

The Role of Psychology in Pediatric Palliative Care

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Abstract

Pediatric medicine increasingly has recognized the value of integrating behavioral health in medical care, but this trend has not yet extended to pediatric palliative care. Results from a recent survey of pediatric palliative care programs across the United States indicate that team composition almost never included a psychologist. This article presents a model of collaborative care to optimize the integration of psychosocial and medical aspects of treatment in pediatric palliative care, delineating how a psychologist adds to this model. This article argues that psychology brings specialized skills in assessment, intervention, and research that fit with the premise of palliative care as a holistic approach that relieves symptoms. Systematic inclusion of psychologists on pediatric palliative care teams may help to improve effectiveness of services as well as extend the knowledge base of mental health in pediatric palliative care.

AS A HOLISTIC MEDICAL SUBSPECIALTY, palliative care aims to improve quality of life, maintain dignity, and reduce suffering for patients diagnosed with a serious illness, within a culturally sensitive framework.¹ Palliative care has emerged over the last decade as a mandate in pediatrics, with strong statements issued by the American Academy of Pediatrics, Institute of Medicine, and World Health Organization about its integration in pediatric medicine.² Palliative care ideally consists of care by multiple disciplines including medical, social, psychological, and spiritual care, with services often continuing into the bereavement period. Thus, inherent to the foundation of palliative care is the consideration of a patient's and family's emotional and behavioral health. Research suggests that children often experience distress, worry, sadness, fear of being alone, loss of perspective, and loss of independence during end-of-life care, as well as clinically significant anxiety and depression when managing a serious illness.²⁻⁴ In order to receive the appropriate care for these symptoms, comprehensive assessment, effective treatment, and improved understanding of prevalence and outcomes are necessary.² The purpose of this paper is to set forth recommendations for how psychologists specifically can be instrumental team members on a pediatric palliative care service in an effort to further the field of pediatric palliative care.

A 2012 survey of pediatric palliative care programs showed that 94.6% of programs did not include a psychologist, with a mean FTE of 0.03. This same survey indicated that other psychosocial disciplines (e.g., chaplain, child life,

social work) were also often not included on a palliative care team (e.g., 66.1% of programs did not have a social worker).⁵ There are clearly distinct benefits and roles for each of these disciplines,² but the current paper will focus on the role of a psychologist for a pediatric palliative care service as providing a combination of clinical and research skills that would help to further the standard of care in pediatric palliative care. As behavioral health has been realized as a part of overall health that needs attention and treatment within medical settings, psychology has become increasingly present as an integrated part of medical care. This value should be even clearer in the area of treating patients and families managing life-threatening and life-limiting illnesses. This paper first describes a collaborative model of care and then presents three defined areas in which a psychologist can elevate any pediatric palliative service's care of the patient and family: assessment, intervention, and integration of research.

Collaborative Model

In pediatric medicine, many psychosocial disciplines are available to maximize the level of child and family support (e.g., child life, social work, psychiatry, chaplaincy, psychology). Although each discipline has a defined scope of practice, boundaries between disciplines can overlap due to the common purpose of providing support to assist children and families with managing overwhelming stress.

A review of the Child Life Council's policy statement clarifies the importance of child life services as supporting

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developmentally normative play and coping with medical stress across the patient population in the hospital.⁶ This invaluable service focuses on optimizing child development and functioning within a hospital setting; however, it is not designed for assessing and intervening with emotional and behavioral symptoms that have reached pathological impairment. The responsibilities of psychologists and social workers also may both include assessment and intervention; in the hospital setting, however, survey research substantiates that hospital social workers spend most of their time on discharge planning and crisis intervention, with little to no time for evidence-based practice or research, partially due to high caseloads.⁷ Child psychiatrists also offer valuable expertise related to the use of psychotropic medications to relieve emotional distress. Due to the side effects and risks of psychotropic medications in the medically ill pediatric population, however, cognitive behavioral therapy is recommended as a first intervention.³ Chaplain support serves a well-defined aspect of care,² although close collaboration between a therapist and a chaplain can inform both practices to best address the family's needs.

The standard of care on pediatric medical teams often includes social workers and child life specialists available to every patient,^{6,7} whereas psychology is not systematically integrated. A psychologist on a palliative care team could work collaboratively with each psychosocial discipline across medical teams in the hospital system. An ideal palliative care team would include several psychosocial disciplines along with medical team members to holistically support the patient and family. For example, a psychologist's input regarding treatment of behavioral disorders may improve the effectiveness of a child life intervention by managing atypical behavioral responses to a procedure.

Due to the intensive nature of psychosocial needs in palliative care, precedent has been set for differentiating between psychology and social work roles: the psychologist addresses the patient's symptoms in order to relieve suffering and maximize participation in medical decision making, and the social worker supports the parents' coping with overwhelming stress.⁸ This delineation of roles illustrates one model of collaboration; depending on the institution, this role delineation may vary.

In addition to the benefits of collaboration among psychosocial disciplines, a psychologist and medical team members also have the potential of enhancing each other's care. For example, pain management for acute and chronic pain often becomes a complex, multifactorial symptom presentation in palliative care. A multidisciplinary assessment of this pain can inform the combination of medical and psychological interventions for more effective symptom reduction.^{2,10} Similarly, physicians, nurses, and psychologists working together to assess symptoms that may have medical or psychological etiologies (e.g., fatigue related to illness or depression, agitation related to medication side effects or anxiety) could enhance the effectiveness of each other's practice.

Assessment

As a cornerstone of palliative care, symptom management encompasses physical symptoms such as pain and dyspnea, as well as spiritual suffering, emotional symptoms

(e.g., anxiety, depression), and behavioral symptoms (e.g., poor medical adherence, oppositional behaviors). With regard to the emotional and behavioral symptoms, a psychodiagnostic evaluation is imperative in distinguishing normative from pathological symptoms.^{2,3} In conjunction with a comprehensive interview, psychologists may administer standardized screening measures to diagnose psychiatric disorders based on valid and reliable measurement tools. Without the evidence-based evaluative skills of a psychologist, medical teams may err on either side of symptomatology—for example, underresponding to depression or overresponding to sadness.³ Psychologists also offer a foundation in child development to further evaluate this distinction within the context of normative development. For example, toddlers confined to a hospital room for long periods of time may show increased oppositional behaviors, but this is considered normative. An adolescent with a preexisting disruptive behavior diagnosis, however, may demonstrate behaviors that increase his medical risks, therefore complicating his treatment, requiring psychotherapeutic intervention. Distinguishing between normative and pathological within the context of child development then informs the level and type of intervention in order to provide symptom relief.²

Intervention

Psychologists are uniformly trained in evidence-based interventions addressing emotional and behavioral symptoms commonly experienced by palliative care patients. These symptoms include anxiety, depression, acute and chronic pain, and maladaptive behaviors (e.g., oppositional, disruptive). Pediatric patients with preexisting psychiatric diagnoses are at higher risk to experience psychopathology in response to medical treatment¹ and often present challenges to medical teams. Even patients without a significant psychiatric history, however, may develop emotional and behavioral problems as part of managing a life-threatening or life-limiting illness.⁹ Evidence-based interventions target symptoms regardless of etiology, and have been found effective in the context of pediatric patients managing medical stress.⁹ Some of these interventions include cognitive behavioral therapy, behavioral therapy, parent management training, and relaxation training.⁹ Specific techniques include developing awareness of emotions and thoughts and modifying cognitions in order to decrease emotional distress. Relaxation strategies such as guided imagery, meditation, progressive muscle relaxation, and diaphragmatic breathing have also been shown to improve pain and anxiety.¹⁰ These therapy interventions can function in conjunction with pharmacological treatment to improve the effectiveness of all modalities in order to provide the symptom relief that is a hallmark of palliative care.³ Although the evidence base for psychological interventions exists for pediatric patients dealing with medical illness, evidence is needed in the context of palliative care.

Research

Although more descriptive information about pediatric palliative care services has emerged, data about effectiveness of these services is scarce. In addition, little is known about prevalence rates of mental health disorders in the pediatric

palliative care population.² Psychologists trained in the scientist-practitioner model bring research skills necessary for evaluating outcomes and adding to the knowledge base about mental health interventions and outcomes in pediatric palliative care patients. These skills include identifying relevant program and patient characteristics and outcomes to evaluate, selecting reliable and valid measurement tools, navigating the institutional research board procedures for ethical psychosocial research with human subjects, analyzing outcomes with sound statistical approaches, and then translating the project into scientific products for dissemination. Especially in the current health care climate of needing to prioritize resources based on proxies of their value, outcomes research is becoming increasingly critical to preservation of services. Despite the clear humanistic value of providing pediatric palliative care, in order to remain sustainable in health care, an evidence base for how palliative care interventions improve emotional and behavioral outcomes, and who is receiving services in pediatrics, is essential.

Conclusion

The Institute of Medicine released recommendations to help formalize pediatric palliative care as a subspecialty in pediatric medicine. Specifically, the report suggested specialty training, guidelines, protocols, and targeted research.¹ Despite these recommendations, pediatric palliative care continues to have substantial variability in terms of team composition and operations, and research remains limited.^{2,5} As a unique medical subspecialty, however, pediatric palliative care deserves resources and recognition to advance effective care for children and families managing life-threatening and life-limiting illness.

As palliative care increases its presence in pediatric medicine, hiring psychologists would follow suit with the entire movement of pediatrics towards integrating behavioral health. The specific skill set psychologists bring by virtue of their training in assessment, evidence-based intervention, and psychosocial research supports ensuring the sustenance of pediatric palliative care in an uncertain health care climate. This paper argues for more systematically including psychologists on palliative care teams as a way to augment the mission of pediatric palliative care in providing holistic and effective services.

Author Disclosure Statement

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