Ethical Issues in Social Work: End-of-Life Care

What We Know

› Social workers involved in end-of-life care frequently encounter ethical issues in their practice because end-of-life care incorporates individual, professional, organizational, cultural, and financial complexities and ambiguities\(^{(8,18,20)}\).

› Ethical issues arising in end-of-life care frequently center on the dying individual’s right to self-determination. This includes issues such as the individual’s right to refuse treatment, proxy decisions, withdrawal or withholding of treatment, food, or fluids, organ donation, termination of life support, and physician-aided dying\(^{(5,6,9,12,16,17,22,25)}\).

• Social workers report encountering situations in which client autonomy is ignored or compromised by family members. A client with an incurable illness may ask for treatment to be stopped because it compromises his quality of life, for example, but his family may overrule his wishes\(^{(11)}\).

• Social workers may observe medical staff not being completely open about the effectiveness of treatments to clients and families and they may find this ethically challenging.

• In medical team meetings, social workers report that decisions about treatment can be confounded by the medical team members’ personal feelings and concerns. This can be ethically challenging in its potential to compromise the client’s informed consent.

• Social workers may encounter clients and families who deny the clinical reality of the situation they face and refuse to accept a diagnosis and prognosis.

• Social workers may observe situations in which a client feels burdened with guilt when he or she wishes to discontinue treatment against his or her physician’s advice.

• The autonomy of frail older adult clients may be challenged when safety issues dominate assessments, when the client has decreasing physical and cognitive capacities, when family caregivers are overburdened, and when family members dominate the attention of social workers.

• A lack of clarity about a client’s end-of-life preferences and instructions can exacerbate ethical issues. An example is when a client’s spouse/partner assumes that he or she is the next of kin yet the client has chosen someone else as next of kin. A next of kin is an individual’s closest living relative, often called upon to make critical decisions and provide instructions in medical emergencies.

– Providing services to a client who is very ill or mentally compromised and cannot communicate his or her end-of-life preferences can create ethical dilemmas\(^{(12)}\).

› Ethical issues can also arise for social workers when a client pursues treatment considered medically inappropriate and which may limit or prevent access to the treatment by other clients who could benefit more\(^{(5)}\).

› Developing ethical awareness and skills to navigate ethical issues is a critical component of social work training and practice. Around the world, professional social work organizations have ethical codes that guide their members in their work. The central features of these codes incorporate human rights, social justice, and professional integrity\(^{(1,2,3,10,13,15)}\).

› In end-of-life practice social workers may face the following types of ethical issues\(^{(10,20,22)}\):

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• Confidentiality and privileged communication
  – For example, when a client at the end of life talks about assisted suicide or self-harm, the social worker is legally obligated to report this knowledge
• Self-determination versus professional paternalism
  – An example of this is when a social worker must limit a client’s self-determination by recommending a move from home to nursing care
• Laws, policies, and regulations
  – Obligations to comply with laws, policies, and regulations may conflict with what a social worker considers to be appropriate and just. For example, decisions regarding end-of-life care that are driven by cost-effectiveness, rather than client well-being, can be especially challenging
• Conflicts of interest and boundary issues
  – Issues of this kind may occur when social workers have dual or multiple relationships with clients. For example, a social worker in small community may be called upon to provide end-of-life care to a former teacher or a family friend
• Professional versus personal values
  – A social worker’s personal values may conflict with a dying client’s wish to discontinue IV hydration or nutrition, for example
• Limited resources
  – End-of-life decisions that are based on resource availability and eligibility requirements may result in inadequate provision of services, which creates ethical dilemmas for social workers working with affected clients

In end-of-life healthcare settings it is recommended that ethical considerations and decision making include:

• Being more responsive to the client than institutional rules may allow
• Developing self-awareness to assist in understanding others
• Valuing ethical discourse and not focusing solely on outcomes
• Being mindful of gender- and culture-based disparities and biases in healthcare
• Understanding that relationship dynamics are important in ethical deliberation
• Recognizing that moral ambivalence exists and that social workers may encounter it in their discussions with clients and families
• Engaging in reflective consideration to improve competence

End-of-life decisions should respect the person’s values and wishes while maintaining his or her comfort and dignity. This can be achieved by improving care at the end-of-life, thus facilitating a “good death”

The Institute of Medicine (1997) defines a good death as “one that is free from avoidable suffering for patients, families, and caregivers in general accordance with patients’ and families’ wishes”

It is critical that social workers pay attention to cultural factors during end-of-life care and facilitate client preferences. Cultural sensitivity involves listening to the client and paying attention to his or her personal identity, learning about his or her relationships, understanding the power dynamics within the client’s relationships, recognizing the rituals and symbols that embody meaning to the client, and recognizing the values that have given the client’s life meaning and that may give meaning to his or her suffering and death

End-of-life agreements, often called advance care directives (ACDs) and/or advance care plans (ACPs), help clients address their end-of-life preferences and in so doing reduce the potential for ethical conflicts

• End-of-life agreements can help clients clarify their values and goals and can guide clinical decisions as they arise
• When an ethical dilemma or disagreement is proving difficult to resolve, social workers can suggest that the hospital’s ethics committee consider the issue

What We Can Do

• Become knowledgeable about social work ethics and how reflective practice can refine deliberations in ethical dilemmas; share this information with your colleagues
• Identify relevant cultural factors that may impact service delivery to individuals at the end of life and adopt skills and techniques that are culturally appropriate
• Learn about the use of groups as a tool to develop ethical and critical thinking in your social work practice
• Develop an awareness of your own cultural values, beliefs, and biases related to end-of-life care and develop knowledge about the
histories, traditions, and values of clients to inform ethical decision-making. Adopt treatment methodologies that reflect the cultural needs of clients. (10, 14, 15, 21, 23, 26)

› Assist the client and family in picturing a realistic outcome they would like to have and help create a guide for treatment decisions that will reduce the suffering experienced by the client and his or her family. (26)

› Encourage the client to create an advance care plan if one has not been completed in order to help reduce uncertainty and minimize confusion and conflict over the client’s wishes. (13)

› Understand that client autonomy and self-determination are key aspects of ethical decision making and must be balanced with protecting the client from harm. (13)

› Continue to treat the client with dignity and compassion, despite changes in his or her level of consciousness and mental state. (24)

› Participate in continuing education to increase understanding of standards of ethical decision making. (13)

References