



THE RIGHT TO DIE AMONGST THE PEDIATRIC POPULATION

by Respiratory Care Student Mong-Chau Jamie Vu

September 4, 1993. There were a few black clouds in the sky and the sun had barely shown her face all day. I was in room 216 of Emory Hospital. From the doorway, I could see two white beds; the bed closest to the door was occupied. The family and the doctor were deep in discussion. I notice a girl about 14-15 years old standing behind the group. She was dressed in a plain white T-shirt and black shorts. Her light brown eyes were focused on the sick man in the bed. Her nose was red from crying and her small pink lips were quivering as she took deep breaths to calm herself.

I tore my eyes away to look at the man. His name was Tony, perhaps 30 years old. His skin was an unhealthy blackish-brownish color like dirt and was so thin that I could see every vein and bone. His hair had fallen out a long time ago and his lips were the same color as his skin. The 15-year old girl's first glimpse of him in two years was of him seated on the toilet, hunched over with support from his brother, too weak to sit alone. She overheard the adults talking about how he was passing chunks of blood. The girl and this man had always shared a close bond.

As the doctor was leaving, Tony opened up his eyes and looked at the girl. She knew that moment would be the last time. She stopped crying because she understood what was about to happen and that he needed her support. The family turned to him and said they were taking him to Houston. There was someone there who could make him better. He shook his head. The little girl stood up. She faced her family and told them to let him be at peace, he had suffered enough. The family protested. They told the girl she was too young to understand. They wanted him to live. She stood her ground. In the end, they folded. Tony took the girl's right hand in his and held on. She turned to look at him. He had a smile on his face. He died that afternoon.

September 30, 1993. I go with the girl to visit the man's grave. I could see her holding a picture of them together. She was around 5 years old in the picture and was perched on his left arm. Her fragile arms were around his neck in a loving embrace. Her left hand

held the statue of a cat with lime eyes and brown ears. She knew she did the right thing standing up to her family. She understood why he wanted to stop treatments. He had already gone through chemo and a bone marrow transplant that was unsuccessful. That girl was me and the man was my uncle. He died from leukemia.

I wanted to share my story to show people that the age of awareness has changed and that even with the best of intentions, adults do not always make life and death decision based on what the patient wants, but what *they* can live with. Adults need to take this into account when making laws and changes

to policies, especially in regards to right to die issues. Adults are given the choice of whether they want to continue treatments or not, whether they want DNR status etc. In situations where the patient and family agree to one decision, there are usually not any complications. Problems arise when the family wants to go against the patient's desires and the patient is too weak or sick to oppose them, like my Uncle Tony. These patients need an advocate.

One population has been ignored for far too long in regards to their "right to die". I am talking about the pediatric population. "Despite extensive law and literature addressing end of life issues within the context of adult patient care, there is little information about the particular concerns and challenges confronting dying pediatric patients". We are not discussing active euthanasia here, but terminally

ill patients. At what age can a person make their own decision about dying? Should age be a determining factor when the patient is a child or adolescent?

Every patient has rights in regards to their health and wellbeing, even children. On November 20, 1989, the UN adopted the Convention on the Rights of the Child. It states that "You have the right to say what you think about any issues that affect you. The adults should listen to the child's opinion before they make decisions, which must always be for the child's best". It addresses the right to life but there is nothing in the document regarding the

Ms. Mong-Chau Jamie Vu is a Respiratory Care Student at Our Lady of the Lake College in Baton Rouge, Louisiana. Her paper on the Right to Die in the Pediatric Population was chosen from 9 papers on various topics submitted to Focus for this issue. Ms. Vu will receive a \$100 gift certificate and a gratis registration to the 2008 Focus Conference. Her school's RC Program will also receive a \$100 donation. Students are encouraged to submit their papers for the Nov/Dec issue by Nov 1st. Papers should be between 1300 and 1400 words and should be submitted as MS Word files to our Craig Baker at BakerCT78@yahoo.com.

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The Courage to Nap... continued from page 38

right to die or refuse life sustaining treatments. It is still the parents who make the final call. What about a patient's autonomy? Autonomy is self government, right to refuse treatment. Respect for an individual's autonomy determines that doctors should inform patients if their illness is terminal. This gets complicated when dealing with children. Does the doctor tell the child or is that determined by the parents? What if the parents don't want to tell the child? Who determines if the child is competent enough to be told?

The basis of determining who has the right to make their own decision about dying is competency. "Competency is a legal term that refers to an individual's ability to make rational, informed decisions concerning oneself or one's property. All adults are presumed to be competent". "Primary decision makers in pediatrics are parents or guardians because minors are presumed to lack the complement of skills necessary for medical decision making. According to St. Louis Children's Hospital, the legal age of competency to make medical decision is 18 years old, an arbitrary limit set by the law. Many states recognize an emancipated minor as capable of making health care decisions if the adolescent is a high school graduate, married, a parent, has joined the military or has attained financial independence. Those younger than 18 years old whose wishes are not the same as the parental figure, the courts would have to get involved. That invariably creates tension among the family. In some cases, even when the parent makes a decision, if the physician does not agree with it, healthcare professionals could get the courts involved on the "child's behalf". This was seen in a case in England involving a 22 month old boy. The baby was determined to have brain damage and received artificial feeding. He was blind, deaf, and subject to fits, cried inconsolably, and had no control over his

limbs. His parents believed that their son was in constant pain, but the doctors argued that he was being treated with sedatives and did not believe he was suffering. The physicians "...insist that his plight is no worse than that of other babies in their care". Just because a doctor says that the patient was not in pain, is it right to keep someone alive by any means? Is this humane treatment of an individual or the wants and guilt of an adult?

It is projected that up to 10% of children in the United States are living with known life limiting conditions for which death is a real possibility. Studies have shown that children as young as 8 years old are capable of an adult understanding of the concept of death. Children and adolescents with life threatening illness generally reach this level of understanding much earlier than healthy kids. Adolescents face another challenge that other age groups usually don't encounter, puberty. Physical changes, emotional changes, and identity independence are all happening at one time. While there are many cases in which a chronically ill adolescent demonstrates a remarkable insight into their condition, there are always exceptions.

In an article by Doig and Burgess, competency is defined as being considered competent to make decisions in regards to "...the ability to express the choice between alternatives; risks, benefits and alternatives are understood; rational and logical reasoning in demonstrated; and the choice is reasonable and made without coercion". According to the article, "...apart from the inexperience, most individuals 14 years of age and older have the same capacities to process information that adults have". The reasoning why a person is still considered a minor under the age of 18 is based on the presumption that the parents possess what a child lacks in maturity, experience, and *continued on page 79*

capacity for judgment required for making life's difficult decisions. In Canada, the law states that "...each individual is legally and mentally capable of giving consent in the absence of contrary. Whether a child can consent or not depends on the child in question, his or her mental ability and the treatment or procedure which the child is asked to understand". Many physicians and healthcare facilities here in the United States try to legitimize some adolescents decisions based on other countries' laws regarding minors and the doctrine of the emancipated minor.

On the other hand, there are arguments to limit the autonomy of adolescents that focus on age specific values and the ability to decide independently. Concerns about changes to their body image have caused many adolescents to reject treatment. In a study done by Weithorn and Campbell, a significant number of adolescents refused treatment for epilepsy due to side effects such as gum swelling, excessive body hair growth, etc. Some may refuse radical surgical debridement for cancer because they did not want a disfigurement of their bodies. Others reject treatments due to their loss of independence, such as with dialysis, and lack of acceptance by peers due to discrimination and ignorance.

The majority of these issues were not a problem a century ago. However, with the new medical advances, dying patients and their families are now given choices that raise questions about what constitutes a "humane death". Childhood deaths do not follow the same course as those in adulthood. Parents and healthcare providers are more reluctant to give up on aggressive treatment options when it involves a child. Though the majority of physicians are unwillingly to give up on life sustaining treatments, they face a dilemma that has plagued them for centuries. "The predominant responsibility of the physician has not been to preserve life at all costs, but to serve the patient's needs while respecting the patient's autonomy and dignity," states the American Medical Association. This is not a support of physician assisted suicide, but in regards to the termination of life supporting treatment. If the population has decided that prisoners on death row must be given "humane" death, then why are we so against a humane death for terminally ill children?

The problem lies in the fact that the laws presume that people over 18 years old are competent and those under 18 are not competent in regards to life or death decisions. The key word here is presumed. These are not facts and each case should be determined by the competency of each individual. The law recognizes an emancipated minor who is a parent or financially independent to be considered an adult. In today's society, people as young as 14 years old have children. Emancipated minor is not defined by an age range. So, are we to assume that a 14 year old mother can decide to refuse life sustaining treatments and a 14 year old girl who is not a parent cannot decide her own fate? Also, just because one has gained financial independence, shouldn't there be some stipulation in regards to how it was attained-thru inheritance or employment?

Researchers are concerned whether "an advance directive could allay parental guilt and grief in decision making about the minor's care and whether an advance directive would impact the interpersonal responsiveness to the pediatric patient during the dying process". If a child is competent to make an advanced directive, parents should support their child. It shouldn't be about the guilt of the living, but the wishes of the dying.

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