

Pediatric Advance Directives: A Voice for the Voiceless

Heather Nelson

University of Kansas School of Nursing

About the author:

Heather Nelson is from Spring Hill, Kansas. While at the KU School of Nursing Heather received the Visiting Nurse Association Scholarship for 2010. For 2011 she received the Hagen Student Opportunity Award, the Sara Patterson Award, and was a nominee for the KUMC Student Leadership Award. Her clinical excellence was recognized with an honorable mention for the coveted Clinical Medical Surgical Excellence in 2010. In 2011 she received the equally prestigious Level III Clinical Excellence Award for her work during her critical care clinical. After graduation she plans to start her professional nursing career in the Medical Intensive Care Unit at the University of Kansas Hospital.

She is the author of "From scrubs to stairs: The innovation of nursing excellence" published in the April/May 2011 edition of *Imprint, The Journal for the National Student Nurses Association* and was a key note speaker at the NSNA 2011 National Convention on "Climbing your staircase: Crafting your own transformational ideal nurse practitioner".

Her goals for the future include immersing herself in the development of her critical care nursing career by pursuing her CCRN certification, developing her role as Education Co-Chair for the Greater Kansas City Chapter of the American Association of Critical Care Nurses, completing training to become a preceptor and joining the hospitals rapid response team.

Her long term goals are to become an Advanced Registered Nurse Practitioner and then to pursue a doctorate of philosophy in nursing (PhD). In 15-20 years she sees herself as providing direction to the nursing role in health care through an advanced nursing administration position. She wishes to thank her family, especially her sons, Kristoffer and Elijah for inspiring her interest in Pediatric Advance Directives. She also wishes to acknowledge the continued support of Dr Nelda Godfrey for her mentorship in developing her skills as a writer and for assisting with her continued pursuit of her passion for nursing excellence.

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Introduction

You have been hospitalized over four times during the previous year in an Intensive Care Unit (ICU), intubated and placed on a ventilator for pneumonia and respiratory distress. You have grown up living with a chronic condition that has deprived you of oxygen, left you with an inability to properly digest foods and little hope of a reproductive future. Daily life involves swallowing 21 different pills, hours of nebulizer treatments, and chest physiotherapy. You have become close to other children who also suffer from this chronic, debilitating disease to watch them die a slow, agonizing death as they starve for air. You are acutely aware that this is your fate, and you want some control over your otherwise powerless circumstance. You are 15 years old with end-stage Cystic Fibrosis and you are ready to die with dignity.

However, your parents have something else in mind. Today you were admitted, once again, to the ICU in increased respiratory distress becoming disoriented as your carbon dioxide levels soared. Your parents have insisted, against your expressed wishes, that everything medically possible be done for you. In accordance with their wishes, you are sedated, intubated, and placed on a ventilator. This is the story of C.G. (Dickey & Deatruck, 2000). It could be your story, the story of your child, or any one of the more than 3,000 adolescents in the United States that die annually from the effects of a chronic illness (Freyer, 2004).

Chronic, terminal illness is a reality that all nurses working in pediatric settings are faced with at some point their careers. When the child is too young to make decisions regarding health care treatments, the decision easily becomes that of their parents and is supported by the healthcare team—but what about the more mature adolescent? Whose decisions do we legally and ethically support as nurses caring for these patients and their families? The purpose of this

paper is to examine adolescents' ability to make competent decisions, and explore the legal and ethical ramifications surrounding the use of Pediatric Advance Directives.

Review of Literature

As defined by Collins English Dictionary (2010), the word competent involves “having suitable or sufficient *skill, knowledge, experience*, etc., for some purpose” (para. 1). There is growing support among respected pediatric health care professionals that adolescents who suffer from chronic, incurable illness through their *experience* possess the *knowledge* required for competency regarding the consequences of deciding to withdrawal life-sustaining care. Nine years of research by Bluebond-Langner (as cited in Freyer, 2004, p. 382) culminated in the conclusion that “dying children reach an understanding of their own impending deaths as the cumulative result of personal experiences with serious illness and medical treatment.” These children have spent an exorbitant amount of time in the hospital, endured countless medical treatments, and have first hand experience coping with the adverse effects associated with those treatments. They have bonded with other children in the hospital setting with similar conditions and watched those friends succumb to the battle of medical futility. These experiences have provided “multiple opportunities to think about the inescapable suffering that characterizes their lives, the features of life that make it worth continuing, the benefits and burdens that accompany medical treatment and the prospect of death” (Weir & Peters, 1997, p. 33). Evidence strongly supports that adolescents living with terminal illness meet the definition of competency in regards to making health care decisions, including the decision to forego medical treatments that merely extend their pain and suffering and prolong their inevitable death—but where does the law stand?

Federal law has long recognized individuals who meet the definition of legal competency as having the right of autonomy, known as patient self-determination in the health care setting (Guido, 2010). For more than 35 years, the United States has defined legal competency as achieving the age of majority, identified as age eighteen (Freyer, 2004). For individuals younger than 18 years old medical decisions, with few exceptions, are deferred to their legal guardian(s).

At the state level, adolescents may seek health care without prior consent from their parents in limited, very specific circumstances when it is believed requiring prior parental consent would result in these individuals not seeking treatment. Examples include treatment for sexually transmitted diseases, pregnancy and pregnancy prevention, alcohol and drug abuse, and in some states, psychiatric illness (Weir & Peters, 1997). Withdrawing life-sustaining care is not one of these circumstances.

The Mature Minor Doctrine is a common-law rule that allows an adolescent to plead their case for competency regarding health care decision making through a judicial hearing on a case-by-case basis (Freyer, 2004). The challenge of the Mature Minor Doctrine is that chronically ill children are often too weak to make petitioning their case in front of a judge plausible. Without support from their guardian(s), they also—by virtue of their age—have limited access to the necessary transportation to travel to court. In addition, the Mature Minor Doctrine is not recognized by all states. Over one-half of all states have no specific mandate to ensure protection for competent minors desiring to make end-of-life care decisions, leaving little autonomy for the vast majority of dying adolescents (Freyer, 2004).

On a national level, congress enacted the Patient Self-Determination Act in 1990 with the goal of protecting patient autonomy at the end of life through the creation of advance directives (Zinner, 2009). This act has been a guiding force in resolving potential legal and

ethical issues surrounding end-of-life care for adults but is not recognized for persons under the age of eighteen. Legal governance—both at the state and federal level—stops short of granting minors authority to make decisions that would ultimately result in their death, giving rise to ethical deliberations.

Ethical debates about pediatric advance directives are well documented, yet argumentatively divided. Weir and Deters (1997) propose that healthy adolescent development is characterized by growing autonomy, fostered by the individual assuming an increasingly active role in determining their future. Chronic, incurable illness cripples developing adolescents with a loss of control over their future, which diminishes their sense of autonomy. Ross (1997) cautions granting decisional authority to adolescents arguing that permitting them the right to autonomy in the present deprives them of having authority in the future. The author makes the case by asking if one should allow a child with Type I Diabetes to refuse insulin shots because they fear needles, provided they understand that the consequence for not taking insulin would result in their death. Freyer (2004) counters Ross by stating that in the case of terminal illness there is no prospect for long-term autonomy. Future autonomy is reserved for otherwise healthy teenagers who are expected to recover from acute illness, as would be the case in Ross's scenario. Immediate autonomy is the only autonomy relevant to the dying teen.

Zinner (2009) contends that the importance of autonomy is strongest near the end of life. Giving these individuals a voice through pediatric advance directives may promote peace by empowering autonomy as death becomes inevitable. In addition, advance directives may offer peace of mind to parents. Discussing and determining in advance what treatments are to be done promotes assurance that they are fulfilling their child's wishes in the final days of life. By working in collaboration with their child, the feelings of guilt and doubt—traditionally

associated with having to determine whether and when to shift the goal of care from cure to comfort—are lessened. Lyon et al. (2009) found that “family-centered advance care planning by trained facilitators increased congruence in adolescent/surrogate preferences for end-of-life care, decreased decisional conflict, and enhanced communication quality” (p. e199).

Physicians and nurses may also benefit from the advent of pediatric advance directives. In the same way that adult advance directives have increased assurance to healthcare providers, pediatric advance directives would also provide clear guidance that they are acting in accordance with the patient’s wishes and respecting their autonomy (Weir & Peters, 1997). Having documentation of the patient’s expressed wishes provides the healthcare team direction in their plan of care and lends support during palliative care consultations with the family, allowing the healthcare team to return to the true priority of their care—the patient.

Conclusion

Provision 1.4 of the American Nurses Association (ANA) Code of Ethics (2001) states that “patients have the moral and legal right to determine what will be done with their own person; to accept, refuse or terminate treatment without deceit, undue influence, duress, coercion, or penalty” (p. 4). Autonomy is a fundamental nursing virtue, which we assert to uphold. There is tremendous evidence in support of adolescents’ competency regarding health care decision-making, especially those who have lived for months, or even years, with a chronic, incurable illness. In light of this evidence, there appears to be lag, or hesitation, on the part of the legal system to make definitive statutes about granting competent minors the right of self-determination when those decisions may result in the termination of their life.

Provision 3 of the ANA Code of Ethics (2001) states that “the nurse promotes, advocates for, and strives to protect the health, safety, and rights of the patient” (p. 6). As nurses, it is our

duty to advocate for our patients' autonomy. We can collaborate with families to provide care for their dying loved one in a way that is respectful of their wishes and avoid the turmoil lived by adolescents such as C.G. Nurses can be instrumental in becoming a voice for these voiceless minors by advocating at the bedside with families, and at the systems level for change in the current Patient Self-Determination Act to include advance directives for competent adolescents.

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