



Pediatric *Perspectives*

Mary Frances D. Pate, RN, DSN
Department Editor

Helping Children Say Goodbye to Loved Ones in Adult and Pediatric Intensive Care Units: Certified Child Life Specialist—Critical Care Nurse Partnership

Jan Crider, MA, ATR, CCLS
Mary Frances D. Pate, RN, DSN

Intensive care units (ICUs) can be stressful places for adults to visit and may be especially distressing for children wanting to be near a loved one. The inter-professional collaboration between certified child life specialists (CCLSs) and critical care nurses (CCNs) has the potential to make a positive impact on children experiencing situations such as saying goodbye to a family member. Both disciplines are knowledgeable regarding principles of family-centered and developmentally appropriate care. Children with loved ones in pediatric and adult ICUs can benefit from CCLS and CCN partnerships.

Overview of the CCLS Role

Child life programs continue to grow in the United States, with most hospitals with pediatric specialization employing CCLSs.¹ These types of programs are also recommended for community hospitals caring for pediatric patients.² In California, CCLSs are reimbursed for bereavement care, and in New Jersey, CCLS is a required discipline for hospital licensing in pediatric ICUs.^{3,4}

These specialists are educated to provide evidence-based developmentally appropriate therapeutic play, information, reassurance, and psychological preparation. Such interventions allow children to plan and rehearse coping.⁵ Certified child life specialists are educated at the bachelor's and master's levels in areas such as child life, child development, or related fields (music therapy, art therapy, etc). Students complete an internship of no less than 480 hours under the supervision of a CCLS.³ To become certified, graduates must successfully complete a standardized national examination. It is common for CCLSs to develop a focused area of expertise, such as critical care.¹

Misconceptions Concerning CCLSs

It is unfortunate that the contributions of CCLSs have been devalued by some, because of perceptions that these professionals do no more than entertain children.⁶ This is especially concerning because the pediatric literature clearly supports preparing children for stressful situations to improve coping ability and mastery of difficult situations. These misconceptions may be caused by a lack of understanding regarding

Jan Crider is Certified Child Life Specialist, Doernbecher Children's Hospital, Oregon Health & Science University, 3181 SW Sam Jackson Park Rd, Portland, OR 97239 (criderj@ohsu.edu).

Mary Frances D. Pate is Associate Professor, University of Alabama School of Nursing, University of Alabama, Birmingham.

DOI: 10.1097/NCI.0b013e31820810b6

developmentally appropriate therapeutic play and/or confusion about the CCLS's role.⁶

Another misconception is that CCLSs are important members of the interprofessional team only in pediatric settings. However, children with loved ones in adult ICUs may also benefit from collaboration between CCNs and CCLSs as they cope with an illness or imminent death. Similar interventions are used with children, regardless of patient location in an adult or pediatric ICU, and can be used by both disciplines (Tables 1 and 2).

Misconceptions About Children Visiting ICUs

Family members and health care providers may think that children visiting loved ones in the ICU could be detrimental, and that these children do not have the capacity to understand the situation. The literature does not support the fact that adverse effects occur in children after visitation to an ICU. Conversely, negative behavioral and emotional responses have been shown to decrease after visitation.⁷

Even young children know when there is something wrong and may be reassured by visiting a loved one.⁸ Reassurance is important because of a child's magical thinking, the loved one's absence, and potentially altered relationships with other family members. During the illness of a parent, the well parent may experience coping behaviors that span from denial of the child's needs to guilt over not knowing how to support the child. Without needed support, children may worry, and positive adjustment to the difficult situation may be impeded.⁸ Certified child life specialists and CCNs are poised to partner to remove misconceptions through ongoing collaborative assessment, planning, and support that is appropriate to the child, family, and patient.

When Visiting Is Not an Option

Visiting is not an option when the collaborative assessment of the involved children, family, and patient indicates that a visit to the ICU is not appropriate for a child. Children should be given a choice of whether they would like to visit and should never be coerced to do so.⁸ In such cases, family members should still be encouraged to bring children to the hospital for developmentally appropriate information, and children should be given the time to write notes or draw pictures for the loved one. These mementos can be taken into the ICU and

placed near patients, or placed on their chests or in their hands. Interventions such as these allow children to be included, comforted, and given information, and also to have feelings validated and concerns addressed rather than being removed from the situation, only to fantasize about what is occurring with their loved one. An example follows of how CCLS and CCN collaboration in an adult ICU supported a child during the imminent death of her father.

Case Study

Emily was an 8-year-old girl coming to the hospital to say goodbye to her father who had been admitted to an adult trauma ICU. He had experienced a life-threatening injury the day before and was to be removed from life support after the declaration of brain death. The child's mother was unable to contact Emily because of a restraining order and incarceration, which decreased the support available to Emily during this stressful time. The CCN initiated a consultation with the CCLS to conduct a collaborative assessment so that a seamless, interprofessional plan, appropriate for Emily, the patient, and the family, could be developed.

While meeting with family members, the CCN and CCLS became aware that the extended family had not been an integral part of Emily's life and they would not be a support for her. The decision was made to continue to prepare Emily to visit her father to say goodbye, as the CCLS and CCN continued to assess potential support systems for her.

Before Emily's visit, the CCLS and social workers collaborated with the CCN to learn more about the patient's injuries and understand more about what Emily would see and experience in the ICU. When Emily arrived on the unit, the CCLS and CCN greeted her to provide a verbal explanation of her father's accident and injuries and any sensory information Emily might experience upon entry to the room. The CCLS then asked Emily whether she would like to pick out a quilt to bring to her father's room. The child picked out a quilt for her father's bed and small stuffed toys for herself so the room would look softer and not so institutional.

During this initial meeting, the CCLS and CCN continued to assess and gather more information about Emily, her father, and their relationship. In many cases, family members join this process to provide information and support to the child, but in this case, it would not have been appropriate. To provide more

Table 1: Interprofessional Plan to Support Children During ICU Visit**Step 1**

- Listen to the adult family members' questions, fears, and concerns.
- Answer questions, validate concerns, and correct misinformation.
- Care more about what "they" feel than what "you" think.
- Assess level of involvement appropriate for family and children.

Step 2

- Meet children and family in a private, contained room.
- Gather information of each child's understanding and perspective of the ICU and loved one's illness/situation—provide individual support depending on age, developmental level, and personality.
- Provide simple, honest verbal information regarding patient condition and prognosis.
- Provide verbal description of what will be seen, heard, smelled, and felt in the ICU.
- Provide information about what the child will "do" once in the ICU and at the bedside⁷ (hold patient's hand, sit on bed, stand on step-stool, etc).

Step 3 (reference 8)

- Prepare alert patients for visit by letting them know children are coming—"OK" this with them.
- Ensure that linens are clean and soiled tape/dressings are changed.
- Elevate the head of bed if appropriate.
- Place bed in a low position.
- Make room look less institutional with pictures, drawings, quilts, etc.
- Discuss potential reactions of children (crying, clinging, etc) and with alert patients and adult family members.

Step 4

- Ask adult family members whether they would like a Polaroid or digital picture of the patient to show the children.
- Take photographs far away from the patient at first, and then move closer.
- Show photographs to children if they want to see them.
- Assess children to ascertain whether they are "OK" or exhibiting stress/anxiety.
- Ask children whether they would like to visit the patient.

Step 5

- Accompany adults and children into patient room.
- Stop at entrance, let children lead into room.
- Accompany children into room and stay near.
- Assist in "interpreting" for patients who are intubated, using gestures, or attempting to write.⁸
- Reassure children that the patient is in a "good hospital" with many experts caring for the loved one.

Step 6

- Encourage adult family members to discuss visit to the ICU with the child soon after the visit to debrief and to assist with any postvisit stress.⁷
- Share symptoms of poor child coping with adult family members (headaches, gastrointestinal complaints, vague pains, poor academic performance, regressive behaviors, change in mood, nightmares, fearfulness, and changes in sleeping or eating habits).

Abbreviation: ICU, intensive care unit.

Table 2: Interprofessional Plan to Help Children Say Goodbye

Encourage children to draw pictures, write notes, cut out Valentine hearts, make handprints, make molds of the patient's hands, gather hair locks in a memory box, or create other mementos.

Encourage children to tell you about their loved one.

Reassure children that they will be cared for if the loved one is a caregiver, and tell them who will care for them.

Help family come up with a plan for when they leave the hospital (eg, who the children will go home with or live with).

Ask the child and family, "What helps you feel better when you are sad?" and then encourage the family to participate in "helping each other feel better."

information for Emily, the art therapy-educated CCLS asked Emily whether it would be OK for her to do a simple sketch of her father with his medical equipment around him so that she would see a drawing of what would be encountered in the ICU room. The child agreed. The simple line drawing was completed and shown and explained to Emily. When the girl was asked whether she wanted to see a photograph of her father in the ICU, she declined and chose to go see him.

With the CCN near, Emily entered the room with the CCLS. The girl stood at her father's bedside and began to cry softly. The specialist quietly asked Emily whether anyone in the room could comfort her, as extended family was sitting and standing around the room's periphery. The child replied, "No." The CCLS then asked whether anyone in her family or at home could offer her comfort. She again replied, "No." The child was asked whether anyone from church or school could comfort her, and she said, "My teacher." The CCLS asked Emily whether she wanted to call her teacher, and she said, "Yes, please."

Emily and the CCLS left the room to call her third-grade teacher, who was called out of the classroom to speak with the child. The girl told her teacher that her "daddy was dying." Emily's teacher told her that her daddy died when she was in the third grade, too. After talking with the teacher, Emily and the CCLS went back to her father's room and made handprints of her father for Emily to keep and prints of Emily's hands to leave on her "daddy's heart." The CCLS then helped the child make hand molds of her father's hands, and "I will love you forever notes," that were placed in her father's hand. Emily made a friendship bracelet for her father's wrist and an identical one for herself.

The CCLS and Emily stayed at her father's bedside for a few hours as the CCN continued to

assess the patient, Emily, and the needs of other family members. Emily kissed her father's forehead before she said goodbye for the last time. The specialist followed up later with Emily's schoolteacher to check on how the child was coping. The teacher shared that the child had joined a grief support group for children her age who had experienced the death of a parent.

Conclusion

Children who have critically ill loved ones who are imminently dying can say goodbye with preparation that is age specific and developmentally appropriate. Certified child life specialists and CCNs in pediatric and adult ICUs are poised to make optimal contributions to patients and families during crisis situations such as these, because both disciplines use their expertise to provide seamless support to children and families during loss.

REFERENCES

1. American Academy of Pediatrics, Child Life Council Committee on Hospital Care. Child life services. *Pediatrics*. 2006;118:1757-1763.
2. American Academy of Pediatrics, Committee on Hospital Care. Facilities and equipment for the care of pediatric patients in a community hospital. *Pediatrics*. 2003;111:1120-1122.
3. Child Life Specialist Pilot Program, California Assembly Bill 606 (Jackson), Chapter 584, Statutes of 1999, added Government Code §13968.5 (1999).
4. New Jersey Department of Health and Senior Services, Division of Healthcare Systems Analysis, Certificate of Need and Acute Care Licensure Programs. Hospital Licensing Standards (N.J.A.C Title 8, Chapter 43G, Pediatrics Authority N.J.S.A.26:2H-1 et seq p 158).
5. Turner JC, Fralic J. Making explicit the implicit: child life specialists talk about their assessment process. *Child Youth Care Forum*. 2009;38:39-54.
6. Cole W, Diener M, Wright C, Gaynard L. Health care professionals' perceptions of child life specialists. *Child Health Care*. 2001;30:1-15.
7. Cullen L, Titler M, Drahozal R. Family and pet visitation in the critical care unit. *Crit Care Nurse*. 2003;23(5): 62-67.
8. Winch A. A nurse's role in helping well children cope with a parent's serious illness and/or hospitalization. *J Spec Pediatr Nurs*. 2001;6:42-46.