

How do life-threatening medical conditions in children impact quality of life?

April 12 2011

How do we assess the current and future quality of life (QoL) for infants and children with life-threatening conditions? In the April issue of *Current Problems in Pediatric and Adolescent Health Care*, "The Quality of Life of Young Children and Infants with Chronic Medical Problems," presents a collection of essays in which physicians, medical ethicists, parents, and caregivers address one of the most contentious topics in pediatric and clinical ethics today, the assessment of QoL). They share their professional and personal experiences and knowledge about this complex topic.

Writing in the foreword, John D. Lantos, MD, Director, Children's Mercy Bioethics Center, states that "any assessment of quality of life necessarily incorporates value judgments about the subjective state of another human being. The stakes go up when such judgments are used to deny people access to medical care, or to justify the withholding or withdrawing life-sustaining treatment. Before making such significant decisions, we need to be clear about what, exactly, we are talking about and why we talk about it the way we do."

The lead essay by neonatologists Antoine Payot, MD, PhD, and Keith J. Barrington, MB, ChB, University of Montreal suggests that quality-of-life assessments require an understanding of the complex relationship between objective measures of function or emotion and subjective reports of one's satisfaction with those feelings or capabilities. Then, one must apply those subjective and objective measures to different interpretations of what it means to be healthy or sick, well-functioning or

disabled. They review the growing body of literature about quality of life that has developed over the past few decades.

Guest Editor Annie Janvier, MD, PhD, neonatologist and clinical ethicist working at Sainte-Justine Hospital in Quebec, describes the task of assembling 12 highly personal and moving accounts of parents who had to deal with critically ill children, many of whom survived only hours or days. She writes, "The following narratives are not meant to be an explanation of the scientific aspects of predicting and assessing quality of life. The Internet is full of statistics; there are hundreds of medical papers dealing with this. Drs. Payot and Barrington wrote an excellent rigorous review on the subject in this issue. Knowing this literature is very important for health care providers who take care of sick and/or disabled children. Reading the review is good exercise for our heads and brain. The following narratives are meant to exercise heart, gut, and emotions."

A series of personal essays illustrate the many ways that doctors, parents, siblings, and patients have dealt with the issues raised by disabilities of one sort or another. The authors of these tales write about wildly different challenges, in markedly different styles, and offer a variety of insights into their own subjective experiences, from the two-and-one-half hour life of Gabriel, born with a severe heart defect, to the reminiscences of a 60-year-old lawyer who was not supposed to have survived her own childhood.

The mother who struggles with guilt that she didn't do the right things during pregnancy and delivered a one-pound son at 23 weeks gestation, who then lived for eight years.

The brother who remembers his sister, born with Down's Syndrome, and writes of the pliable nature of his memories of her. Now a pediatrician, he uses this experience to counsel others with special needs children.

The doctor who learned something important from the young parents of a boy who would live only a short time: "All they wanted was for their child to love them, to have sex, and to be able to put the pepperoni on the pizza." When he died, "They told him that they loved him very much, that they were grateful they had been parents, his parents, even for only five weeks. And that those five weeks with him were the best weeks of their lives."

Those essays and others paint a poignant picture of parents, caregivers, healthcare providers and children dealing with and healing from severe hardships. They also teach that doctors and other healthcare providers may often handle these stressful situations in inadequate ways. In a final essay, Peter A. Ubel, MD, Sanford School of Public Policy, Duke University, discusses how doctors make uncalled-for value judgments about the future quality of life of such children and their parents. Yet, he also suggests that doctors can provide needed guidance to parents who might not be able to make rational decisions in the face of the impending death of a child. Doctors are taught to operate autonomously, using only good medical judgment and logic to come to conclusions. Others will act paternally, protecting their patients from bad news and making decisions for them.

Dr. Ubel suggests a different path. "The moral practice of medicine should value empathy more than autonomy. A clinician who understands where her patients are coming from is more likely to give good advice—or even know when such advice is not wanted—than a clueless clinician who respects autonomy or a tone-deaf one who favors paternalism. What doctors say is less important than what doctors hear and understand and reflect. Listening and watching are at the core of good clinical ethics."

More information: These articles appear in *Current Problems in Pediatric and Adolescent Health Care* (www.cppah.com), Volume 41,

Issue 4 (April 2011), "The Quality of Life of Young Children and Infants with Chronic Medical Problems," published by Elsevier.

Provided by Elsevier

Citation: How do life-threatening medical conditions in children impact quality of life? (2011, April 12) retrieved 2 May 2024 from <https://medicalxpress.com/news/2011-04-life-threatening-medical-conditions-children-impact.html>

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