

Ethics and the New Conditions for Coverage for End-Stage Renal Disease Facilities

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Social workers bring a unique perspective of values and ethical decision-making skills to their work environments. Trained in the basic values of service, social justice, dignity and worth of individuals, importance of human relationships, integrity and competence, social workers are equipped to help the health care team face ethical dilemmas and use these values to promote ethical decision making. The new Conditions for Coverage for End-Stage Renal Disease Facilities include some new guidance on current ethical dilemmas. These include the patient care environment, patient rights, advance care planning and involuntary discharge. At this critical juncture, social workers can assist their health care team in creating new processes and policies for ethically-sound practice with people on dialysis.

INTRODUCTION

For as long as there has been an organized profession, social workers have been faced with ethical dilemmas. However, ethics have evolved over time, and different aspects of ethics have been emphasized throughout the profession's history. In the late 19th century, social workers focused on ethics related to their clients more than the social work profession. When more formal training programs were established, debate centered on determining the profession's core values. In the 1970s, more educational programs added curriculum on ethics and, with the advance of technology, professional conferences began discussing ethics in relation to topics such as life support, organ transplantation and *in vitro* fertilization. Most recently, another area of ethics has evolved related to risk management. This area of ethics has focused on professional negligence and liability in response to client complaints and lawsuits (Reamer, 2006a).

Ethical Dilemmas in the Dialysis Setting

Nephrology social workers may find themselves faced with a host of ethical dilemmas. Ethics practiced in a medical setting takes many forms, including allowing patients to assume personal responsibility for their health, practicing the principle of nonmaleficence, being truthful to patients, maintaining confidentiality and bodily integrity, caring for those who cannot pay for services and allowing patients to die if therapy to counteract illness or disease imposes a severe burden upon patients (or their families) or is ineffective (Bone, 1996). In practice with dialysis patients, social workers may find themselves faced with ethical dilemmas regarding access to care, late referrals to health care resources, appropriate patient education and conflict and interpersonal relationships between patients, health care providers and others.

When faced with an ethical dilemma, an ethical decision-making framework is important to guide social workers through the process of identifying the ethical issues to helping the health care team make the most appropriate decisions. The following step-by-step process should be used when confronted with an ethical dilemma:

1. Identify the ethical issues, including conflicting social work values and duties.
2. Identify the individuals, groups and organizations likely to be affected by the ethical decision.
3. Tentatively identify all viable courses of action and the participants involved in each, along with the potential benefits and risks.
4. Thoroughly examine the reasons for and against each course of action.
5. Consult with colleagues and appropriate experts.
6. Make the decision and document the decision-making process.
7. Monitor, evaluate and document the decision (Reamer, 2006a).

When one is in the midst of a confusing situation, it can often seem overwhelming. However, breaking it down using the previous framework can provide direction to the health care team and create a more concrete approach to overwhelming situations.

The Centers for Medicare and Medicaid Services (CMS) released revised Conditions for Coverage (CfCs) for U.S. dialysis facilities in April, which will go into effect October 2008. The following areas identify common ethical situations in dialysis settings, and the new CfCs provide some guidance for the health care team in protecting the best interests of both dialysis patients and providers. Section 494.60 (Physical Environment) contains a standard to maintain a comfortable temperature within the facility and make reasonable accommodations for the patients who are uncomfortable. Although

this situation may seem at first like a minor ethical dilemma, the dialysis facility temperature is often an area of low patient satisfaction, which can lead to conflicts between patients and dialysis staff. Patients are sitting for several hours at a time, whereas staff are moving and wearing personal protective equipment. Whose comfort is most important? The CfCs' preamble encourages dialysis facilities to "arrive at a middle ground so that the room temperature is at least marginally acceptable to both patients and staff. Patients who continue to feel cold could use coverings or blankets" and "should not be deprived of the ability to use covers or blankets" as long as they keep their access and line connections uncovered (CMS, 2008).

Section 494.70 (Patient Rights) includes a new area to inform patients about their right to execute advance directives and the facility's policy regarding advance directives. A study of 80 dialysis patients found that although 69% of patients thought completing an advance directive was a good idea, only 35% had followed through to complete one (Holley, 1997). While many dialysis facilities have implemented policies related to discussing advance directives with patients, the new CfCs bring this important issue to a standard of care. Dialysis health care teams should discuss the roles of each team member in advance care planning with patients and strive to provide education to both professionals and patients to increase the level of comfort in end-of-life care discussions. The dialysis community has recognized this issue as an important one and has formed the Kidney End-of-Life Coalition, which provides tools and resources on their Web site (www.kidneyeol.org).

A higher level of patient participation in care is expected in the new CfCs. In Section 494.80 (Patient Assessment) and Section 494.90 (Patient Plan of Care), a number of new requirements include patients in assessing problems, determining interventions, evaluating the outcomes of those interventions and determining new goals. For example, the comprehensive patient assessment must include an area designated to evaluate the desired level of patient participation in care and the patient's expectations for care outcomes. This type of patient-centered language has not been seen in the past CfCs and reflects the current practice of increased patient involvement in health care, encouraging transparency and including patients as vital members of the multidisciplinary health care team. The Patient Plan of Care condition requires individualized care plans for each patient's needs and patients be given the opportunity to participate in the

care plan process. Patients cannot participate fully without knowledge, and the condition also requires documentation showing patients were educated about the dialysis experience, dialysis management, infection prevention, home dialysis and self-care, quality of life, rehabilitation, transplantation and the benefits and risks of various vascular access types.

Ethical dilemmas may arise in determining the participation level of patients in their care. Patients may refuse to participate in care planning or may be nonadherent to their treatment plan. Language barriers may exist, making a standard of education difficult to achieve for each patient. Although the CfCs recognize that patients cannot be forced to participate or adhere to their treatment plan, a higher expectation will be placed on the health care team to include patients in decisions about their care and educate them appropriately. The new CfCs attempt to move the health care team to provide a higher level of individualized, comprehensive care. As Lori Hartwell, a person living with kidney disease, states, "I've heard the phrase 'the patients' uttered countless times during my 37 years of living with renal disease. We tend to be viewed as an amorphous group. Nothing could be further from the truth. We might have lost our kidney function, but we have not lost our identities" (2006).

Involuntary patient discharge from dialysis facilities is arguably the most difficult ethical dilemma a nephrology social worker can face. This issue includes the rights of patients and the rights of dialysis providers and health care staff. Social workers also have a professional responsibility not to abandon their clients. When a patient is involuntarily discharged, the patient leaves the care of the dialysis facility, including the professional relationship with the social worker. The National Association of Social Workers (NASW) code of ethics states, "Social workers should take reasonable steps to avoid abandoning clients who are still in need of services. Social workers should withdraw services precipitously only under unusual circumstances, giving careful consideration to all factors in the situation and taking care to minimize possible adverse effects. Social workers should assist in making appropriate arrangements for continuation of services when necessary" (NASW, 1999). Termination of services must always be handled carefully to protect patients and minimize risk to patients, dialysis providers and professional liability and integrity. As Reamer states, "Clients whose services are terminated unethically may not receive the services they need and, as a result, may pose a threat to themselves and others" (2006b).

In Section 494.180 (Governance), the CfCs provide criteria for circumstances under which patients can be involuntarily discharged. These circumstances include termination of reimbursement by patient or payer, facility closing, necessary transfer for the patient's welfare and disruptive and abusive patient behavior to the extent that the delivery of care or ability of the facility to operate effectively is seriously impaired.

The process for involuntary discharge must include these steps, which must be guided by the medical director. The patient's interdisciplinary team:

1. Documents the reassessments, ongoing problem(s) and efforts made to resolve the problem(s)
2. Provides the patient and local End-Stage Renal Disease (ESRD) Network with a 30-day notice of the planned discharge
3. Obtains a written physician's order signed by both the medical director and the patient's attending physician concurring with discharge
4. Contacts and attempts to place the patient in another facility and documents that effort
5. Notifies the state survey agency and the ESRD Network that services the area of the involuntary transfer or discharge.

In the case of immediate severe threats, the facility may utilize an abbreviated involuntary discharge procedure. The CfCs' preamble includes a suggestion from CMS that dialysis facilities use materials developed by the Decreasing Dialysis Patient-Provider Conflict National Task Force to prevent conflicts and disruptive situations. These materials are available from any ESRD Network.

Clearly, a number of ethical issues arise in caring for people on dialysis because of the nature of life-

sustaining therapy and the ongoing inter-relatedness of people on dialysis, the dialysis facility staff and dialysis provider companies. Social workers should employ their training in basic values of providing services and an ethical framework for decision making to help the dialysis health care team make the most appropriate decisions when confronting ethical dilemmas. The new CfCs provide some new guidance to some of these situations and encourage the dialysis health care team to provide a higher level of care focusing on patient-centeredness and involvement in decision making.

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