

# Certified Child Life Specialist within Hospice and Palliative Care: State of the Profession

A review prepared by the  
Child Life Hospice and Palliative Network (CLHPN)  
with special thanks to

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# Introduction

Approximately 400,000 children in the United States are currently living with a serious illness that could benefit from the provision of palliative care.<sup>1</sup> The National Hospice and Palliative Care Organization defines pediatric palliative care as a model that “focuses on enhancing quality of life for the child and family, preventing and minimizing suffering, optimizing function, and providing opportunities for personal and spiritual growth.”<sup>2</sup>

Certified Child Life Specialists (CCLS) are integral members of hospital, clinic, and community-based palliative and hospice care teams. The Association of Child Life Professionals defines a CCLS as a provider that plays “a critical role in supporting child health and wellness, leveraging expertise in helping children and their families cope with stressful experiences in a variety of settings.”<sup>3</sup> CCLS improve patient and family care, satisfaction, and overall experience.

CCLS work in multiple settings, including hospitals, clinics, and home, providing care to children with serious illness. There is tremendous variability to the extent and nature of the CCLS position within various organizations. Many CCLS fill a role as the sole member of their profession on a pediatric or adult palliative care team. This often leads to professional isolation or the sense for the CCLS that he/she/they are practicing on an island. While collaboration with the entirety of an interdisciplinary team is critical, the inability to consult with colleagues of one’s discipline regarding challenges and obstacles can limit professional growth and confidence.



## The Child Life Hospice and Palliative Network (CLHPN)

In 2010, the original founder of CLHPN started the first community-based Child Life Hospice and Palliative Care program in Illinois. In engaging with this exciting work, she began to encounter obstacles, barriers, and challenges that would benefit from discipline-specific, collaborative input. To that end, she started to contact other Child Life Specialists in the same field because she was struggling to find the support she needed as a single-person CCLS program. While engagement with other members of the interdisciplinary team was meaningful, she was looking for community with other CCLS who were working in similar spaces.

In 2013 she formed a Facebook group called Child Life Specialists in Hospice and Palliative Care, providing a space for the then small group of CCLS to connect and communicate. The goal of this group was to bring people together to support each other, share resources, collaborate and problem solve. In 2022, the Child Life Specialists in Hospice and Palliative Care group connected with the director of the Greater Illinois Pediatric Palliative Care Coalition (GIPPCC), a program of The HAP Foundation, which provided the infrastructure to begin monthly meetings. This partnership resulted in the name change to the Child Life Hospice and Palliative Network (CLHPN). Today, CLHPN has over 200 members who participate in the program's planned activities.

The current goal of the monthly meetings is to provide education, offer opportunities to discuss complex cases, collaborate on projects, engage in community-driven research, and elevate the profession of CCLS within the hospice and palliative care community. Recently, with input from the professionals within CLHPN, a community-engaged research team conducted a needs assessment to better understand the work experience, education, and support needs of CCLS working in hospice and palliative care. This project was undertaken with support from academic and community partners.



## Methodology

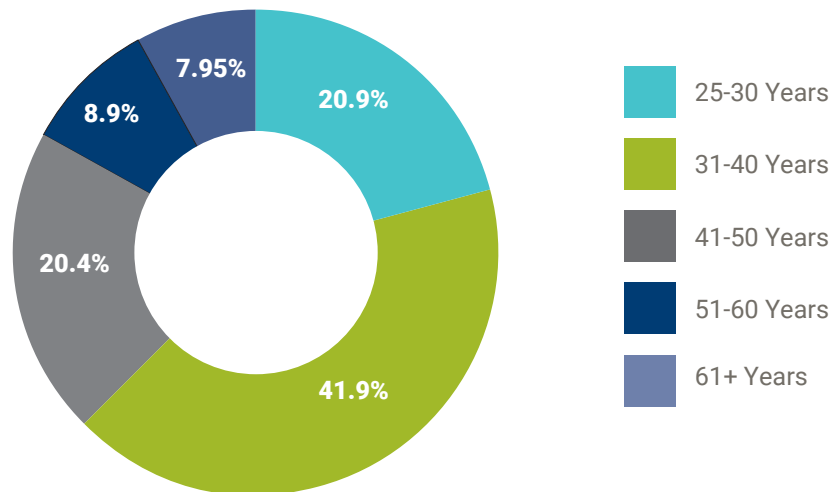
To better understand the current work environment and education needs of CCLS working in hospice and palliative care, CLHPN conducted a needs assessment in collaboration with GIPPCC – a program of The HAP Foundation, and a nurse researcher from University of Tennessee, Knoxville. The needs assessment was conducted through an Institutional Review Board-approved online survey that was distributed through various listservs and email groups that reach CCLS working in hospice and palliative care, including the Association of Child Life Professionals. During the study period of 60 days, 191 CCLS completed the survey.

The survey was developed by a team of clinicians with extensive experience in the field of pediatric palliative and hospice care that included two CCLS, a Licensed Clinical Professional Counselor, a nurse with experience in the field of public health, and a PhD nurse researcher. The tool asked quantitative questions that elicited specific, limited responses but also included space for narrative answers, allowing the respondents to have some control and decision-making about content shared.

# Demographics of Survey Respondents



The CCLS who completed the survey were predominately female (96.3%), within the age range of **31-40 years (41.9%)**. The remaining age spread of CCLS practicing in hospice and palliative care was as follows: **25-30 years (20.9%)**; **41-50 years (20.4%)**; **51-60 (8.9%)**; and **over 61 (7.95%)**.



CCLS responding were predominantly Caucasian (87.4%), with the small remainder reporting diverse racial and ethnic backgrounds. The majority of the CCLS responding reported that they had a master's level of education; there was a wide variety in the noted fields of study both for undergraduate and graduate work.

## SAMPLING OF BACHELOR DEGREE TITLES

Child and Family Development  
 Bachelor of Arts  
 Bachelor of Science  
 Child Development  
 Child Life  
 Communications  
 Counseling Psychology  
 Education  
 Elementary Education  
 Family and Child Development  
 Family and Consumer Sciences  
 Human Development  
 Human Development & Family Sciences  
 Psychology

## SAMPLING OF MASTER DEGREE TITLES

Child Life  
 Child Life & Pediatric  
 Psychosocial Care  
 Child Life and Family Centered Care  
 Child and Family Studies  
 Child Development  
 Child Development and  
 Child Life Specialization  
 Applied Developmental Psychology  
 Elementary Education  
 Healthcare Administration  
 Master of Science  
 Social Work

# Survey Findings



## ➤ WORK SETTING

CCLS working in hospice and palliative care are primarily found in the hospital or clinic setting, with 34.1% reporting work within a community-based hospice program and 4.4% spending time in private practice. Of those in the hospital, about 54% were members of a palliative care team.

Within community-based palliative and hospice programs, 18.7% were part of a dedicated pediatric program. The community programs employing the CCLS were located primarily in urban and suburban areas.

Most CCLS in hospice or palliative care reported that their positions were funded through philanthropy or a dedicated line item on the organizational budget. Grant funding was another common mechanism for supporting the CCLS position. It is worth noting that 9.9% of the CCLS surveyed worked at more than one job; the reasons for this choice were not evaluated as part of this work.

A smaller cohort of CCLS reported working with the perinatal population (only 35.2%). The predominant ages of patient populations for CCLS in the hospice and palliative care included toddlers (77.5%), school age children (78.6%) and adolescents (79.1%). There are CCLS that report working with adults with developmental disabilities (34.1%); a larger number of respondents, however, work regularly with adult caregivers (63.2%) to provide support, interventions, and appropriate language for communication at a child's specific development phases.

## ➤ EDUCATION NEEDS

To date, CLHPN has experienced that participating CCLS who work in palliative care or hospice are seeking continuing education opportunities. The respondents to the survey indicated an interest in certain content areas, including grief-informed care crafted specifically for CCLS; global hospice and palliative care education for the discipline; and standardized tools to ensure benchmarking and quality of services. However, as much as there is a need and interest in discipline-specific continuing education, there is an equal if not louder cry for community within the profession of CCLS practicing in hospice and palliative care, and networking to bolster and sustain CCLS who are often working as the sole CCLS in their organization. The initial understanding that there are other professionals in the same discipline, working with children and families around hospice, palliative care, grief, and loss has provided great encouragement to many in the field. In fact, in the narrative response, one CCLS recognized that there was a dearth of support working as a CCLS in this area, in part because, "there aren't many of us!"

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# Survey Findings



## THEMES

Several themes emerged in the narrative responses provided by the participating CCLS. While staffing, funding and self-care were mentioned with regularity, many of the comments focused on the lack of understanding of the clinical team regarding the capacity and best practice for involvement of CCLS. Also, there was an expression of interest in and commitment to increasing the field's professionalism. Finally, many CCLS felt that family and staff education were necessary to ensure integration of the CCLS into the hospice and palliative care team.

### **Lack of understanding regarding the capacity of the CCLS**

CCLS said there was a general lack of understanding about their role, capacity, and contribution to the palliative care interdisciplinary team. In fact, many CCLS reported that their role was often confused with other team members, like a social worker or chaplain. Or worse, clinicians assumed that the CCLS was interchangeable with other team members. One respondent commented, "CCLS (is) not recognized well...especially in the community. (It is) often assumed I am a social worker."

In community-based hospice, CCLS often experienced barriers resulting from the hospice leadership's focus and understanding of needs, payment models, and traditional services in adult care models, making prioritization of CCLS services challenging. A respondent who experienced this phenomenon shared, "I feel pediatric-only focused hospices are rare so when it's a combined adult/ped hospice those often tend to have leaders that lean towards knowing more about the 'adult hospice world' and it can be hard to have to educate on your role and the importance of your role."

Some CCLS reported a barrier to involvement in care that went beyond a lack of understanding to actual resistance to involvement. In some cases, clinicians were resistant to learning about the role of a CCLS; in other cases, hospital departments were territorial about patients, making it hard for the palliative care CCLS to integrate into the patient's care. One respondent noted, "In palliative care it can be harder to integrate yourself into that team and into a child life team as there are CCLS assigned to areas and (to) patients (that) may have overlap. It can get kind of territorial feeling in those situations."

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# Survey Findings



## THEMES

### **Commitment to Increase Professionality of the Field**

CCLS reported a need for greater professionalism of child life work in hospice. Since many CCLS have branched away from the hospital and into community-based settings, it was identified that there is a lack of standardization in these spaces, paired with a need for more specific training and education for clinicians.

One issue surrounding the perceived lack of professionalism, is a lack of standardization, with one CCLS noting “a wide variety of settings, skill sets, and a lack of standards for (child life) services.” Per another CCLS, “I feel we need more standardization which includes more educational opportunities, specialized practice experience, funding, and the ability to bill for services.” The core child life education and training require little focus on end-of-life and bereavement. The CCLS surveyed expressed an interest in and notable commitment to needing more opportunities for learning. While many CCLS reported receiving excellent “on the job” training, it was identified that additional formal didactic education would be one way to increase this standardization, and in turn, increase professionalism within the space. According to one respondent, “I received almost no training in working with children and families who are facing loss, grief, and end of-life issues. Most of the training that I have I sought out on my own because I knew this is the area that I wanted to work in.”

To further the conversation around additional education and training, multiple CCLS expressed interest in a specific certification for those working in hospice. One respondent expressed, “I would LOVE to see a formal certification for CCLS for palliative care and bereavement! Most of my training is from years of experience.” While many noted that they have received additional certifications and education, there appears to be further need for a certification tailored to this specific space. As explained by one CCLS, “Most of my training and education has come from experience and self-sought out materials. I would love to see a specialized certificate or training for hospice and palliative care for CCLS.”



# Survey Findings



## THEMES

### Importance of Family Education

In addition to a need for education for the medical teams that they work with, the respondents of this needs assessment also identified a need for better education for families about the role of the CCLS. As noted by one CCLS, one of the barriers to providing services is “ensuring that families know the child life supports are available and what they are.”

Some respondents identified that families are unaware of the role’s existence, which prevents them from receiving appropriate interventions at the right time. For example, one CCLS stated, “I would like to make families aware of resources earlier in their treatment journey.” If families were given appropriate education on the child life resources available to them, they would be able to access these interventions earlier, leading to more effective coping. As described by another CCLS, there is a “lack of understanding of the child life role and how it can be beneficial when talking to children about death or providing resources.”

Another issue identified is families declining services, which may be aided through education and better awareness of the role. One CCLS notes “families declining support for education for siblings about death/end of life” as a barrier to their work. While many of these examples go together with educating the medical teams about the role, there is a clear need for families to be more aware of the services available to them.

### Future Research

This needs assessment has uncovered several topics for future research including exploration into the homogeneous demographics reported and salary/compensation for CCLS in hospice and palliative care. Because insufficient staffing was reported as a key barrier for the respondents of this survey, it would be interesting to learn of any correlation between insufficient staffing and pay. The group is also interested in learning more about the reason behind the profession’s homogeneous demographics. With 96.3% of respondents identifying as female, and 87.4% as Caucasian, there is interest in learning why this is the case and how to promote diversity and inclusion within the profession.

### Closing

CLHPN looks forward to continued collaboration within the community on further research and education in this field. We thank all who have participated and supported this important work. We look forward to building upon this foundation to expand knowledge about the child life profession in hospice and palliative care.

<sup>1</sup>Center to Advance Palliative Care. Palliative Care: Facts and Stats. [capc.org/documents/download/665/](https://capc.org/documents/download/665/)

<sup>2</sup>National Hospice and Palliative Care Organization (NHPCO). Pediatric Palliative and Hospice Care. <https://www.nhpco.org/pediatrics>

<sup>3</sup>Association of Child Life Professionals, What is a Certified Child Life Specialist? <https://www.childlife.org/practice/why-child-life>