Partnerships Between Pediatric Palliative Care and Psychiatry

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Children with life-threatening illnesses and their families may face physical, emotional, psychosocial, and spiritual challenges throughout the children's course of illness. Pediatric palliative care is a model of care that is designed to meet such challenges, and the number of programs available in the United States continues to increase. Given the psychosocial and emotional needs of children and their families it is clear that psychiatrists can, and do, play a role in delivering pediatric palliative care. In this article the partnership between pediatric palliative care and psychiatry is explored. The authors present an overview of pediatric palliative care followed by a summary of some of the roles for psychiatry. Next, 2 innovative pediatric palliative care programs that psychiatrists may or may not be aware of are described. Finally, the authors discuss some challenges that are faced in further developing this partnership and suggestions for future research.

OVERVIEW OF PEDIATRIC PALLIATIVE CARE

Annually in the United States about 53,000 children die from a variety of causes.[1] In addition, it has been estimated that there are about 500,000 children coping with

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life-threatening conditions and about 1 to 1.5 million children coping with complex, chronic conditions each year in the United States.[2,3] As advances in technology and medical interventions prolong the lives of seriously ill children, it becomes clear that many of these children could benefit from pediatric palliative care. Pediatric palliative care is defined by the World Health Organization (WHO) as "the active total care of the child's body, mind, and spirit, and also involves giving support to the family"[4] The WHO goes on to say that care should begin at diagnosis, should alleviate physical, psychological, and social distress, and should improve the child's quality of life.[4]

Pediatric palliative care is provided in several settings such as general and children's hospitals, skilled nursing facilities, long-term care facilities, hospices, and community settings. There is limited comprehensive information about the prevalence of pediatric palliative care in the United States. Local and national directories do exist, but these are often sponsored by national organizations, such as the National Hospice and Palliative Care Organization (NHPCO), Children's Hospice International (CHI), and International Association for Hospice and Palliative Care (IAHPC), and therefore only list members.[5,6] Another possible reason that there is not a national directory of pediatric palliative care services may be due to the lack of a common definition. For example, a pediatric oncology unit in a hospital may have a social worker and a physician with specialty training in providing psychosocial support or pain and symptom management for children, whereas a community day care center for children with life-threatening illnesses may only employ an expressive therapist. It is unclear whether both of these programs would be considered a pediatric palliative care program. Nonetheless, the number of pediatric palliative care providers has likely increased alongside the general increase in palliative care providers. In 1974 the first hospice legislation was introduced in the United States and today there are roughly 4500 hospices in the United States.[5] It is unclear how many hospices serve children, but a 2007 national survey completed by 378 hospices found that 294 are willing to serve pediatric patients.[7] Another study of 1527 deceased, publicly insured children in Florida found that 11% used hospice care in the last 6 months of life.[8] Regarding inpatient palliative care, 2 recent studies found that 20% to 25% of hospitals have a palliative care program[9,10] and 58% of organizations that participate in the Children's Oncology Group have a pediatric palliative care program.[11]

Provision of pediatric palliative care is limited by the availability of providers. Many studies have found that end of life or palliative training, particularly in pediatrics, is not addressed at all, or in a limited way, throughout medical education for physicians. Two-thirds of medical school administrators felt that not enough time in their programs was devoted to palliative care and only one-third reported that they had a formal course in palliative care.[12] Knowledge of palliative care is critical to primary care providers because they are often the referring physicians to palliative care programs. A 2009 study by Thompson and colleagues[13] of 303 pediatricians in Florida found that 49% had ever referred a child to palliative care, 29% did not know what palliative services were available in their area, and when asked about 11 diagnoses there was no consensus on whether children with those diagnoses should be referred. Lack of knowledge also affects pediatric nurses. A 2009 study by Knapp and colleagues[14] of 279 pediatric nurses in Florida found that being employed in an area where a pediatric palliative care program was offered and having worked in a hospice in the past were associated with higher levels of knowledge about palliative care. Although these studies primarily focus on physicians and nurses, it is likely that the lack of palliative care education and training also affects other members of the interdisciplinary team such as social workers, clinical psychologists, psychiatrists, chaplains, child life specialists, expressive therapists, and volunteers. There is a need for