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The Evolution of Child Life in Hospice & Palliative Care

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Certified Child Life Specialists (CCLS) serve as pillars of strength, providing invaluable emotional support and guidance to young patients and their families during times of uncertainty and distress. They offer a holistic approach to care, recognizing the innate resilience of children and the importance of addressing their emotional and developmental needs. Their goal is to minimize the stress and anxiety that children and families may experience. Historically, they have worked primarily in hospitals. However, the profession has evolved to meet the growing demand in various healthcare settings.

In 2011, a hospice organization in Illinois hired a CCLS to create the first child life program for pediatric hospice and palliative care in Illinois. The goal was to provide emotional support, education, therapeutic play, sibling support, and legacy building focused on children diagnosed with a terminal illness and their families. Identifying other professionals engaged in this work was challenging. Many were working in one-person programs. In 2013, an online group was established to foster communication, collaboration, and camaraderie among CCLS in hospice & palliative care. The aim was to diminish the sense of isolation experienced by many individuals and foster a community where resources, ideas, and care-related needs could be shared and discussed.

By 2022, that group had grown to over 200 members working with children at the end of life. Through this group, many areas of interest have been identified for research. A needs assessment was conducted of the community, with results that provided great insight into the field's current landscape. It showed that, as the need for child life services becomes more widely identified, CCLS have been finding new ways to deliver services to children and families. Many CCLS have branched out from the hospital setting and are now providing services to community-based organizations in full-time, part-time, consulting, and private practice capacities. This shift represents an exciting new trend in the field, that will ultimately benefit children and families, along with the organizations that choose to partner with CCLS.

The future for CCLS in the field of hospice and palliative care will benefit from ongoing research to ensure that the work continues to be evidenced-based and is rooted in the needs of children and families. CCLS need research and data to support their advocacy around implementing new programs and obtaining additional positions, all with the goal of being able to provide support to as many children as possible. It was found in the needs assessment that many CCLS in hospice and palliative care are concerned with burnout and staffing, so having data to support the

need for additional CCLS is key. There is also a need for research around DEI in the field, as the most recent needs assessment identified a widely homogenous field. Future research in this area will help push the profession of child life forward, making services more accessible to families who need them most.

It is an exciting time of change and progress in the field of child life, especially within hospice and palliative care. There's ample opportunity for growth, which will continue to benefit both organizations and families.



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