How Do We Talk to the Children? Child Life Consultation To Support the Children of Seriously Ill Adult Inpatients

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Abstract

Background: Families with young children often struggle to talk about and cope with a parent’s life-threatening illness and potential death. Adult interdisciplinary palliative medicine teams often feel unprepared to facilitate the open communication with these children that has been shown to reduce anxiety, depression, and other behavioral problems. In pediatric settings, child life specialists routinely provide this support to hospitalized children as well as their siblings and parents. Although these services are the standard of care in pediatrics, no research reports their use in the care of children of adults with serious illness.

Objective: Our aim is to describe a pilot child life consultation service for the children of seriously ill adult inpatients.

Design: We summarize the support needs of these children, their families, and the medical staff caring for them and report our experience with developing a child life consultation service to meet these needs.

Setting/Subjects: Our service assists seriously ill adult inpatients and their families in a university medical center.

Results: Informal feedback from families and staff was uniformly positive. During consultations, family and child coping mechanisms were assessed and supported. Interventions were chosen to enhance the children’s processing and self-expression and to facilitate family communication.

Conclusion: All hospitals should consider providing broad-based in-service training enabling their staff to improve the support they offer to the children of seriously ill parents. Medical centers with access to child life services should consider developing a child life consultation service to further enhance this support. More research is needed to evaluate both the short- and long-term clinical impact of these interventions.

AA was a 54-year-old man with severe liver damage caused by blunt trauma during a farming accident months earlier. His course was complicated by hemorrhage, multiple infections, and surgeries, and ultimately multi-organ system failure requiring extensive life-sustaining interventions. The palliative care service was consulted by the intensive care unit (ICU) team 3 days prior to AA’s death. A family meeting was held with his wife, sister, and sister-in-law, during which they chose not to further escalate medical interventions. It was clear to all involved that AA was dying. It was equally clear that it would be hard to let him go.

Foremost among his family members’ many concerns was how they would talk to his three children, ages 7 to 15 years old, during a planned visit to the hospital. Struggling with her own sense of impending loss, AA’s wife needed emotional support and the words to tell her children that their father was going to die. The children needed help to hear and process those words. A child life specialist was consulted.

Introduction

Background

One of the most common concerns of seriously ill parents is the welfare of their children.1-3 Twenty-five percent of oncology patients have under-age children at home.4 In the United States, between 3.5% and 5% of children under age 18 will experience the death of a parent.5-6 Millions of parents are therefore struggling with the challenge of raising their children even as they struggle with their own or a partner’s serious illness.3,7 Although hospitalized adult patients with serious illness increasingly have access to palliative medicine services, the children of these patients frequently do not. Various ad hoc strategies may be used by palliative medicine interdisciplinary teams to support these children and their parents, but team members rarely have specific training to work with...
children. In pediatric settings, by contrast, child life specialists routinely fill this support role, mediating and facilitating communication with children to help them and their parents cope with serious illness.

In this paper we review the needs of patients as parents, the emotional responses of children to a parent’s serious illness, and the challenges experienced by the staff caring for both. We then review the role of the child life specialist and describe our 3-year experience developing a novel child life consultation service to extend these services to the children of seriously ill adult patients.

Patients’ needs

AA’s wife struggled to explain her husband’s deteriorating condition to her children. She was also at a loss as to how to support each of them given their different ages and temperaments. Prior to the arrival of her children, a child life specialist met with her to discuss these issues.

A parent’s terminal stage of an illness exposes children to significant levels of stress, such as disruption of routine, change in discipline levels, and change in the level of support a parent can offer. Unfortunately, there are limited resources available within most health care settings to support families during this tumultuous time. Additionally, in many in-patient and intensive care settings, visits by children are restricted, prohibited, or discouraged by institutional rules or due to staff concerns, creating further barriers to time together as a family. Seriously ill patients may struggle to maintain their role as parents. Meanwhile, nonill partners often take on responsibilities previously handled by the patient even as they struggle to support their family and cope with their own emotional response.

Patients are often uncertain how to discuss their illness with their children, not knowing what words to use, how to discuss treatment and side effects, or how to explain the possibility of death. All of these factors add significant stress to an already difficult situation.

Children’s needs

When the children arrived, informal assessment confirmed each child’s developmental level as well as immediate coping style. With support from the child life specialist, AA’s wife was able to introduce the idea that AA’s body was getting tired, that his heart and lungs were slowing, and that it was likely that he would die in the next few days. This was the first time the children had formally heard of his impending death. Anticipatory grief was cyclical. Breaks and stories were interspersed with emotional processing and anguish. Children were encouraged to think about what they would like to do with, or say to, their father prior to his death.

For the children of patients facing terminal illness, the practical and emotional changes are profound. As family unity and communication are disrupted, children may experience confusion and anxiety, and require more emotional support. Up to 25% of children will experience lowered and/or anxious mood, sleep problems, poor concentration, or difficulties at school. Most children respond to the stress of illness in the family with developmental regression. School-age, pre-adolescent, and adolescent children whose parents are in terminal stages of illness display significantly higher levels of depression and anxiety than community controls. Children (notably adolescent girls) whose parents are ill are more likely to exhibit both short- and long-term emotional and psychological problems such as adjustment disorder, decreased self-esteem, and an increased risk of other emotional disturbances. Better psychological outcomes, such as lower levels of depressive symptoms and anxiety for the children, have been associated with openness of general communication with the surviving parent and sharing of information about the other parent’s death. Similar results have been shown in siblings of sick children. Children’s anxiety is lessened in the long term when the truth about treatment and prognosis is disclosed. Finally, much of the emotional distress experienced by the children precedes a parent’s death, suggesting a need for support services before an anticipated death.

Staff needs

The staff caring for seriously ill adult patients may not feel prepared to discuss the support needs of those patients’ children. Providers are frequently asked how best to communicate with children during a parent’s terminal illness; yet, they may avoid discussions because they fear they will distress the patient or they are reluctant to engage with the children. Although they often have training in and experience with breaking bad news to adult patients, staff usually lack this training and experience in dealing with children. Many professionals from the fields of health care, education, and social work do not feel equipped to facilitate conversations about the illness and death of a parent within families, putting vulnerable children at risk of inadequate support.

Several papers, primarily in the nursing and social work literature, bring attention to this gap and offer resources to close it. Recommended interventions focus on educating staff (teaching developmental theory and child communication skills, focusing on the child in the context of the family), educating families (providing written and multimedia information to parents and children, encouraging role play, recommending contact with schools and therapists), and changing the environment (liberalizing ICU visitation, creating safe play spaces for children, reducing unneeded medical equipment). None of these interventions has yet been systematized or tested with staff in the adult medical context. In the pediatric context, however, these techniques and principles fall under the purview of the child life specialist.

Child Life Services in Adult Palliative Medicine

What are child life services?

The child life specialist is a master’s degree-prepared health professional who provides developmentally driven psychosocial assessments and interventions to pediatric patients, their parents, and their healthy siblings. These interventions promote effective coping through play, preparation, education, and self-expression activities. Child life specialists also facilitate communication among the patient, family members, and the health care team as well as within the family itself. Child life programs have existed for more than 50 years and are considered by the American Academy of Pediatrics to be “a quality benchmark of an integrated child health delivery system and an indicator of excellence in
pediatric care."75 In hospitalized children, these interventions have been shown to decrease emotional distress, improve coping effectiveness, promote comfort, reduce sympathetic activation, improve understanding of hospitalization and procedures, speed surgical recovery, and facilitate overall adjustment both during and for at least a month after a hospital stay as measured both directly and by parents.76–78 The anxiety and depression symptoms experienced by siblings of hospitalized children are also reduced while medical knowledge and health-related quality of life are improved.53,73,79 For parents of hospitalized children, these interventions have been shown to decrease anxiety and increase participation in care.76

The support of child life services differs from that of psychology and social work in that the primary focus is acute coping with hospitalization and illness issues based on the child’s developmental level rather than the longer-term model used by psychology or the resource-based model sometimes favored by social work. The child life model is short term, aiming to increase a child’s understanding of the situation and assist him or her with immediate coping mechanisms—aspects that make it ideal for dealing with the acute trauma of a parent’s rapid decline. Child life specialists are active members of many pediatric and neonatal palliative medicine teams,13,80–83 but have so far been rarely utilized within adult palliative medicine.

The following day, the children returned for one more visit prior to the withdrawal of life-sustaining interventions from their father. The children were offered the choice of visiting, and final tasks they hoped to achieve were discussed. Each child was allowed time at AA’s bedside. The oldest son preferred to visit his father’s bedside, choosing to talk to his comatose father and share his sense of guilt for not preventing the accident. The middle daughter also had time alone with her father, reading a letter she had laboriously worked on the night before sharing her love and admiration of her father and listing the emotional gifts he had given her. The youngest child struggled, using denial and refusing to initiate closure with his father.

The role of child life services in adult palliative medicine

At the University of California, San Francisco (UCSF) Medical Center since 2007, the palliative care service and other teams have offered the support of a child life specialist to families of patients with life-threatening illnesses who have children under the age of 18. In the context of adult palliative medicine, referrals to child life focused on issues of communication between parents and children, changes in parent’s health and prognosis, and support both before and during hospital and end-of-life visits. Interventions were either directly with the children or indirectly with the parents/caregiver/staff. If the patient was discharged prior to a visit, the specialist offered phone support.

Referrals to child life services were often helpful after milestone events in patient care such as difficulty explaining prognosis to a child, an abrupt decline in physical health, a relapse, a change in treatment plan, or a child’s visit with a parent who is dying. Referrals were also made when a patient reported poor coping by the children at home or had specific questions about emotional support, legacy work, or how to talk with their children.

Assessment and interventions provided by child life services

Interventions with the children of adult patients varied depending on the child’s developmental level and coping style. For children of all ages, overall needs were assessed by talking with the patient, the partner/spouse of the patient, and/or the health care team to determine what the children had already heard and how they had responded to the information. Previous coping style was discussed as well as previous experiences with illness, injury, or loss.

Based on their goals, the family then chose one or more support options. Given the stress they were experiencing around the patient’s illness, the family’s pre-morbid communication style was supported and not challenged. The ultimate goal of each intervention was to facilitate the use of pre-illness coping and communication methods.

If the children were present in the hospital, the child life specialist met directly with them away from the patient’s bedside. Using art materials, books, and props such as dolls and puppets, informal assessments of each child’s anticipated stress points, misunderstandings, questions, and unresolved feelings were assessed with the pertinent issues then communicated to the parent.84–86

Additionally, the child life specialist helped each child and family to prepare for and structure visits, providing information and using activities designed to enrich understanding, promote coping, and decrease stress.72 This preparation might include a review of the medical equipment the child would see on the parent or specific behaviors and roles the child could use during a visit (e.g., touching a hand, giving a hug, the role of hair dresser or storyteller) to reduce the child’s stress and encourage connection with the ill parent.16,84–88 These interventions worked equally well for emotionally laden visits involving rapid change in the physical state of the parent or for preparatory visits when the parent was able to engage and participate. Coping techniques were rehearsed to allow the child a sense of control and to decrease fear about the visit.

(Additional resources to support these families are provided in Appendices 1 and 2.)

Time and other barriers to providing child life services

The time required for a consult visit varied depending on the emotional needs of the patient. Shorter interventions (approximately 30 minutes) took place when the patient and family members had very specific requests, such as how to tell the children that the parent’s cancer had returned. Other interventions required multiple visits, and the most complex interventions required many hours, such as when the children were supported through the withdrawal of life-sustaining interventions or witnessed the death of their parent in the hospital.

Patient and family factors may impede the use of child life specialists in the adult palliative medicine setting. In our experience, referrals to meet a family were often generated during psychologically charged moments in the patient’s care such as a relapse, a change in care plan, or the choice to withdraw life-sustaining interventions. Adults in the family may not be emotionally ready to focus on or discuss the needs of their children at the time that the intervention is offered.
Finally, as in other areas of medicine, differing cultural norms may prove challenging when supporting the children of seriously ill patients. These cultural factors include ethnicity, national origin, family structure, faith, parenting style, generational differences, and socio-economic status.

Workplace barriers to implementing this type of service may include difficulty incorporating child life services into previously existing programs, difficulty accessing child life services in hospitals without pediatric programs (see below), scarcity of funding, resistance to a new role within the team, or administrative pressure to incorporate psychosocial support of the children of patients into the roles of existing team members. Despite some of these same barriers, child life consultation services have been successfully incorporated into the palliative medicine program at UCSF with uniformly positive feedback from staff and families.

Providing additional support

In medical centers that do not serve children there may be limited or no access to child life services. Even when child life specialists are available, they are unlikely to be the first line of contact for every family. Cross-training of other staff (e.g., physicians, unit nurses, and social workers) and attention to environmental factors therefore remains critical. Where child life specialists are available, they may be able to help provide this training and advice. As with other palliative medicine services, we believe that child life consultations are best used to provide an extra layer of support to families and staff.

Future Directions

Although the value of child life services is already well documented in inpatient pediatric settings, the novelty of this service in adult inpatient medicine means that clinical outcomes for this group have not yet been studied. For the affected children, important endpoints for investigation might include immediate and long-term measures of coping, anxiety, grief, and other psychiatric dysfunction (e.g., depression, behavioral disorders), especially in those who witness the death of their parent. For both seriously ill parents and their partners/families, it might additionally be helpful to document rates of complicated grief as well as satisfaction with their hospital experience and fulfillment in their parental role. Given the relative scarcity of child life programs in adult settings, it is also important to compare the effectiveness of child life specialist consultation with structured, developmentally based training of unit staff and/or other palliative medicine team members.

Conclusion

For millions of seriously ill parents, the health and welfare of their children is a top concern. Although they are often asked for help, practitioners trained in adult medicine may not feel prepared to support these children and their families. Our 3-year experience suggests that a child life specialist consultation service can bridge this gap. Using proven techniques to improve coping, processing, and self-expression in a developmentally appropriate manner, child life specialists help to facilitate the open communication that has been proven to reduce children’s anxiety, depression, and other behavioral problems. For medical centers with access to child life services, it may be beneficial to explore the creation of a child life consultation service to support these children and their families. All hospitals should consider providing broad-based in-service training enabling their staff to improve the support they offer to the children of seriously ill parents.

Author Disclosure Statement

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(Appendix follows →)
Appendix 1: Resources to Offer Families

Books for the adults

- How to Help Children Through a Parent’s Serious Illness by Kathleen McCue. Offering supportive, practical advice from a leading child life specialist, this book includes information such as what to tell a child about the illness, how to recognize early-warning signs in a child’s drawings, sleep patterns, schoolwork, and eating habits, and when and where to get professional help.
- A Tiny Boat At Sea: How to Help Children Who Have a Parent Diagnosed with Cancer by Izetta Smith. This booklet is easy to use and touches on how to support children without hiding the information in pages of explanations. An outstanding resource and a short read.
- Raising an Emotionally Healthy Child When a Parent Is Sick (a Harvard Medical School Book) by Paula Rauch and Anna Muriel. Two Harvard Medical School psychiatrists help prepare for the special parenting challenges that come with illness.
- Can I Still Kiss You? Answering Children’s Questions about Cancer by Neil Russell. A question and answer book written by a cancer patient who journaled the questions he was asked by his children during his cancer experience. Appropriate for all ages.
- Cancer in the Family: Helping Children Cope with a Parent’s Illness by Neil Russell. A question-and-answer book written by a cancer patient who journaled the questions he was asked by his children during his cancer experience. Appropriate for all ages.

Books for the children

- When Someone Has a Very Serious Illness by Marge Heegaard. A cartoon-illustrated workbook for kids to color themselves to help them understand their feelings when their parent is ill.
- Someone I Love Is Sick by Kathleen McCue. For the very youngest children, with pages that can be added or removed for simple language explaining illness in a parent. For ages 2 to 6
- The Invisible String by Patrice Karst. Specifically written to address children’s fear of being apart from the ones they love with an emphasis on connection to family despite not being together.

Appendix 2: Scripts for Parents to Use When Talking with Their Children

About the fear that they will die

Yes, some people die of cancer but mostly they are older. I am young and healthy other than the cancer. The treatment available now is more powerful than ever before. The possibility of my dying really doesn’t occur to me/rarely occurs to me/sometimes occurs to me (which ever is true for you). Is it something that you think about? Remember, you did nothing to cause the cancer. I love you so much. No matter what, you will be all right.

About dying of cancer

The doctor has told me that the medicine has not worked. That means that the cancer is growing and that at some point it will grow in such a way that I will not be able to live anymore. I will die. I am hoping that something will happen and the cancer will stop growing on its own, but I have heard that most likely this will not happen. Remember that this cancer has nothing to do with anything you did. I don’t know why I got this cancer. I am really mad and sad about this. Most of all, I want you to know that I love you and want so much to be alive for as long as I can so I can see you grow. If I do die before you grow up, I feel really good that (the person who will take care of your child) will be there for you. I love him/her very much and know he/she loves you and will take good care of you.