

Do Not Resuscitate Orders for Adults with Developmental Disabilities: Ethical Considerations in the Dialysis Center

Renata Sledge, LCSW, Cancer Support Community of Greater St. Louis, St. Louis, MO

Each discipline in the nephrology community has a specific code of ethics with clearly defined principles, values, and standards of practice. Reconciling these often similar values and principles with differences in professional language (jargon) and perspectives is a challenge experienced by all members of the interdisciplinary team. The following is a brief discussion of four principles of medical ethics defined by Beauchamp and Childress (1994) and the relationship of these principles to those in the National Association of Social Workers (NASW) Code of Ethics (2008). A model for resolving ethical conflicts is described and a case study using the model is presented.

Each discipline in the nephrology community has a specific code of ethics with clearly defined principles, values, and standards of practice. Reconciling these often similar values and principles with differences in professional language (jargon) and perspectives is a challenge experienced by all members of the interdisciplinary team. Social workers are trained in resolving ethical dilemmas using models such as those created by Loewenberg, Dolgoff, and Harrington (2000), Reamer (2006), and Congress (1996). These models are effective but may not be familiar or accessible for the interdisciplinary team. The “So Far No Objections” or SFNO Model developed by DuBois (2008) offers an opportunity to explore social work values and medical principles in resolving ethical differences.

Case One illustrates how end of life issues were addressed without the use of a model to help the interdisciplinary team members explore appearances of conflicting values and principles.

CASE ONE: INTRODUCTION TO THE PROBLEM

Michael was a 35-year-old male with diabetes, hypertension, and multiple cardiac issues on in-center dialysis for 3 years. Michael was diagnosed with mild mental retardation (I.Q. approximately 60) and was residing in a skilled care facility. Michael participated in recreational activities in the skilled care facility. He had limited family interaction, because his parents died many years before and his siblings were only peripherally involved in his care. Michael had the same state guardian for five years. Michael continued to present to dialysis with uncontrolled blood pressure and slept through most of his treatments. Dialysis staff had limited interaction with Michael due to the sleeping; however, their interaction with Michael was mostly positive as he seemed eager to please and answered almost all questions from staff with attempts to mollify.

The dialysis center staff was invited to participate in a care conference at the skilled care facility to discuss Michael's status and treatment options; the nephrology social worker attended on behalf of the interdisciplinary team. During the meeting, Michael's guardian, a Qualified Mental Retardation Professional (QMRP), the Director of Nursing, and a

primary care doctor indicated they would like to change Michael's resuscitation status in the skilled care facility to a do not resuscitate (DNR) order and requested Michael's status be changed in the dialysis center as well. The phrase, DNR is used here, as opposed to the phrase allow natural death (AND), because this is the language used in state documentation for physician orders. When later presented with the request, Michael's nephrologist as a concurring doctor refused to sign the Office of Guardianship and Advocacy Consent Request, consenting to the change in resuscitation status. In other words, Michael would maintain a full resuscitation status at the dialysis center and the guardian would need to find another doctor to sign for a change in resuscitation status at the skilled care facility. The nephrologist wanted to discuss the DNR decision with Michael to ensure he was comfortable with the decision. She stated Michael was in “too good of health” to have a change in resuscitation status. The nephrologist asked Michael during her next rounds at the dialysis center if he wanted “CPR” (cardiopulmonary resuscitation). The patient replied, “Yes,” and the nephrologist refused to designate Michael a DNR for the dialysis facility or complete the consent request as a concurring doctor.

An uneasy agreement was reached between the two facilities to have separate orders and to revisit Michael's resuscitation status should he be admitted to a hospital. Approximately three months later, Michael “coded” at the skilled care facility, resuscitation was not performed, and he died at the skilled care facility.

The compromise reached between the stakeholders left both treatment teams uncomfortable and made further communication between them difficult. The skilled nursing facility felt the dialysis center staff were not cooperative in coordinating Michael's care; the dialysis team felt the skilled nursing facility staff was simply “waiting for Michael to die”; and the social worker was left to mediate between the two. The management of this case was based on stakeholder value and a desire for a quick resolution, rather than on a framework or model that would have facilitated an evaluation of norms, facts, and consideration of other options.

Direct correspondence to: Renata Sledge, LCSW, Cancer Support Community of Greater St. Louis, 1058 Old Des Peres Road, St. Louis, MO 63110

What follows is a brief discussion of four principles of medical ethics defined by Beauchamp and Childress (1994) and the relationship of these to the principles included in the National Association of Social Workers (NASW) Code of Ethics (2008). A description of a model for resolving ethical conflicts is described and a case example using the model is presented.

Reconciliation of Principles

The first principle articulated by Beauchamp and Childress (1994) is the principle of “beneficence.” “Beneficence” requires the practitioner to consider potential benefits and harms of an action, and positive steps to help others and do good in general. The value of service and the NASW stated ethical principle that “social workers’ primary goal is to help people in need and to address social problems” speaks to the proactive expectation of social workers (NASW, 2008).

“Non-maleficence,” the second principle, is generally understood to refer to the obligation to avoid the causation of harm. Medical intervention often includes some pain on the part of the patient; therefore, the medical professional should provide the least invasive intervention first and the most aggressive intervention to prevent and treat pain. The NASW encourages social workers to provide competent service with integrity. The focus on ethics in social work training and some state licensure mandate for continuing education ethics training further demonstrate the expectation to be aware of and minimize potential harm in social work interventions (Beauchamp & Childress, 1994; NASW, 2008).

The third principle of “respect for autonomy” refers to the right of the individual to make choices, be informed, consent to treatment, and accept responsibility for the choices made. This principle is often cited in the context of discussing surrogate decision making, versus decision making capacity of patients. In order to understand autonomy, the NASW Code of Ethics includes values emphasizing the importance of human relationships, and the impact of those relationships on clients and their decisions. Social workers are also expected to respect the dignity and worth of a person, which includes the client’s right and ability to make decisions (Beauchamp & Childress, 2001; NASW, 2008).

Finally, the principle of “justice” generally describes the responsibility to distribute risks and benefits fairly. The principle of justice is often referred to when discussing access to treatment by privately-insured versus publicly-funded patients, or distribution of solid organs for transplant. The ethical values of social justice, dignity, and worth of the person often challenge social workers to consider the impact of their intervention on those within the patients’ immediate system and in the larger system (Beauchamp & Childress, 1994; NASW, 2008).

Identifying Ethical Disagreements

Ethical disagreements arise when there is uncertainty between stakeholders, facts or norms. These uncertainties and dilemmas are sometimes called “volitional,” “cognitive” and “social” differences. The “volitional” or “stakeholder” dilemma refers to challenges faced when stakeholders have different and competing interests (DuBois, 2008). Dialysis patients with a high spenddown would benefit from state-funded transportation to and from dialysis, but states must manage their limited resources. In this case, there is an ethical disagreement between dialysis patients and the State because their goals are divergent—that is, patients would like to benefit from subsidized transportation, but the State must exercise fiscal responsibility and prioritize allocations based on the greatest needs of all stakeholders.

“Cognitive” disagreements refer to uncertainty about the next step (DuBois, 2008). Often stakeholders with cognitive disagreements do not share the same understanding of relevant facts, probability of benefits, or magnitude of harm. For instance, a patient or family may refuse home dialysis options given reports from friends that home options are less favorable than in-center dialysis.

Social disagreements occur when stakeholders are confronted with different ethical norms and values (DuBois, 2008). Staff may not understand the cultural tendency of a particular group to pursue all treatment options when the staff believes quality of life is so poor, the patient should withdraw from dialysis (Dubois, 2008).

Possible Framework for Resolution

There are multiple frameworks available to interdisciplinary teams to aid in addressing ethical conflicts. The “So Far No Objections” or SFNO model uses a root cause analysis approach to explore the dilemma or conflict, and then reviews options for resolving the issue. The root cause analysis process is often used in clinics for the Quality Assurance Performance Improvement (QAPI) process and can be easily adapted to dialysis clinic culture. The SFNO model asks the following questions:

1. Stakeholders: Who has a stake in the decision being made? That is, who will be significantly affected by the decision made?
2. Facts: What factual issues might generate disagreement? What facts are relevant to a solution?
3. Norms: What ethical principles, norms, and values are at stake? Which do you think are relevant, and which might appear to conflict or generate disagreement?
4. Options: What actions or policies deserve serious consideration? If the ethical ideal is not possible, what compromise solutions are most attractive? (Dubois, 2008)

Once an option has been selected by a team, there are five criteria for evaluating whether a recommended solution to an ethics case is justified. The five criteria and questions to consider include:

1. **Necessity:** Is it necessary to infringe on the values or norms under consideration in order to achieve the intended goal?
2. **Effectiveness:** Will the action be effective in achieving the desired goal?
3. **Proportionality:** Is the desired goal important enough to justify overriding another principle or value?
4. **Least Infringement:** Is the policy or action designed to minimize the infringement of the principle or value that conflicts with it?
5. **Transparency:** Has the decision been made using proper processes? (Dubois, 2008)

The next case example uses the “So Far No Objections” or SFNO approach to case analysis.

CASE TWO: A SNFO-BASED RESOLUTION

Steven was a 38-year-old male diagnosed with end stage renal disease (ESRD), diabetes, and hypertension. Steven was also diagnosed with mild mental retardation and metabolic encephalopathy. An uncle, who lived several states away, had guardianship of Steven since his parents’ death ten years before. Steven was on dialysis for approximately three months and continued to present with uncontrolled blood pressure and diabetes. Steven continued to work full time and participated in group home activities. The group home doctor and staff were concerned about Steven’s high blood pressure and the potential for stroke or heart attack. In the last care planning meeting at the group home, the home’s Qualified Mental Retardation Professional (QMRP), director of nursing (DON), and primary care doctor recommended that Steven’s resuscitation status be changed to DNR. Based on group home reports of an increase in fatigue, decreased activity, change in mood, and family reports of malaise for Steven, the guardian agreed to change the resuscitation status to DNR. The guardian contacted the dialysis center and requested Steven be designated DNR at the dialysis center as well.

Based on the dialysis interdisciplinary team experience with Michael and citing a value of respect of dignity and worth of the person (NASW, 2008), the social worker’s recommendation was to honor the guardians request for a change in resuscitation status, citing the principle of respect for autonomy as the primary justification. The nephrologist at the dialysis center stated her concern that this change was inappropriate at the time as Steven was in “too good of health.” The SFNO model was used by the social worker and reviewed with the interdisciplinary team and guardian to discuss options for Stephen’s resuscitation status.

Stakeholders

The primary stakeholder in this case was Steven as the decision and discussion affected his body and health and any ambiguity regarding resuscitation status would affect his medical care. Conflict between group home staff and dialysis center staff may also fragment Steven’s care. The staff in the group home was invested both personally and professionally in Steven. The uncertainty of resuscitation status for Steven may increase anxiety during treatments for the dialysis center staff working with Steven. They also were working to preserve Steven’s life and may have experienced some ambivalence about not continuing that action through CPR. The statement referring to Steven being in “too good of health” suggested the nephrologist, who had been his nephrologist for ten years, had hope for Steven and perceived a change in resuscitation status as “giving up” on him. Steven’s uncle was given the task of making decisions for another human being and was cognizant of the responsibility associated with that task. A contentious battle regarding resuscitation status may lead to resentment or guilt on the part of the guardian.

The decision made by the nephrologist, group home team, dialysis center team, and guardian would affect how resuscitation status was evaluated in the future for other dialysis patients and group home residents. Advocacy groups could closely monitor this and other cases to ensure appropriate change in resuscitation status for persons with disabilities. The residents of the state and other taxpayers might have concerns about the cost of ongoing care should Steven experience further physical challenges from resuscitation.

Facts

Facts that may have influenced decision making or recommendations in this situation included understanding the process for changing resuscitation status for a ward of the state, dialysis center’s policy for changing resuscitation status, the patient’s likelihood for cardiac arrest, and understanding Steven’s current health and prognosis.

From a dialysis perspective, Steven was stable and thriving; he was alert and interacted positively with staff. Steven regularly achieved good clinical outcomes, tolerated dialysis without cramping or significant changes in blood pressure, and historically tolerated medical procedures well. Steven was new to dialysis and the expectation by the nephrologist was the concern of the group home staff and guardian would resolve itself. The perspective of the group home staff differed, as they believed Steven was more tired and less active. They were concerned that Steven’s quality of life was negatively impacted by the strict diet and fluid restrictions. Steven was still able to work and participate in activities at the group home, but did not have as much enthusiasm as he exhibited before starting dialysis.

Steven’s uncle and the group home staff evaluated a change in resuscitation status by considering the potential quality of life post-resuscitation, including ventilator dependency

and decreased participation in activities meaningful to Steven. Steven's uncle and group home staff discussed the resuscitation status with Steven, who agreed that he did not want CPR. According to his family, Steven's parents stated prior to their death that they did not want Steven to ever be placed on a vent for an "extended period of time"; however, this was not documented in the form of an advance directive. Steven's uncle did not know anyone on dialysis and the group home staff reported having only one other patient on dialysis who died within the first year.

Because Steven lived and was treated in Illinois, the dialysis and group home staff reviewed the state requirements for changing resuscitation status. The State Office of Guardianship and Advocacy required the attending physician and a concurring physician to determine if the patient lacked decisional capacity. The physicians' documentation of the last physical exam must include a description of the medical condition that supports the consent request, available treatments, and recommendations if these treatments should be continued. The physician has the option of consulting an ethics committee; if consulted, a representative of the committee must include a consult note and signature (IGAC, 2006). The Illinois Health Care Surrogate Act (Illinois Guardianship & Advocacy Commission, 1998) also requires that a "qualifying condition" exists prior to changing the resuscitation status. A qualifying condition would include a terminal condition, permanent unconsciousness, or an incurable or irreversible condition. ESRD would be considered an incurable or irreversible condition under the Illinois Health Care Surrogate Act.

The dialysis center policy required the social worker to review advance directives, including resuscitation status, with all patients or their surrogates at least once a year. The dialysis center accepted the Illinois Department of Public Health Uniform Do Not Resuscitate (DNR) Advance Directive (Illinois Department of Public Health, 2006) if it had been signed at another center and also accepted the Office of Guardianship and Advocacy Consent Request as documentation regarding resuscitation status. The dialysis center did not have a policy regarding a nephrologist's refusal to concur with a decision to allow natural death because physicians are not employees of the dialysis center. Only two of the 100 patients at the dialysis center had a DNR status.

While reviewing the facts, it became clear the dialysis interdisciplinary team and group home team had a different understanding of the facts regarding Steven's health; the nephrologist and interdisciplinary team felt Steven was thriving, while the group home felt Steven was dying.

Norms

The nephrologist's resistance to signing the consent form as a concurring physician was likely founded on a principle to do good (keeping Steven alive) while not causing unnecessary harm (preserving bodily integrity). Steven's uncle also had a legal responsibility to protect Steven from prolonged,

unnecessary suffering. However, when considering treatment options, the guardian must remember the patient's right to receive medical care in order to preserve health, minimize and relieve pain, or otherwise promote well-being (McKnight & Bellis, 1992). Therefore, the interdisciplinary team was presented with a need to balance the principles of beneficence and non-maleficence with autonomy. In this case, autonomy referred to the decisions the guardian made for Steven. This means the guardian would be accountable for considering Steven's wishes, despite his impaired abilities.

With the absence of a traditional protective network of friends and family, clear guidelines were needed to protect Steven while considering treatment options. Through the Illinois Health Care Surrogate Act, Steven's uncle was given clear guidelines for considering treatment options. Three approaches to surrogate decision making were available: "substituted judgment," "pure autonomy," and "best interest." Case law generally focuses on formerly competent patients, or competent but disabled patients when recommending the "substituted judgment" approach. Family members had reported to Steven's uncle, the state guardian, that Steven's parents had said they did not wish to have him dependent on a ventilator for breathing. However, this was never formally documented as an advance directive.

"Pure autonomy" typically applies exclusively to previously competent patients with the use of advance directives or statements. As the state had declared Steven incompetent, the pure autonomy approach would not apply even though Steven had stated to his uncle and the group home staff that he did not want CPR. Steven tacitly consents to dialysis treatments three times a week, because he allowed dialysis to be performed without objections or negative behaviors. Cea and Fisher (2003) reported adults with mild mental retardation were able to balance the risks and benefits of treatment, and partially or fully understand medical information provided to them. As Brock (1995) suggests, while Steven may not have procedurally consented to the change in resuscitation status, he may have been able to give informed consent and act with self-determination.

The "best interest" standard requires the surrogate when to consider making treatment decisions for the relief of suffering, preservation or restoration of functionality, quality and duration of life, satisfaction of present desires, opportunities for future satisfaction, and opportunity to regain self-determination (Beauchamp & Childress, 2001; McKnight & Bellis, 1992). Steven's uncle and the group home staff believed, given the risk of intubation, anoxic injury and further pain associated with CPR, that allowing natural death would be acting in Steven's best interest (Kidney End of Life Coalition, n.d.; Robert Wood Johnson Foundation, 2004).

Steven had previously been declared incompetent by the State of Illinois and assigned a guardian, his uncle, by the Office of Guardianship and Advocacy. It was required that the guardian must be consulted before any medical or financial decision was made for Steven. However, neither

the staff at the group home nor the dialysis staff regularly consulted the guardian for minor issues, such as confirming a headache and authorizing the use of an appropriate analgesic.

Beauchamp and Childress (2001) offer a schema to understand the competing standards of competence. The schema evaluates the person's ability to:

1. state a preference;
2. understand information; and
3. appreciate one's situation.

Research by Cea and Fisher (2003) and staff observation of decisions made by Steven demonstrated that, with an IQ of 69, Steven was capable of stating a preference and understanding information provided to him. However, he was limited in appreciating situations and the consequences of his decisions.

The nephrologist has the obligation to respect autonomy, but must also honor the principles of beneficence and non-maleficence, and has the obligation to provide benefits balanced against risks to a patient's health. These principles guided each decision the nephrologist made regarding Steven's dialysis. Dialysis is an intrusive procedure that involves needles, changes in blood pressure, and cramping. However, these risks come with a potentially improved quality of life, and increased quantity of life. Steven was monitored consistently throughout dialysis procedures and any changes in blood pressure, heart rate or respiration were monitored and addressed by the staff at the center. CPR if it was needed during dialysis sessions could have potentially "restored and preserved" Steven's life (McKnight & Bellis, 1992).

The beneficent act in this case may have been to also to question the best interest decision reached by the guardian and the group home treatment staff. It is reasonable to question the rationale for changing Steven's resuscitation status, given the low number of DNR designations at the dialysis center and Steven's diagnosis of mental retardation.

Goal and Options

Before contacting the group home and Steven's uncle, the social worker needed to clarify the goal. The goal was not to advocate for autonomy, which was the social worker's initial inclination; the goal was to facilitate an environment with the dialysis interdisciplinary team and group home staff that allowed Steven to thrive through his desired activities, minimizing physical intrusions, and maintaining his bodily integrity.

The social worker listed five options for meeting the above goal. These included:

1. Transfer Steven to another doctor or to request a new guardian
2. The nephrologist could cooperate in the change in resuscitation status despite her reservations

3. The guardian could withdraw the DNR request
4. The resuscitation status could be modified to allow for a DNR at the group home and a full resuscitation status at the dialysis center (as illustrated previously in Michael's case)

The group home staff and dialysis center staff could arrange another consultation in which Steven, his guardian, the group home staff, and dialysis center staff would discuss resuscitation with the nephrologist present.

Given the basic disagreement of facts about Steven's general health, the social worker proposed a meeting with the nephrologist, group home staff, primary care physician and Steven's uncle/guardian to discuss the matter. General education was provided to the group home staff, Steven and his guardian regarding dialysis, dialysis treatment options and expectations regarding Steven's quality of life. This provided insight into the behavioral changes that had been observed since Steven had started on dialysis. The group home team and guardian provided more information regarding the observed behavioral changes in Steven. Based on this, changes were made to Steven's dialysis prescription, fluid management, and dietary guidelines to address the concerns of the group home staff. In return, the nephrologist, primary care physician, Steven, and his guardian agreed to reconsider a change in resuscitation status on an annual basis or if there was a dramatic change in Steven's health.

Justification

Effectiveness

The proposed action plan was effective in ensuring that all stakeholders involved in the case participated in treatment planning. The proposed action respected the shared autonomy of Steven and his uncle, while maintaining the uncle's accountability as Steven's surrogate. The proposed plan was effective in achieving the goal of creating an environment that allowed Steven to thrive and created an ongoing channel of communication among his treatment professionals.

Proportionality

The proposed plan facilitated an opportunity for Steven's uncle to communicate with the nephrologist regarding a change in Steven's resuscitation status, and created an opportunity to coordinate treatment goals. The plan supported the guardian's rights to autonomy while giving the state the burden of justifying the decision. This burden of proof is proportional to the need to protect the more vulnerable Steven.

Least Infringement

Because the plan did not require the nephrologist to consent to a change in resuscitation status the plan did not infringe on the nephrologist's concerns regarding beneficence and non-maleficence. The burden of justification for the guardian's decisions infringed least on the state and Steven's autonomy, when compared to outright refusal by the nephrologist to consent to the change in status. The goal

was also to maintain Steven's bodily integrity. His surrogate, considering in Steven's "best interest," regarded performing CPR as violating Steven's bodily integrity. Therefore, the DNR plan infringed least on the goal of maintaining bodily integrity.

Steven's uncle arrived at the decision to change Steven's resuscitation status following the group home staff expressing concern about a potential stroke or cardiac arrest due to Steven's uncontrolled hypertension and given his perceived changes in mood and activity level. The nephrologist continued to believe that Steven was in "too good of health" to change his resuscitation status. The proposed plan respected the guardian's autonomy in decision making as well as the team's responsibility to the principles of beneficence and non-maleficence. Participation of the family, Steven's age and comorbid conditions, and community setting were all factors that could change the outcome of this case.

CONCLUSION

The first case, Michael's, was resolved and managed based on stakeholders' values and a sense of urgency of team members. The interdisciplinary team and skilled nursing team were certain of a conflict, but unable to articulate the reason for the conflict beyond a difference in values. The resolution was tenuous and required further peacekeeping by the social worker between the dialysis team and skilled nursing facility team.

Using the SFNO framework, the resolution of Steven's case allowed the stakeholders to explore the facts, values and norms influencing the initial request for change in resuscitation status and collaborate in resolving the conflict. Use of this model illustrated three distinct differences between the cases of with Michael and Steven: first, in Steven's case, the social worker was able to help the stakeholders identify the disagreement of facts; second, Steven's group home and dialysis center interdisciplinary team was able to work with a clear and positive goal; and finally, the cooperation between the two teams created an environment of collaborative treatment and continuity of care between facilities, Steven and his guardian.

Further study of ethics in the nephrology community could explore the question and bias regarding appropriate patients for whom to allow natural death. Ethical reviews at the institutional level regarding the use of advance directives and end-of-life planning for dialysis patients could also be explored. As evidenced by the two case studies, an evaluation of the relationship between patient and provider, as well as communication and ethical conflicts would also be interesting avenues for exploration.

Social workers are a resource for the interdisciplinary team in considering ethical conflicts in the dialysis clinic. It is important for the social worker to be aware of the values and principles of other professionals in the clinic, as well as tools to facilitate efficient exploration of differences. A framework that is familiar to the team, such as a root cause analysis (SFNO) of a conflict, can help them consider

options and develop a plan to resolve issues when an ethics committee is not available.

REFERENCES

- Asch, A. (2005). Recognizing death while affirming life: Can end-of-life reform uphold a disabled person's interest in continued life? *Hastings Center Report, Special Report*, 35(6), 31–36.
- Beauchamp, T. L. (1994). The "Four-Principles" approach. In R. Gillon (Ed.), *The principles of health care ethics* (pp. 3–12). New York: John Wiley and Sons.
- Beauchamp, T. L., & Childress, J. F. (2001). Respect for autonomy. In *Principles of biomedical ethics* (5th ed.) (pp. 57–112). New York: Oxford University Press.
- Bouvia v. Superior Court, 179 Cal. App. 3d 1127, 225 Cal. Rptr. 297 (California Court of Appeals, 1986).
- Brock, D. W. (1995). Surrogate decision-making for incompetent adults: An ethical framework. In D.C. Thomsma & P.A. Marshall (Eds.), *Clinical medical ethics cases and readings*. Lanham, MD: University Press of America.
- Cea, C., & Fisher, C. (2003). Health care decision-making by adults with mental retardation. *Mental Retardation*, 41(2), 78–87.
- Congress, E. P. (1996). *Social work values and ethics*. Chicago: Nelson-Hall.
- DuBois, J. M. (2008). Solving ethical problems: Analyzing ethics cases and justifying decisions. In *Ethics in Mental Health Research* (pp. 46–57). New York: Oxford University Press.
- Illinois Guardianship and Advocacy Commission (IGAC). (1998). *Illinois Health Care Surrogate Act*. Retrieved from <http://gac.state.il.us/hcsa.html>
- Illinois Guardianship and Advocacy Commission (IGAC). (2006). *A guide to adult guardianship in Illinois*. Retrieved July 7, 2008, from <http://gac.state.il.us/pdfs/GTAGII/GuideAdultGuardianship2006.pdf>
- Illinois Department of Public Health. (2006, June 27). *Illinois Department of Public Health uniform do-not-resuscitate (DNR) advance directive*. Retrieved July 7, 2008, from http://www.idph.state.il.us/public/books/guide_individual.htm
- Kidney End-of-Life Coalition. (n.d.). *What happens if my heart stops beating?* Retrieved July 7, 2008, from http://www.kidneyeol.org/CPR_DNR.pdf
- Loewenberg, F. M., Dolgoff, R., & Harrington, D. (2000). *Ethical decisions for social work practice* (6th ed.). Itasca, IL: FE Peacock.
- Lohiya, G., Tan-Figueroa, L., & Crinella, F. (2003). End-of-life care for a man with developmental disabilities. *Journal of the American Board of Family Practice*, 16(1), 58–62.
- McKnight, D., & Bellis, M. (1992). Foregoing life-sustaining treatment for adult, developmentally disabled, public wards: A proposed statute. *American Journal of Law and Medicine*, 18(3), 203–232.

- National Association of Social Workers (NASW). (2008). *Code of ethics of the National Association of Social Workers*. Washington DC: Author. Retrieved June 12, 2012, from <http://www.socialworkers.org/pubs/code/code.asp>
- Reamer, F. (2006). *Social work values and ethics* (3rd ed.). New York: Columbia University Press.
- Robert Wood Johnson Foundation (RWJF). (2004). *CPR: It's not quite like ER*. Retrieved July 7, 2008, from <http://www.rwjf.org/pr/product.jsp?id=21335>