

Preface

Pediatric Palliative Medicine

“Although the world is full of suffering, it is also full of the overcoming of it.”

–Helen Keller

Introduction to pediatric palliative medicine: an interesting notion. How do we introduce this specialty to our trainees, to our colleagues, to our students, to our patients and their families? It depends on our definition, of course.

Pediatric palliative medicine clinicians usually begin with the World Health Organization (WHO) definition from 1990: “the active total care of patients *whose disease is not responsive to curative treatment*. Control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families [1].”

There are two shortcomings to this definition.

The first is “not responsive to curative treatment.” If we limit palliative care to those children with a terminal prognosis, or those whose parents have come to believe that their child’s prognosis is terminal, then no one will be served. This is *the* most important barrier to getting children referred to palliative medicine teams. When health care team members try to refer a child, they are frequently met with replies such as, “Not yet. We are still trying to cure Sally.” Then, when the child is near death and the referral is made, the family meets strangers to help with the death, when instead they could have been re-introduced to familiar, trusted faces at this most crucial hour. Until we define the palliative medicine clientele as *all* children who have a life-limiting condition, even while they are receiving the most aggressive curative therapy possible, we will remain in the untenable position that we are in: palliative medicine teams are allowed in the door for children only when children are very close to death, far too late for the team to forge relationships.

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The second problem with the WHO definition is the goal of “achievement of the best quality of life,” which is stated in the context of good symptom control. What health care team does not tend to the psychological, social, and spiritual well-being of patients, and what team does not strive for the best quality of life? Palliative care teams often find primary teams feeling that if a referral is suggested, the implication is that they are not doing their job well. The important message here is this: Palliative care teams work alongside of, not instead of, the primary team. Rather than taking over, they complement that team’s efforts. They ease some of the burden of caring for and communicating with the family when complex medical and psychosocial decisions must be made.

To address the need to improve access to quality pediatric palliative care, the Institute of Medicine, the American Academy of Pediatrics, and The International Society of Pediatric Oncology, among others, have put forth position and policy statements and care standards. This process has generated an honorable flurry of studies and publications, out of our duty to educate and implement. This work leads to a new definition of Pediatric Palliative Medicine: “Viewed broadly, palliative care is a multidisciplinary approach that prevents or relieves the symptoms produced by a life-threatening medical condition or its treatment. The goal is to help patients and their families live as normally as possible, and *to provide them with timely and accurate information and support in decision-making*. Such care and assistance is not limited to people thought to be dying, and it can be provided concurrently with curative or life-prolonging treatments [2].”

For children with life-limiting conditions, it is imperative to attend to all of their symptoms, physical and psychological, in an integrated fashion, without resort to artificial boundaries. This volume is in the *Child and Adolescent Psychiatric Clinics* series; as editors, we recognize our duty to a primary psychiatric readership but, we hope, to a much broader one as well. As an editorial team, we comprise a pediatric psychiatrist (JPG), oncologist (JMH), and psychologist (DYP), and our contributors further include anesthesiologists, nurses, educators, social workers, ethicists, and child life specialists. We approach the task by bringing together expertise from the many disciplines our children, adolescents, and families require both in clinical practice and in the education of ourselves, our colleagues, and our community.

The provision of “*timely and accurate information and support in decision-making*” is the most crucial, the least discussed, and the most poorly understood aspect of pediatric palliative medicine. It is also the most rewarding one for caregivers. This is something that most physicians believe they do quite well, yet parents hear caregivers through the fog of fear, panic, bewilderment, or numbness. It is the privilege of the palliative medicine team, if allowed in the door early enough to build meaningful relationships, to come alongside the family and the primary health care team, to look at the exchange of information, and to make sure it is understood, despite inherent ambiguities. We liken it to being “medical interpreters.” If we do it well,

parents look back on having made difficult yet informed decisions (Ventilator? Another surgery? More chemotherapy?) with information that they understood and assimilated. They can say they were good parents, even though their child died! “I wouldn’t change a thing about how my child died.” To hear this means we provided information that parents could understand and that helped families make their decisions, decisions that they will look back upon for years, after the rest of us have moved on.

Yet an even greater privilege: to do as much for the child patient. Helping children to understand what is going on, encouraging them to express their fears and hopes while actively listening to them, and helping them to feel part of difficult decisions is especially rewarding. We must recognize that serious illness accelerates cognitive and psychological development, varying from child to child, and we must be sure that we include even younger children in decision making to the extent appropriate for that child and family (see the article by Yaldoo and Glazer in this issue). If the outcome is that a child dies, it is both empathic to child and family and rewarding for the clinician to allow the child or teen to be involved enough to say goodbye, but first, to have quality time on their own terms, free from pain, delirium, guilt, anxiety, and depression to the greatest extent possible. To be allowed to learn directly from the children themselves throughout this process is the true golden nugget of pediatric palliative medicine.

Can any one person or subspecialty do this? No. The pediatric palliative medicine team consists of nurses and nurse practitioners, pediatric and psychiatric physicians, pediatric psychologists, social workers, child life specialists, pharmacists, chaplains, and sometimes ethicists and attorneys. The challenge is to bring diverse expertise together in a manner at once collaborative and distinguishable. In *The Confluence of Psychiatry, the Law, and Ethics* [3], Lederberg speaks to the need for clarity in addressing clinical situations presenting vexing cross-discipline ambiguities. A case recently facing the Helping Hands Palliative Medicine Service at our institution is illustrative: The intensive care team conferred regarding medical indications for continuing or discontinuing ventilator support to a 9-month-old infant with a progressive neurodegenerative disorder. Simultaneously, biological and adoptive parents, with opposing views about medical management, engaged in a custody dispute in the courts. Until resolution of legal decision-making authority among biological and adoptive parents and the County child protective service agency was finalized, meaningful medical decision making and preparation could not occur.

About 55,000 children aged 0–19 die annually in the United States, and an estimated 384,000 live with “special health care needs” as defined by the Maternal and Child Health Bureau of the United States Department of Health and Human Services [1]. The palliative medicine team works with families over time, as they traverse an increasingly complex health care system. The child will have ups and downs as his condition waxes and wanes, relapses and responds, or slowly and inexorably worsens. The team may

work with a child who is ultimately cured, and rejoice with the family, having made an excellent contribution during the worst of times. Even cured children have families who have been through a catastrophic experience and who may have experienced post-traumatic stress or other psychological symptoms over the years; we hope that those families of cured children who had access to a palliative medicine team along the way have more favorable psychological and biological outcomes—moreover an important topic for empirical research.

The palliative medicine team works hardest, of course, with the child who worsens to the point of dying. Some palliative medicine teams are able to become “the hospice team” and provide the true end-of-life care, and others make hospice referrals. The palliative medicine and hospice teams also have a crucial role in bereavement support.

For those who work in this field, we hope to have put together a collection of articles that teach and help in the work. We appreciate all those involved in pediatric palliative medicine and encourage their efforts. To them we say, “Well done.” To the families of children with life-limiting conditions who might make their way to this volume, we hope to have provided some guidance and comfort. To them we say, “Well done. You honor your child.”

John P. Glazer, MD

Joanne M. Hilden, MD

Dunya Yaldoo Poltorak, PhD

Department of Psychiatry and Psychology

The Children’s Hospital Cleveland Clinic Lerner College of Medicine

Cleveland Clinic, 3500 Euclid Avenue

Cleveland, OH 44195, USA

E-mail addresses: glazerj@ccf.org; hildenj@ccf.org; yaldood@ccf.org

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