

Chapter 4

Palliative Care and Hospice

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ABSTRACT

This chapter explores the emerging field of child life specialists' (CLS) role in hospital and community-based palliative and hospice care services. Relying heavily on their knowledge of child development, play, family systems, and grief to support patients and families through the trajectory of one's illness, child life specialists can adapt their skills to provide support in this environment. A CLS cannot change what is happening medically but can promote positive experiences for children involved to mitigate the potential trauma, ideally resulting in more positive psychosocial outcomes. Goals of care for CLSs in these settings can include developmentally appropriate education about a diagnosis, treatment plan, physical changes, prognosis, or end of life; various forms of play and therapeutic interventions for processing and the expression of feelings or emotions; memory-making; legacy building; anticipatory grief support; promoting opportunities to say goodbye; funeral or memorial preparation and advocacy for involvement; and bereavement support.

INTRODUCTION

In 2022, the Childhood Bereavement Estimation Model (CBEM) predicted that 1 in 13 children in the United States would experience the death of a parent or sibling by age 18, equivalent to approximately 5.6 million children (Judi's House/JAG Institute, 2022). This number increased to 1 in 7, or 13.9 million when examining bereaved youth by age 25. Parental and sibling loss is considered an adverse childhood experience (ACE) (Mersky, Janczewski & Topitzes, 2017). Adverse childhood experiences are traumatic events that affect the child's sense of safety and security. ACEs have detrimental effects that last a lifetime (e.g., psychosocial, emotional, physical, cognitive, financial, and educational) (Felitti et

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al., 1998, Mersky, Janczewski & Topitzes, 2017). Measures examining a child's exposure to adverse experiences and risk for negative outcomes now include loss exposure, including parental and sibling death, as opposed to original studies focusing on forms of abuse and neglect (Finkelhor, 2020, Mersky, Janczewski & Topitzes, 2017).

When considering the causes of death in the 2022 CBEM National Report, life-threatening and life-limiting illnesses such as conditions related to birth, congenital disabilities, cancer, heart disease, and liver disease also leave children and youth at risk for other adverse childhood experiences outside of the death itself. Life-threatening and life-limiting illnesses have the potential for families, and children specifically, to endure prolonged toxic stress, or "extreme, frequent, or extended activation of the stress response that causes distress for the child and may lead to negative psychological and physical health outcomes" (Hornor, 2015).

Toxic stress related to chronic illness can be due to decreases in communication, disruption of daily activities, schedules, and routines, changes in social and familial relationships, emotional distress, the financial impact of illness, role conflicts and strain, and even one's overall health and well-being (Golics, Khurshid, Basra, Salek, and Finlay, 2013; Ell, 1996). In addition, chronic exposure to adverse childhood experiences without adequate support has shown to have the potential for long-term adverse psychosocial outcomes, including depression, anxiety, post-traumatic stress, fear, poorer school performance, lower levels of self-esteem, increased health problems, social-relational problems, and even physical changes to the developing brain (Phillips, 2014; Boullier & Blair, 2018; Eklund, Kreicbergs, Alvariza, and Lovgren, 2020; Bugge, Helseth, and Darbyshire, 2008; Hornor, 2015).

Alternatively, research on adverse childhood experiences showed that those with high positive experiences reported fewer mental and physical health challenges in adulthood. These outcomes lead to increases in resiliency through stable relationships with their caregiver and other caring adults, a sense of purpose, better self-regulation, positive coping skills, and increased social connections among friends and their community (Phillips, 2014; Eklund et al., 2020; Christ & Christ, 2006; Bugge, Helseth, and Darbyshire, 2008; Buchwald, Delmar, and Schantz-Laursen, 2011). The research focused on children's coping with serious illness and death found that families equipped with ample resources and support, such as access to staff with experience in talking to children and support programs, experience increased confidence and more positive psychosocial outcomes for all involved (Barnes, Kroll, Burke, Lee, Jones, and Stein, 2000; Fearnley, 2010; Christ & Christ, 2006; Bugge, Helseth, and Darbyshire, 2008).

Child life specialists in palliative care and hospice have the professional responsibility to advocate for the individualized needs of children coping with a loved one's serious illness or imminent death. Promoting open communication, processing feelings and emotions, developing coping skills, encouraging visitation, memory-making, and legacy building throughout a loved one's illness decreases the potential for long-term adverse effects (Christ & Christ, 2006; Buchwald, Delmar, and Schantz-Laursen, 2011; Barnes et al., 2000).

BACKGROUND

Palliative care and hospice are often used in tandem or interchangeably by providers, patients, and family members. However, palliative care and hospice are two different approaches in medicine focusing on quality of life. Palliative care is a specialty within the medical field focused on symptom management for those facing serious illnesses (Center to Advance Palliative Medicine, 2018, 2022; National Hospice

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