Is It Ethical to Do Dialysis But Not Cardiopulmonary Resuscitation?

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Scenario 1

Henry Jones* is a 46-year-old with a history of Alport syndrome (a genetic mutation causing defects in type IV collagen found in the kidneys, ears, and eyes).[1] His medical/surgical history includes bilateral hip replacements, renal failure requiring hemodialysis, nearly 100% hearing loss in both ears, low visual acuity, chronic obstructive pulmonary disease, and a 15% cardiac ejection fraction. He describes his quality of life as declining and states ''I require help to do just about everything.''

In March, Mr Jones was hospitalized with a myocardial infarction. Prior to discharge, Mr Jones had a discussion with his primary care provider (PCP) about his prognosis. Because of his age and the fact that he had a high school–age daughter, Mr Jones and his PCP completed a Clinician Order for Life-Sustaining Treatment (COLST) form stipulating that cardiopulmonary resuscitation (CPR) was desired in the event of an arrest. After discharge from the hospital, Mr Jones returned to living in his condo with a personal care assistant and resumed outpatient hemodialysis.

In May, Mr Jones experienced a cardiopulmonary arrest while receiving hemodialysis treatment. The dialysis staff initiated CPR and transferred to the local emergency department by ambulance. Mr Jones died a day later without ever regaining consciousness. Following this event, patients began asking questions about why a person might arrest while receiving dialysis treatment. In a staff meeting, Mr Jones' dialysis nurse wondered: ''Did I do something to make him die? I didn't realize that I could break his ribs doing chest compressions. Knowing how bad his heart was, why wasn't he a *no code*?''

*Scenarios modified to protect confidentiality.

Scenario 2

Ivana Petry* is 77-year-old with congestive heart failure and diabetes. She had her first coronary artery bypass graft (CABG) surgery 12 years ago and underwent

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a second CABG in January. Five days after the repeat CABG, Ms Petry experienced a cardiac arrest. Although CPR was effective in reestablishing her cardiac rhythm, she developed renal failure and now requires hemodialysis. She spent months in and out of the intensive care unit with various complications including pneumonia, decubitus ulcers, *Clostridium difficile*, and difficulty weaning from the ventilator. In May, she is transferred to an assisted-living facility with outpatient hemodialysis treatment. During her new client orientation to the dialysis center, Ms Petry told the nurse, ''I was coded once, and I never want to go through that again!'' After hearing Ms Petry's treatment preferences, the dialysis nurse asks the dialysis center nurse manager, ''Isn't dialysis a life-sustaining treatment? Is it ethical to do dialysis but not CPR?''

After learning about these 2 different patient events, the nurse manager realizes that the dialysis nursing staff is raising thoughtful questions related to not only the clinical goals of dialysis, but also legal and ethical concerns.

Clinical Realities of Dialysis

Hemodialysis is used for patients with end-stage renal disease (ESRD) as an aggressive treatment to save or maintain life as well as improve the person's overall quality of life. The immediate objectives of hemodialysis are to correct electrolyte and fluid imbalances and remove toxins from the blood. Longer-term objectives for treating persons with renal failure with hemodialysis are to optimize functional status, including comfort and hemodynamics blood pressure, prevent uremia and its complications, and improve overall survival.

Through the process of removing toxins and fluid from the bloodstream, a shift in electrolytes may lead to complications. After dialysis, patients may experience cramping, pruritus, nausea/vomiting, lethargy, headaches, and/or chest and back pain. These symptoms may be associated with shifts in blood volume or dialysis disequilibrium related to sudden shifts in blood toxins, but sometimes the cause for these complications is unknown.[2] Other less common complications include infection or bleeding (hemorrhage) at the dialysis access site (fistula, graft, or catheter), dyspnea, and sepsis. In addition, an air embolism may result if air is accidentally introduced into the patient's bloodstream through a small break in the central venous catheter line, a malfunction of the dialysis machine, or when staff is administering fluids/medications. Some of these complications, such as air embolism and infection, may be related to iatrogenic causes rather than the ESRD. Nevertheless, the therapeutic benefits from receiving hemodialysis typically are perceived by patients and healthcare professionals as being greater than the potential harms.[3]

If a patient becomes hemodynamically symptomatic during dialysis, universal protocols for restoring hemodynamic stability including discontinuation of the hemodialysis treatment and standard interventions are implemented. If despite the implementation of these universal protocols the patient experiences a cardiopulmonary arrest, the dialysis staff would initiate chest compressions and ventilation (CPR) (unless directed otherwise by a written physician order) until emergency assistance arrives to begin advanced cardiac life support algorithms.

It is important that dialysis nurses, persons with renal failure, and their significant others recognize that hemodialysis treatment may be perceived in a variety of ways. For example, chronic dialysis patients, who have few or no comorbidities, may view hemodialysis as life sustaining, a necessity for promoting the best quality of life possible and possibly providing a bridge to kidney transplantation. For a patient in an acute crisis, such as a hospitalized patient with the possibility of multiple organ failure, hemodialysis can be lifesaving as a means for reversing toxic damage. For those patients with ESRD and/or nearing the end of life, however, hemodialysis may be regarded as life prolonging; that is, it modifies the natural history of the disease and delays the time to deterioration. Unless the patient is fortunate enough to obtain a kidney transplant, which depends on a number of extraneous factors, kidney failure is generally progressive, irreversible, and inevitably fatal—only the rate of progression is variable.

Despite the benefits associated with dialysis, approximately ''23% of dialysis patients in the United States die per year.''[4(p172)] Ross[3] noted that cardiac disease is responsible for 45% of the deaths for persons receiving hemodialysis. In a meta-analysis performed in 1998, Ebell et al[5] noted that less than 10% of persons with ESRD who arrest in the hospital survive to leave the hospital after being coded. In addition, Moss et al[6] found that, 6 months after receiving CPR, 3% of the patients in the dialysis group were alive compared with 9% of the control group ($p = .044$). Thus, hemodialysis is more appropriately viewed as life prolonging, as it is altering the natural history of progression and prolonging the time to death or intractable symptoms.

As time goes on, without the intervention of a kidney transplant or some other technological breakthrough, the delicate balance of benefit versus burden will shift, and then it becomes imperative that the patient and the dialysis staff both understand the goals guiding the dialysis treatment. As the patient's condition changes (either improving and declining), the patient's goals related to dialysis should be discussed, or if needed, the treatment plan clarified. As the treatment plan is clarified, a discussion with the patient regarding what his/her wishes are

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pertaining to end-of-life decisions would be appropriate. In light of the low survival rate, it is imperative that patients with renal failure and receiving hemodialysis are educated on the clinical outcomes associated with CPR.

Ethical Issues

Several ethical questions are associated with these scenarios.

- Given the potential for a cardiopulmonary arrest related to the dialysis process and Mr Jones' significant medical history, do the healthcare professionals at an outpatient dialysis center have an ethical (or legal) obligation to attempt to reverse his cardiopulmonary arrest?
- Is Ms Petry being ethically consistent when refusing CPR while concurrently seeking renal dialysis?
- Given the fact that other dialysis patients might witness Ms Petry's arrest because outpatient dialysis services are often provided in a shared common space, would the trust dialysis patients have in their dialysis treatment and healthcare professionals be undermined if CPR were not initiated?

Identifying Treatment Goals

Persons in the prime of life generally opt to treat unexpected injuries and symptoms aggressively with the goal of regaining their previous level of health. In contrast, persons near the end of life may select to focus the goals of care toward palliation not prolonging life or postponing death. Ms Petry appears to be in between these 2 decision perspectives. She now has a chronic disease (renal failure) that without routine dialysis will cause her death in a short period (days to a couple of weeks), depending on her renal function, current cardiac status, and dietary intake.[7] Given this, quality of life becomes even more important. The dialysis nurses, together with Ms Petry, her PCP, and family, should collaboratively discuss potential treatment or health decisions Ms Petry may encounter as her renal and cardiac diseases progress, including discussion of iatrogenic-related complications. Nurses may find the various quality-of-life tools available from the Robert Wood Johnson Foundation[8] as well as the Personal Death Awareness Exercises from the Kidney End of Life Coalition[9] helpful for initiating and promoting open discussion. As treatment goals are identified, the healthcare professionals will be able to clarify intentions and ensure that Ms Petry's decision to receive dialysis while concurrently refusing resuscitation is consistent and clearly understood by all stakeholders.

Decisions about withdrawing or discontinuing treatment are not always easy, particularly when the treatment can be classified as both lifesaving and life prolonging. The complexity of these decisions is compounded only when the nurses and the nurse manager are uncertain about their legal obligations and have concerns about legal liability. Generally, as a matter of law, healthcare providers cannot treat an individual against his/her wishes. In addition, healthcare providers must honor a valid advance directive.

The Patient Self-determination Act,[10] enacted as federal law in 1991, grants all persons or their surrogates the right to refuse or discontinue treatment, and it makes advance directives completed in any state legal and portable. This same law also requires all medical facilities receiving federal funds to ask, at the time of admission, whether a prospective patient has completed a written advance directive, which usually includes the naming of a surrogate decision maker. Nursing facilities must document at regular intervals whether a resident has an advance directive or has designated a surrogate decision maker.[11]

One might think that it would be a fairly simple issue of abiding by the patient's preferences; both the Patient Self-determination Act[10] and the National Kidney Foundation's[12] Dialysis Patients' Bill of Rights and Responsibilities are about respect for patient autonomy. However, as of 2003, only 6% to 35% of chronic dialysis patients have completed written advance directives.[3] And although 67% to 77% of dialysis patients have discussed their wishes about life- sustaining treatment with their families or someone close to them, researchers have found that patients often do not have clear, reliable data with which to make these determinations, and many patients who claimed to want CPR during an acute illness changed their mind after learning the probability of survival to discharge.[3] This full disclosure fulfills the principle of informed consent, which requires that the decision maker understand not only the problem, but also the pros and cons associated with the available options. Respect for patient autonomy does not equal respect for any choice: respect for patient autonomy is respect for the informed decisions that a patient makes.[3]

A do-not-resuscitate (DNR) order may be considered when a patient and/or their caregivers feel that the balance has shifted, and the benefits of dialysis no longer outweigh the harm that may incur from CPR. When a patient and caregiver agree to a limitation of treatment through a DNR order or COLST, everyone needs to be clear under what circumstances life-sustaining treatment (such as CPR) should and should not apply. Healthcare providers need to document in detail what measures should be applied and in what circumstances. For example, a patient's advance directive may include broad language (such as ''if after a trial period'') to leave some discretion to either the healthcare provider or a healthcare proxy. In addition, the phrase *do not resuscitate* can be misinterpreted by healthcare professionals as well as patients and their families as *do not treat*. The 2 statements are not interchangeable. Thus, documentation of the patient's

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goals and desires related to treatment details may be extremely helpful in the event that the patient is unable to participate in decision making, such as during an emergent change in condition.

Obligations

In the first scenario, the dialysis nurses did fulfill their professional obligations (as directed through Mr Jones' COLST) when initiating CPR and activating emergency assistance. In the second scenario, the nurses have a professional obligation to document Ms Petry's values and beliefs about resuscitation and to communicate these requests to the PCP. Thus, even though Ms Petry's wishes and goals are known in the absence of specific written orders (eg, DNR order or COLST), the nurses would be obligated (unless directed otherwise by the outpatient dialysis center's life-sustaining treatment policy) to initiate CPR and activate emergency assistance if Ms Petry were to experience a cardiopulmonary arrest. To be found liable for ''malpractice, the patient must have been harmed by a negligent act.''[13(p134)] Thus, nurses and their managers should remember that fulfilling professional obligations involves knowing and implementing the standard of care as outlined in the agency's policies and procedures as well as state regulations related to advance directives.

Issues of liability can become more difficult, however, when there is no advance directive, and the patient's wishes are unknown. At that point, decisions about medical interventions fall upon the family members, often in the following order: spouse, adult children, siblings, and then other family members. However, it is important to note that state laws vary tremendously in the order of decision making. Some states have created a rigid hierarchy of surrogates; other states have recognized that personal involvement and knowledge, as well as having the patient's best interests at heart, supersede any such hierarchy, so no order is specified. Whereas some states recognize common-law spouses and grant them decision-making power, others do not; similarly, some states recognize the category of *friend*, which may apply to a long-time companion or partner.[11] In rare cases, where the family or loved ones cannot agree on how to proceed, or where there are no family members or friends to step forward and make decisions, the institution may find it necessary to petition the court for a guardian to act on the patient's behalf.

Trust

When a patient arrests while concurrently receiving dialysis, and resuscitation efforts are not initiated, other patients may experience mistrust in their dialysis team based on the assumption and/or fear that ''They didn't try to save Joe, how can I trust that they'll resuscitate me if I arrest?'' ''Trust and mistrust always have to do with relationships, which have important implications for how trust is retained or restored''[14(p170)] or earned in the beginning. Acting ethically is foundational to establishing trust. The importance of trust between patients and their healthcare team is sometimes underemphasized in the current patient autonomy milieu.[14]

Interestingly, nurses have been identified as being the ''most trusted profession''[15(p1)] 11 times since 1999 based on a Gallop Poll.[16] When establishing a trusting relationship, the patient places confidence (places trust) in the nurse's competence, and the nurse reciprocates by being a competent practitioner while also communicating a sense of caring or moral concern about the patient's well-being. Creating a trusting relationship is promoted when the nurse has an understanding of the patient's values, fears, and life experiences.[17]

When encountering questions from patients reflecting questions of trust, dialysis nurses and their nurse managers need to be transparent in their interactions and communication with persons receiving dialysis and their significant others.[14] Transparency would include open access to agency policy and procedures and routine discussion of advance directives and the goals for dialysis. However, transparency cannot replace basic caring, honest professional conversations between dialysis staff and the patients receiving dialysis about their fears and assumptions. Dialysis nurses and their nurse managers must remember that ''Deception and misinformation are the enemies of trust.''[14(p172)] Loss of trust can result from withholding information or failing to communicate truthfully.[18]

Nurse managers should work prospectively with the dialysis nurses to develop a standardized response to be used in the event that a patient witnesses another dialysis patient (with a DNR order) arrest while receiving dialysis. After first responding to the patient's emotional reactions and loss, the nurse manager may want to review the agency's policy related to resuscitation. The nurse manager should highlight how the individual patient's values and beliefs regarding life and death as well as the goals for dialysis treatment direct how the dialysis nurses respond to an emergent event. Patients should be reminded that the ethical principles of patient autonomy and respect for persons guide all healthcare decisions. Finally, the nurse manager should offer to review the patient's plan of care to ensure that the plan does accurately reflect the patient's values and goals.

In addition to responding to the needs of the dialysis patients, the nurse manager must also be cognizant of the dialysis nurses' personal and professional responses after implementing a patient's plan of care that does not include resuscitation. The nurse manager

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should offer the nurses a time to debrief their experiences. The nurses should be allowed time to work through their feelings of loss. The nurse manager must be quick to recognize and respond if a nurse is experiencing guilt related to ''allowing my patient to die.'' Similar to working with the dialysis patients, the nurse manager may need to assist the nurses to remember and affirm the role of patient autonomy when developing the comprehensive plan of care including the level of care desired in the event of a life-threatening event. The nurse manager's candid and caring response to both patients and staff following the death of a patient while receiving dialysis in addition to transparency about policies and procedures will create a culture of trust and empowerment.

Recommendations for Nurse Managers

- Review clinic policies and procedures related to life-sustaining treatment.
- During admission to the agency, discussion should first focus on identifying the patient's goals for treatment and life. A discussion of a specific code status should follow only after the patient's goals and possible goals of medicine/dialysis have been clarified.
- Collaborate with a palliative care program to promote pain and symptom management as well social workers and chaplains to assist with psychosocial and spiritual support for all dialysis patients and families regardless of the patient's code status.[19]
- Develop bereavement programs to assist patients, families, and dialysis staff to cope with unexpected deaths of ESRD patients while receiving dialysis.[19]
- Promoting Excellence in End-of-Life Care, a national program of the Robert Wood Johnson Foundation,[19] has issued a report on ESRD that includes a series of recommendations for healthcare providers. Of particular relevance is the ESRD Workgroup Recommendations to the Field report, which contains a Model Policy and Procedure for DNR Orders in Dialysis Facility. Although the report is geared more toward nephrologists, many of the recommendations would be of use to nurse managers.

Future Research Questions

- What is the lived experience of a person receiving dialysis services who has made the informed choice to refuse cardiopulmonary resuscitation?
- What are the perceptions of persons receiving dialysis services when the dialysis healthcare team does not initiate lifesaving actions when a person in the process of receiving dialysis experiences a cardiopulmonary arrest?
- How many dialysis healthcare teams have adapted or adopted the Model Policy for Do Not Resuscitate Orders in Dialysis Facility?
- What is the dialysis healthcare professional's view of the health status of persons receiving dialysis services (terminally ill vs healthy)?
  Is this perspective consistent with how ESRD patients view themselves (living vs dying)?

Summary

A patient's desire to have a DNR order while concurrently receiving hemodialysis is not ethically inconsistent, but rather reflects a clear understanding and integration of the patient's values and beliefs and the specific goals for dialysis treatment. Nurses have an ethical obligation to assist patients to explore their values and beliefs and to execute an advance directive if desired. Transparent agency policies and open honest communication between the dialysis staff and patients and their significant others should promote a mutual trusting relationship.

REFERENCES

1. Alport Syndrome Foundation. What is Alport syndrome? 2010. http://www.alportsyndrome.org/what-is-alport-syndrome/. Accessed February 22, 2011.
2. Norris K. Why do I feel nauseous and lethargic after dialysis? 2002. http://www.aakp.org/aakp-library/feel-nauseaus-and-lethargic/. Accessed March 25, 2011.
3. Ross LF. Do not resuscitate orders and iatrogenic arrest during dialysis: should ''no'' mean ''no''? *Semin Dial*. 2003; 16(5):395–398.
4. Moss AH, Holley JL, Davison SN, et al. Core curriculum in nephrology: palliative care. *Am J Kidney Dis*. 2004;43(1): 172–173.
5. Ebell MH, Becker LA, Barry HC, Hagen M. Survival after in-hospital cardiopulmonary resuscitation: a meta-analysis. *J Gen Intern Med*. 1998;13(12):805–816.
6. Moss AH, Holley JL, Upton MB. Outcomes of cardiopulmonary resuscitation in dialysis patients. *J Am Soc Nephrol*. 1992;3(6):1238–1243.
7. National Kidney Foundation. When stopping dialysis is your choice: a guide for patients and their families. 1989-2006. http://www.kidney.org/atoz/pdf/StopDialysis.pdf. Accessed March 22, 2011.
8. Robert Wood Johnson Foundation. Promoting excellence in end-of-life care: quality of life. http://www.promotingexcellence.org/tools/quality_life.html. Accessed March 22, 2011.
9. Kidney End of Life Coalition. Personal death awareness exercises. http://www.kidneyeol.org/PersonalDeathAwarenessExercises.pdf. Accessed March 22, 2011.
10. Omnibus Budget Reconciliation Act of 1990. H.R. 5835.ENR.
11. American Medical Directors Association (AMDA). White paper on surrogate decision-making and advance care planning in long-term care. http://www.amda.com/governance/whitepapers/surrogate/decisionmaking_hierarchy.cfm. Accessed March 24, 2011.
12. National Kidney Foundation. Dialysis patients' bill of rights and responsibilities. 2003, 2006. http://www.kidney.org/atoz/pdf/DialysisBillRights.pdf. Accessed February 9, 2011.

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13. O'Keefe ME. *Nursing Practice and the Law: Avoiding Malpractice and Other Legal Risks*. Philadelphia, PA: FA Davis Company. 2001.
14. O'Mathuna DO. Trust and clinical research. *Res Pract*. 2009; 10(5):170–180.
15. American Nurses Association. News release: Gallup poll votes nurses most trusted profession. December 9, 2009. http://www.nursingworld.org/FunctionalMenuCategories/MediaResources/PressReleases/2009-PR/Gallup-Votes-Nurses-Most-Trusted-Profession.aspx. Accessed March 26, 2011.
16. Jones JM. Nurses top honesty and ethics list for 11th year. December 3, 2010. http://www.gallup.com/poll/145043/nurses-top-honesty-ethics-list-11-year.aspx. Accessed March 26, 2011.
17. Whitbeck C. Trust. In Post S, ed. E*ncyclopedia of Bioethics*. 3rd ed. New York: Macmillan Reference USA; 2004: 2523–2529.
18. Richard C., Lajeunesse Y., Lussier MT. Therapeutic privilege: between the ethics of lying and the practice of truth. *J Med Ethics*. 2010;36:353–357.
19. Robert Wood Johnson Foundation. Promoting Excellence in End of Life Care Program. 2002. http://www.promotingexcellence.org/downloads/esrd_full_report.pdf. Accessed March 12, 2011.

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