

Original Article

Management of Ethical Issues Related to Care of Seriously Ill Dialysis Patients in Free-Standing Facilities

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Abstract

Context. There are few data on the frequency and current management of clinical ethical issues related to care of seriously ill dialysis patients in free-standing dialysis facilities.

Objectives. To examine the extent of clinical ethical challenges experienced by care providers in free-standing facilities and their perceptions about how those issues are managed.

Methods. A total of 183 care providers recruited from 15 facilities in North Carolina completed a survey regarding the occurrence and management of ethical issues in the past year. Care plan meetings were observed at four of the facilities for three consecutive months. Also, current policies and procedures at each of the facilities were reviewed.

Results. The two most frequently experienced challenges involved dialyzing frail patients with multiple comorbidities and caring for disruptive/difficult patients. The most common ways of managing ethical issues were discussions in care plan meetings ($n = 47$) or discussions with the clinic manager ($n = 47$). Although policies were in place to guide management of some of the challenges, respondents were often not aware of those policies. Also, although participants reported that ethical issues related to dialyzing undocumented immigrants were fairly common, no facility had a policy for managing this challenge. Participants suggested that all staff obtain training in clinical ethics and communication skills, facilities develop ethics teams, and there be clear policies to guide management of ethical challenges.

Conclusion. The scope of ethical challenges was extensive, how these challenges were managed varied widely, and there were limited resources for assistance. Multifaceted efforts, encompassing endeavors at the individual, facility, organization, and national levels, are needed to support staff in improving the management of ethical challenges in dialysis facilities. *J Pain Symptom Manage*

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Key Words

Ethical issues, renal dialysis units

Introduction

Since federal funding for dialysis began four decades ago, the number of dialysis patients has rapidly grown; these patients are now older and more varied in cultural background, and they live longer but often with multiple comorbid conditions.¹ To meet the needs of 550,000 patients with end-stage kidney disease¹ who require maintenance dialysis, there are roughly 5500 dialysis facilities certified by Medicare.² More than 80% of these facilities are free-standing.² Whereas most hospital-based dialysis units can rely on their hospital ethics committees or ethics consultation services to respond to ethical issues and help patients, families, and health care providers, free-standing facilities do not have such an established mechanism.

Facility staff face many difficult ethical issues in caring for dialysis patients. Some of the documented issues include caring for disruptive or non-adherent patients and balancing the needs of a disruptive patient against the welfare and safety of other patients and staff;^{3–9} dialyzing geriatric patients with multiple comorbidities and frailty and continuing dialysis when the therapy seems no longer beneficial;^{10–15} stopping or continuing dialysis for seriously ill patients;^{16–23} selecting or denying patients for kidney transplantation;^{24–27} providing renal care for undocumented residents with end-stage kidney disease;²⁸ dialyzing patients with cognitive impairment;²⁹ dealing with pregnancy in dialysis patients;^{30,31} and handling abusive or inadequate family caregivers of dialysis patients.³²

Some facilities have written policies about managing issues such as handling disruptive patients or making end-of-life decisions, although they are not required to do so. Clinicians also have access to guidelines and recommendations addressing these issues (e.g., “shared decision-making practice guidelines in dialysis”).^{33–36} However, there are few data

on the frequency and current management of clinical ethical issues that could be used as a basis for guiding practice or further research. The purpose of this study, therefore, was to examine ethical challenges that care providers in free-standing facilities experience and their perceptions about current practices in managing these ethical challenges.

Methods

Design, Setting, and Participants

This was a descriptive study using a survey of dialysis care providers, field observations, and document reviews.³⁷ The potential care providers for the survey included approximately 300 individuals, including physicians (MD), advanced nurse practitioners (ANP), physician assistants (PA), nurses (RN and LPN), social workers (SW), dietitians (RD), and patient care technicians (PCT), from 15 free-standing facilities located in North Carolina. Participants who had provided care for at least six months in the facility were eligible so as to be able to respond to questions regarding the frequency and nature of ethical issues in the facility. Our goal was to obtain at least 150 responses, with an anticipated response rate of 45%–50% based on response rates achieved in previous clinician survey studies.^{38–40}

For field observations, four of the 15 facilities were purposefully chosen to gain information on current practices regarding ethical conflicts. The facilities reflected variations in characteristics that might influence management of clinical ethical issues: one small (<50 patients), one medium (50–99 patients), and two large clinics (≥ 100 patients); one clinic where an attending nephrologist is on site and three clinics where a nephrologist visits once a week; two with academic affiliations and two with no academic affiliation. Care plan meetings were observed for three consecutive months for each of the four

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