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The Demented Patient Who Declines to Be Dialyzed and the Unhappy Armed Police Officer Son: What Should Be Done?

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Summary

Dialysis personnel are responsible for ensuring that patients' rights and physical safety are protected in dialysis centers. Treatment of patients with cognitive impairment, including patients with dementia, presents special challenges. These patients may attempt to pull out their dialysis needles during treatment, potentially endangering themselves, dialysis center personnel, and other patients. Such patients may also compromise the care of other patients in the center by upsetting them and requiring a disproportionate amount of staff attention during treatment. Dialysis centers have learned to require families of such patients to provide a sitter to ensure that the patient remains safe during the dialysis treatment; however, some patients may exhibit unsafe behaviors despite a sitter, and not all families are willing to provide a sitter. In some instances, family members respond to the stress of a loved one who is unsafe on dialysis by being verbally or physically abusive to dialysis staff. This article presents a case in which the family member was a police officer who was not only verbally and physically intimidating to the staff but also insisted on bringing his police service weapon into the dialysis center. It describes the psychosocial, ethical, and legal responses to a family member who is disrupting what should be a calm environment in the dialysis center and recommends that dialysis centers proactively develop policies concerning safety for patients, family members, and other visitors that make no exceptions. The case also highlights the importance of adopting a no weapons policy and posting and enforcing a no weapons sign.

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Case Presentation

A 75-year-old woman with advanced dementia who resides in a nursing home has been on hemodialysis for 12 months. She lacks decision-making capacity and her son, who is a police officer, is the patient's medical power of attorney representative. She was transferred to the present dialysis center from another center, where the decision to start dialysis had been made with a different nephrologist. This nephrologist had discouraged the son from initiation of dialysis for the patient because of her poor prognosis. At the present dialysis center, despite multiple face-to-face sessions during which time the son was further educated about his mother's poor prognosis, he insisted on continued dialysis to prolong his mother's life as long as possible, regardless of her level of function. The hospital lawyers inform the Medical Director of the dialysis center that he is required by state law to continue dialyzing this patient if her legally-designated decision maker insists on it. The patient routinely starts to refuse dialysis whenever she is brought to the dialysis facility from the nursing home. Her son insists that the dialysis center is legally required to dialyze his mother against her will, even if that entails physically restraining her. The dialysis center declines to do so, and the ESRD Network supports its decision. The son instructs the dialysis nurses to call him whenever his mother refuses to dialyze so that he can come in person and try to change her mind. When the son is not available, the patient is returned to the nursing home without receiving dialysis. The son threatens to sue the dialysis center if it does not dialyze his mother each time she arrives for a treatment. The nurses learn that they can coax the patient to stay on dialysis by offering her candy, and, temporarily, the impasse with the son seems to be averted.

Subsequently, the patient's dementia deteriorates, and on two separate occasions, she tries to pull out her dialysis needles. The Medical Director and dialysis staff educate the son about the risk of exsanguination and require him to provide a sitter for his mother during dialysis to ensure her safety. The son reluctantly agrees to sit with his mother during dialysis. He shows up three times a week wearing his police uniform and gun. He tries to stipulate which dialysis staff can care for his mother, intimidates the staff by continually peering over their shoulder, loudly criticizes the competence of some nurses to their faces, and creates a very hostile environment. In another face-to-face meeting, the son is informed that it is against unit policy to bring weapons into the dialysis center and that he should refrain from doing so. He responds that, according to state law, he is entitled to wear his uniform and gun anywhere, even when he is off duty. In fact, he claims that the dialysis unit should be grateful for the extra protection that he is providing.

Nephrologist Commentary by M.A.

Outpatient dialysis centers have unique features that can intensify conflict and harm, which might not occur in other outpatient settings (Table 1). Because of this uniqueness, the dialysis center's Medical Director has a professional responsibility to ensure that patients are being treated appropriately and do not threaten the safety of other patients and the staff and their calm treatment environment. The ordering nephrologist and/or the Medical Director have the right and responsibility to refrain from ordering dialysis treatments that they judge not to be medically indicated, because they may do more harm than good, specifically if the patient does not understand why she is receiving dialysis and cannot cooperate with the dialysis process (1). These features contribute to this case, which presents an extremely challenging situation for the dialysis center staff and the Medical Director. Patients are entitled to decline medical care, even when that decision may lead to their direct harm or even death. However, this patient lacks decision-making capacity and does not comprehend the medical consequences of refusing dialysis. Theoretically, the son has medical power of attorney authority and can decide that she should continue dialysis against her wishes. In the hospital setting, patients with temporary, reversible mental incapacity can be sedated before dialysis. However, such an approach is neither feasible nor safe in the outpatient dialysis setting. Providing dialysis in this case would require physical restraints for several hours three times per week, causing emotional anguish. More importantly, physical restraints on an outpatient are a violation of some dialysis center policies. Fortunately, an ethical consensus is emerging that physically restraining and forcing dialysis on such individuals has the potential for harms: emotional distress, infringement on one's dignity, possible physical harm, and potential demoralization (2).

Table 1. Unique features of outpatient dialysis centers relative to other outpatient medical settings

1	Frequency of contact (three times per week versus typically a few times per year)
2	Duration of each contact (3–4 h versus 10–60 min)
3	Presence of other patients (multiple other patients present versus one-on-one visit)
4	Therapeutic community of patients and caregivers rather than an individual provider–patient interaction
5	Close proximity of patients, which increases the likelihood that one patient's behavior might disturb others and that patients might be exposed to other patients' blood and body fluids
6	Risk of patient exsanguination within minutes from needles dislodged from an arterial circuit and risk of blood-borne pathogen exposure to other patients from exsanguination
7	Life-sustaining treatment required for the remainder of the patient's life with fatal consequences of missing/stopping treatment (life or death versus usually not life or death)
8	Difficulty in discharging patients and finding alternative treatment settings

In contrast to an individual physician–patient encounter, the dialysis unit is a therapeutic community of patients and caregivers. As a consequence, cognitive or behavioral problems of an individual patient may cause severe distress to other patients who are exposed to them three times per week. Moreover, problem patients distract the staff from providing optimal care to the other dialysis patients. When the situation is not remedied expeditiously, it can depress staff morale and potentially result in staff turnover.

All dialysis facilities have a zero tolerance policy regarding credible verbal or physical threats of violence or actual physical violence in the workplace. Staff members should not be expected to work in a hostile environment or fear for their safety. When a legally competent patient acts violently or threatens violence, the dialysis facility has the right and duty to discharge the patient to protect the other patients and the dialysis staff. The current scenario is far more complex, because the son is the perpetrator of the violent behavior and not his mother, who is the patient. Although barring the son from the dialysis facility would address his threatening behavior, the patient's safety concerns would persist. Moreover, the son's roles as family member and police officer become enmeshed, and he claims that his status as police officer exempts him from the facility's no weapons policy. The staff is fearful of his short fuse and potential to act out, despite the presence of the unit's security guard. Calling 911 and requesting another armed officer to confront the son in the unit presents a potentially volatile situation. Finally, transferring the patient to another dialysis facility is an unlikely option given the difficult circumstances.

As this case evolved, it became evident that the hemodialysis staff had not been documenting in the electronic records some of their interactions with the patient's son. Subsequently, they were instructed to enter detailed summaries of each face-to-face or telephone interaction. This documentation was very important in obtaining critical support from the ESRD Network and the State Board of Health in enforcing the dialysis center policies. Hemodialysis staff are extremely busy and often do not take the time to document such interactions. It is clear how essential this documentation can be in some cases.

Case Epilogue

The dialysis center is prepared to bar the son from sitting with his mother and require him to hire an outside sitter. However, the son lodges a complaint with the State Board of Health, alleging that the dialysis center is discriminating against his mother. A nurse from the Board of Health visits the center and records her findings. She then calls the son's police department to voice her concerns. The precinct captain determines that the patient's son is acting unprofessionally and giving the police department a bad name. The captain instructs the son to refrain from wearing his uniform or gun when he sits with his mother, and the son complies.

Nurse Commentary by G.H.

This case highlights several contextual features relating to the presence of other patients (multiple other patients

present versus one-on-one interaction) in the outpatient dialysis environment (Table 1) and raises the consideration of the ethical principle of justice. Justice requires that patients be treated fairly. When a patient pulls out a dialysis needle, she is creating a risk of blood-borne pathogen exposure and jeopardizing the health and safety of other patients and staff. The risk to others in the dialysis environment brings up a second ethical principle, nonmalfeasance, which requires that professionals do no harm. Because the physician is ordering dialysis for a demented patient who has the potential to harm others with her behaviors, the risk of the patient's behaviors to other patients should be considered in the shared decision-making process and the determination of whether the patient is appropriate for dialysis (1). A separate and additional hazard arises from the weapons and confrontational behaviors described in this case. In both types of risk, employers are bound under Occupational Safety and Health Administration regulations (3) to provide a safe workplace and therefore must act to mitigate the risk.

As described in the Conditions for Coverage for End Stage Renal Disease Facilities (4), dialysis patients have a right to treatment that is free of disturbing outbreaks or threats by another patient or family member. In §405.2136 Condition: Governing Body and Management, the Conditions for Coverage (4) state that "[t]he governing body adopts and enforces rules and regulations relative to its own governance and to the health care and safety of patients, to the protection of the patients' personal and property rights…" When a patient continuously or frequently moans, screams, or demands to be taken off dialysis, other patients suffer anguish and may wonder if they will be forced to dialyze against their will. Patients and staff experiencing moral distress witnessing such behavior have contacted their ESRD Network for guidance In these cases, a family conference or ethics committee consultation is often recommended to discuss the goals of care and burdens of treatment with the desired outcome of an agreed plan of care that meets the needs of the patient and other patients in the facility, respects patient autonomy, and provides dignity and comfort to all.

Optimal individual and family functioning throughout all phases of disease management are the primary goals of nephrology nursing (5), and nurses often feel a conflict of professional integrity in such cases. Both the American Nephrology Nurses' Association's *Nephrology Nursing Scope and Standards of Practice* (6) and *Core Curriculum for Nephrology Nursing* (7) provide direction to the nurse and offer guidance for ethical considerations and dilemmas. These works reference *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis* (1), a clinical practice guideline, and the 5th edition of *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine* (8).

The *Decreasing Dialysis Patient–Provider Conflict Toolkit* (9) is a resource developed by a national task force to provide tools and techniques for staff to use in coping with conflicts that occur in the dialysis environment. The collaborative effort was funded by the Centers for Medicare and Medicaid Services, undertaken by key national ESRD stakeholders, and coordinated through the Forum of ESRD Networks. Health care professionals and unlicensed staff may feel unprepared to effectively address conflicts, because understanding, appropriately responding to, and resolving the conflict are difficult challenges that require training, practice, and experience. The toolkit provides dialysis professionals with conflict management resources that enable them to practice and respond appropriately, objectively, and confidently to family members like this son.

ESRD Networks disseminated the toolkit to all Medicare-certified providers in 2005 and provided training on use of the resources in the toolkit. The toolkit is available on many ESRD Network websites and the Network Coordinating Center website (10). Several networks continue to provide the toolkit and interactive CDs on request or to new providers.

Social Worker Commentary by R.B.-C.

Seeing the debilitation of a parent is stressful. Perhaps the son's behavior is a response to his fear of losing his mother, having no control, and feeling vulnerable. Most bullying behavior stems from feeling inferior or insecure (11). The son might benefit from counseling, which may be available through his employer, because many law enforcement agencies have early warning systems to identify officers whose behavior is problematic and intervene before the situation becomes severe (12). The patient's overall status might warrant monthly care plan meetings, which should include participation from the son and discussion of advance care planning (13). Care plans could be used to promote continued discussion and better understanding of the son's behavior as well as his needs and his mother's needs. The advance care planning could facilitate the son's understanding of his mother's overall condition and poor prognosis and include a discussion about appropriate medical orders for the patient's condition, such as a do not resuscitate order and orders to limit intensive measures, such as intubation and mechanical ventilation, on a Physician Orders for Scope of Treatment form (13). Tools and guidelines are available to assist clinicians with these discussions (1,14).

Difficult or uncomfortable situations and behavioral issues typically trigger a handoff to the social worker to deal with the social issue. In a situation such as presented in this case, no one should be left to manage it alone. The team best serves patients and staff by ensuring that they understand their rights (to not feel unfairly threatened or work in a hostile environment) and responsibilities (to help maintain a comfortable and safe environment for all) and by setting limits and reinforcing them consistently. Standing together not only provides support and confidence to the individuals, but it is also a mechanism for taking power away from a bully.

What understandably threw this team off was the psychological manipulation of a socially recognized authority figure. Had the circumstances been different, the facility might have thought independently to verify the son's claims with its legal advisors, the Network, or the police department. A toxic environment creates stress that can disable effective thought processing.

Anecdotally, very few patients voice grievances about other patients to the Networks. However, there are the occasional grievances from patients who do not feel that

the facility is responding effectively to another threatening patient and express concern not only for themselves but the other patients and staff. How frightening must it be for patients tethered to a machine to witness an anxious, powerless staff? What message is sent to other patients who would prey on recognized weakness? It is vitally important for facilities to train staff in conflict/crisis management. If the institution does not have high standards for the way that people treat each other, then crises will be more prevalent. It is not uncommon for staff to underreact in potentially volatile situations. Staff must be empowered to call for help whenever safety is questioned. Additionally, a perceived hostile environment can cause avoidance in both patients and staff, which is reflected in poor attendance, transfers, and high staff turnover.

Staff turnover and the general complacency that routine can bring further underscore the need for facilities to conduct regular reviews of conflict management as part of other emergency preparedness training. The master's degree–prepared social worker possesses the skillset to help the team come together to process, plan, execute, and debrief. The social worker could lead staff in regular meetings to review concerns, share best practices, problem solve, agree on a strategy, and offer much-needed emotional support.

Legal and Ethical Commentary by S.V.R. and A.H.M.

Typically, a disruptive patient is at risk for involuntary discharge. When families cause disruption, however, discharging the uninvolved patient seems inappropriate. The son in this case study, and in general any individual who is not a patient and not in the clinic in an official capacity, is a visitor. All facility rules apply to such individuals. Their presence is a privilege that can be revoked. Before doing so, the dialysis provider should have made several attempts at convincing the son that his inappropriate behavior could not only get him removed from the property but also, potentially result in discharge of the patient. Another option included sending the son a warning letter with the signatures of the administrator, Medical Director, and treating nephrologist outlining the expectations for his behavior while on the dialysis provider's property. An option that was used in this case was for the son to meet face to face with the interdisciplinary team to discuss concerns over his behavior and solutions to ensure that his mother was not adversely affected by his poor choices. If the son's actions remained hostile and disruptive, the dialysis provider should have sought to discharge the patient, because it had a duty to ensure the safety and wellbeing of its other patients and staff who could be negatively impacted by the son.

This case presents a frequent and increasingly common scenario: the performance of dialysis on a cognitively impaired patient (15) who does not understand that dislodging her dialysis needles poses serious consequences to staff and other patients and potentially life-threatening consequences for her. Dialysis centers have learned that such patients need one-on-one supervision to be safely dialyzed, and they have required families to provide a sitter to ensure that the patient's behavior during dialysis conforms to center policy so that the patient can be dialyzed safely. This case presents an extra twist, because a family member was physically threatening and abusive; the dialysis center was initially perplexed in regard to how to proceed, because the family member claimed an exceptional privilege (to be allowed to sit next to his mother during dialysis in a police uniform [which by its nature is intimidating to staff] with a loaded weapon [which increases the intimidation factor even more]).

The solution for dialysis centers is to make no exceptions for family members who are visitors to their centers. They all need to abide by center policies. In 2000, 26% of dialysis personnel responding to a survey at a national meeting reported that their center posted a no weapons sign (16). King and Moss (16) encouraged all dialysis centers to develop policies for responding to "difficult/disruptive" dialysis patients (16). The case presented in this paper expands the recommendation to dialysis centers to include a policy for difficult/disruptive family members or other visitors. The case highlights the importance of adopting a no weapons policy consistent with state law (17) and posting and enforcing a no weapons sign.

The dialysis center's Medical Director and other dialysis personnel are responsible for ensuring that patients' rights and physical safety are protected in dialysis centers (4). This obligation to all patients may limit the accepted behaviors of individual patients or their family members. This limitation on the autonomy of individuals is necessary for the good of all. The dialysis center is a unique environment (Table 1), and ethical policies and practices for dialysis centers need to take into account the particular nature of this health care setting. For patients with cognitive impairment whose behavior is not able to be controlled (despite a sitter) and who present a risk of harm to themselves or others because of an inability to safely cooperate with the dialysis process, the *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis* clinical practice guideline recommends that consideration be given to stopping dialysis (1). The case presented in this article illustrates how a dialysis center, after much conflict and tension, implemented a procedure that enabled the continued dialysis of the patient and preserved the peace of the facility. The authors hope that the lessons learned from this case will be valuable to other centers so that they can proactively establish policies and procedures necessary to maintain a calm environment and manage conflict systematically and competently (10).

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Disclosures

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