CASE ONE – ROUND ONE

The Need to Know: Disclosure of Information to Pediatric Patients

Case Presentation

An ethics consultation was called for assistance in the case of a nine-year old girl with a two year history of AIDS. At the time of the consultation, her disease had progressed, and it was the opinion of her physicians that she would probably die within the next six months. During the previous two years, she had multiple hospital admissions for treatment of various infections and for poor growth. In addition, she had developed chronic lung disease and required intravenous fluids for nutritional support. More recently, she had developed AIDS nephropathy that had progressed to end stage renal failure requiring daily peritoneal dialysis. She developed pneumonia, and was hospitalized with hypoxia that was compounded by the other aspects of her disease process. At the time of admission, her grandmother (guardian) requested that the patient not be told about the diagnosis of HIV or AIDS, and that information about the predicted terminal course of her disease be withheld from her. Members of the health care team were uncomfortable with this request and asked for an ethics consultation.

Things to note: The patient’s mother also had AIDS and was expected to die before her daughter. Because of the mother’s illness, the patient’s grandmother became the legal guardian. In the past, the mother noted that she wanted to tell her daughter about AIDS but did not want to “upset” her. At the time of the consultation, the patient’s mother had developed a severe, terminal encephalopathy and was unable to communicate in any meaningful way.

Question

Should a nine-year old patient be told about her terminal medical condition?

http://cbhd.org/content/need-know-disclosure-information-pediatric-patients
CASE TWO– ROUND TWO

To Dialyze or Not to Dialyze

Case:
A comatose 64 year-old man was brought to the Emergency Room by ambulance. Someone who remained unidentified had called “911” only to say that he needed immediate dialysis. There was no family with him, and the patient’s records were retrieved from a nearby hospital. His history included Type 2 Diabetes Mellitus for many years with multiple complications: end stage renal failure (Stage 5 Chronic Kidney Disease), hemodialysis dependence, bilateral above knee amputations (AKA), a previous cardiac arrest with post-resuscitation cerebral anoxia, multiple prior strokes, and heart disease with many admissions for heart failure. He had not dialyzed for nearly one month, and the dialysis unit was also contacted regarding his previous treatments at their facility. Apparently, his course had been complicated by his verbally and physically abusive behavior towards other patients, their families, as well as dialysis center staff. Although he was not disruptive in other environments, when he arrived at the dialysis unit he exhibited multiple dysfunctional and potentially dangerous behaviors. He struck and insulted people in the waiting room, he spit at nurses and dialysis technicians while on the machine, and he pulled out his needles when he was unattended. Occasionally, the bleeding from this activity was substantial and startled other patients. The unit decided to discharge him from their care and to discontinue dialysis.

After Emergency Department evaluation, he was admitted to the hospital with a critically elevated potassium level. He was dialyzed emergently one time, and his family was contacted by the primary care team and nephrologist for a conference. His divorced wife and a 28 year-old daughter comprised the patient’s entire family, and neither had obtained legal decision making authority through durable power of attorney. As the patient was not competent to make his own decisions regarding his dialysis and other essential care, they were queried as to what statements, if any, the patient had made in the past regarding future medical care. They insisted that he be chronically dialyzed despite the preceding history of abusive behavior. They said that “when he wakes up, he says that he wants to dialyze.” He was temporarily dialyzed three times a week, and an Ethics Consultation was obtained to assist in decision-making.

A review of the past medical history noted that about one year ago, when the patient suffered a heart attack, he also had post-resuscitation anoxic brain injury. Prior to the episode, he did have bizarre behaviors that were primarily self-directed. (He deliberately slammed his below-the-knee amputations into the floor to the extent the bleeding necessitated that AKA be done.) Sometime after the brain injury, he began to exhibit the more violent behaviors that were threatening, dangerous, and abusive to others.

Is it mandatory to dialyze a combative patient who is a threat to himself and to others?

http://cbhd.org/content/dialyze-or-not-dialyze
CASE THREE– ROUND THREE

The Rights and Responsibilities of Pregnant Women

Melissa Rowland, a 28 year old woman who had been pregnant with twins, was charged by the State of Utah in 2004 with murder and child endangerment for refusing to permit a timely cesarean section that resulted in the death of one of her twins. The story is complicated by the fact that Melissa had four other children (two of which were previously delivered by cesarean section): two were given up for adoption, and one was taken away by child protective services. She carried a diagnosis of oppositional defiant disorder and had been convicted of felony larceny, as well as endangerment of another child in the past. She apparently had traveled from Florida to Utah in order to give these twins up for adoption, and had sought no prenatal care.

In the three weeks prior to her eventual delivery, Melissa did contact two different hospitals in the Salt Lake City area. On December 25 she contacted one hospital by telephone complaining of no fetal movement and was advised to go to a hospital immediately. She did not. She was then seen on January 2 by a physician at another hospital who recommended an immediate cesarean section due to oligohydramnios (abnormally small amount of amniotic fluid), fetal growth retardation, and repetitive fetal heart rate decelerations, but Melissa left against medical advise stating that the scar would “ruin her life” (in spite of the fact that she had had two previous cesarean sections and was warned of the risk of death or brain injury to her twins if she refused treatment). She presented to another hospital on January 9 to see if her babies were alive; no heart rate could be found on one of the twins by external monitor, but again Melissa left against medical advice. Finally she returned to one of the hospitals on January 13, and was delivered by cesarean section; twin A was a stillborn male infant, and twin B, a girl, was found to have cocaine and alcohol in her blood at birth. The medical examiner determined that the stillborn male had no congenital anomalies and had died about two days prior to delivery.

After being charged with murder and child endangerment, Melissa ultimately pled guilty to two counts of child endangerment. Her sentence of consecutive prison terms and fines were suspended in lieu of 100 hours of community service and 18 months of probation, including completion of outpatient mental health and substance abuse treatment, a rehab program, and a parenting skills class. Melissa, however, left the state and complied with none of her probation stipulations. Ultimately, her surviving child was removed from her home as well. The Utah district attorney declined to have Melissa returned to the state.

Question

Is it ethically permissible for a woman to forgo potentially life-saving treatment for her unborn child?

http://cbhd.org/resources/case-studies
CASE THREE– ROUND FOUR

Is It Permissible to Shut Off this Pacemaker?

Case
Dorthea is a 69-year-old woman who was well and active until about five years ago when she developed diabetes. She was admitted to the hospital 18 months ago with recurrent fainting and was found to have an intermittent transient heart block. She reluctantly consented to insertion of a permanent pacemaker.

Three months ago her kidney function was found to be diminished to about 10% of normal, probably caused by her diabetes. It was expected that she would soon require dialysis. However, her kidney function has since improved so that dialysis will not likely be needed for some time. She has since said she would refuse dialysis even if it were needed, and she has refused treatment of her profound anemia. She did consent to a colonoscopy last month to see if she had cancer (malignant change was found in one small area, presumably cured). She is now asking that her pacemaker be turned off so that she can die.

The ethics consultant met with the patient and two of her daughters. Dorthea says she wants to die now because (a) she misses her husband who died three years ago after 45 years of marriage; they were very close, did everything together, and she says she can't live without him; (b) she can't stand to live in their home (memories), but refuses to move; and (c) she wants to "set her children free." She has resisted attempts by her three daughters who have encouraged treatment, including grief counseling, and have even offered for her to live with them. She has guns in her home and knows how to use them, but she says she is unwilling to take her own life. She is an inactive Methodist. She says her only pleasure is having her children, grandchildren and great-grandchildren visit, but she feels her misery is also making them miserable.

The patient says she was told when the pacemaker was inserted that it could be shut off whenever she didn't want it. It is her impression that she will die quickly without it, however, her cardiologist expects this would not be the case. Though she demonstrates no intrinsic rhythm when the rate of the pacer is turned down to 30 beats/minute on testing, most patients do develop some rhythm after several seconds of not beating at all. Thus she might not die, but could suffer symptoms of congestive heart failure with an unknown outcome. She says she is miserable, is not eating (though her weight is down only 5-10 pounds), and cannot care for herself or her home, but she doesn't want treatment for her anemia or her grief. When asked, she said she did not have the colonoscopy last month in order to protect her life. The only reason she consented to the procedure was that she hoped it would show she had cancer that would end her life.

Her daughters have run out of ideas for helping her, and are now supportive of her request. They believe "she wants quality of life over quantity of life," but they recognize that she is refusing treatment which could enhance her quality. They realize she has not dealt with her grief, but are convinced that she never will.

The patient’s primary care physician requests an ethics consultant to address the question of whether this patient’s pacemaker may be shut off.

http://cbhd.org/resources/case-studies