her terminal diagnosis is myelodysplasia, and she has a history of cardiac and vascular problems. Diana has been bed bound with an extremely low level of consciousness for several months. She has decubitus ulcers, one of which is believed to be gangrenous. She has been receiving blood transfusions on a regular basis, along with frequent blood tests. The blood transfusions were to decrease with hospice, and the routine blood tests were supposedly discontinued. In early April, a complete blood count was drawn, and Diana was found to be anemic. Her family asked the facility to have her transported for a blood transfusion. The request was approved, but the hospice staff voiced some concerns. The same situation recurred two months later. At this time, upon ordering the blood, the hospice received a call from the blood bank questioning why the hospice was using the last units of O positive blood available in the area. The hospice was trying to honor the requests of the patient’s family, but was it just to give blood transfusions to a dying patient when so many in the larger community were in need?

Case Vignette #4

A 62 year old Hispanic woman was admitted into an inpatient hospice unit from an acute care hospital. The patient was Spanish speaking, raised Catholic, and was a full time homemaker raising six children who were now young adults. Two of her six children spoke English fairly well. Many of her extended family lived in Mexico. Several months before admission, she developed severe weakness and fatigue secondary to anemia. Since she did not have health insurance, she went to Mexico several times to seek medical treatment. In Mexico, she received blood transfusions, but no workup for her anemia. Eventually, she developed symptoms of anemia, such as persistent epistaxis, nausea, and severe back pain. She was taken to a local emergency room, received blood transfusions, but no workup for her anemia. Eventually, she developed cirrhosis of the liver and hepatorenal syndrome, where she was found to be severely anemic and was admitted. A diagnosis of multiple myeloma was made and oncology was consulted. The oncologist felt that the prognosis was grim and documented that “the social situation will make management a problem.” He did not speak Spanish and therefore deferred to the primary admitting doctor, who also did not speak Spanish, to discuss her options. The primary doctor spoke with the patient’s family, who did not want to tell her mother that she was going to die. The patient was not offered treatment for her illness and was not told her diagnosis. The family decided to sign their mother into hospice and transfer her to an inpatient unit to get better symptom control. Is it ethical to follow the lead of the primary doctor when the family wants to keep her terminal diagnosis a secret?

The Culture of Hospice

How do our own norms, rules, beliefs and customs create the potential for ethical conflict?

“The assumption is that social workers shouldn’t get too lost worrying about the ingredients of the mythical ‘good death’ and closure. While such concepts can be useful, they often obscure the face that life is messy, there are rough edges, and it really is all about standing in the fire with compassion beside those who are feeling its heat.”

-Scott Janssen, MA, MSW, LCSW
Duke Hospice, Durham, North Carolina

A girl is seen sitting after it's been fired, she looks, I wonder if it's the same for me.

Rudolf Nureyev by Trace Parrish