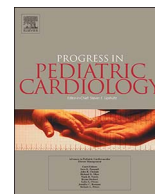




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## Review

## Supporting the family left behind – Loss of a child to congenital heart disease

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## ABSTRACT

Congenital heart disease is a significant cause of childhood morbidity and mortality. Advances in medical and surgical therapies for children with congenital heart disease have both prolonged and enhanced the lives of children and their families affected by congenital and acquired heart disease. While many of these children will ultimately lead happy and productive lives, a significant proportion of this patient population will succumb to their disease. This paper will briefly highlight the incidence and outcomes of congenital heart disease as well as provide an in-depth review of techniques, such as hospital-based bereavement programs, for supporting the families of those children who do not survive.

## 1. Introduction

In the United States, approximately 1% of live births are affected by congenital heart disease, with similar rates in the rest of the world [1]. Approximately 25% of children born with congenital heart disease require intervention in the first year of life due to critical congenital heart disease, including those born with hypoplastic left heart syndrome, tetralogy of fallot, coarctation of the aorta, and transposition of the great vessels [1]. Improvements in surgical techniques and advances in post-operative care have enhanced survival in children with congenital heart disease and there are now more adults living with congenital heart disease than children [1,2]. Many children with congenital heart disease will go on to live long lives, however, a subset of children will succumb to their disease, before or after their surgical palliation or repair. Losing a child is a devastating and impactful experience for surviving family members. These effects encompass both short and long term physical and psychological consequences, affecting everyday lives, year after year.

## 2. Background

The landscape of children dying from advanced heart disease is different from other conditions such as death associated with oncologic processes; the children are often younger, usually less than one year of age, and commonly require a high amount of technologic support at the time of their death [3]. The clear majority of children with advanced heart disease are intubated and many receive mechanical circulatory support (e.g. extracorporeal membrane oxygenation, ventricular assist device) near and at the end-of-life [3]. In one study by Blume et al.,

78% of children with advanced heart disease died during withdrawal of life-sustaining therapies and 16% died during resuscitative intervention [3]. Communication regarding the expected disease course and prognosis is imperative with families in this patient population. In the same study, despite requiring aggressive supportive therapies, realization that their child had no chance for survival did not occur until very near to the death, with a median of 2 days prior to the child's death [3]. Some parents did not realize that their child did not have a chance for survival until death was imminent. Interestingly, once parents identify that their child had no chance of surviving from their advanced cardiac disease, parents often perceive a 'good death' and peacefulness [3]. These findings underscore the need for clear communication with families regarding expectations of their child's underlying cardiac disease and clinical course. In a study by Snaman et al., parents described what clear communication means to them; it includes giving clear information in a timely manner, offering support and assistance with making decisions, providing guidance over what end-of-life is like, and remaining non-judgmental during the time of difficult decision making. Parents specifically do not want over-positive prognostication and appreciate when the physician engages in difficult conversations directly rather than avoiding these conversations [4].

Many parents also report perceived suffering during their child's illness, particularly surrounding the last few months of life. One study [3] demonstrated that up to 47% of parents report that their child with advanced heart disease suffered "somewhat", "a lot", or "a great deal" during the time surrounding end of life. In this study, parental reports of symptoms contributing to suffering varied based on child age [3]. In children less than two years of age, parents reported feeding and breathing difficulties to be associated with suffering and fatigue and

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difficulty sleeping were associated with suffering in older children [3]. Despite most parents in this study (84%) reporting ‘very good’ or ‘excellent’ quality of care delivery near the end of life, most parents (71%) reported that their child’s quality of life was ‘fair’ or ‘poor’ in the last month of life [3]. In another study, a cross sectional survey of parents and cardiologists, Balkin et al. (2015) also described that physicians and parents report that children suffered ‘somewhat’, ‘a lot’, or ‘a great deal’ at the end-of-life. However, there was not agreement between the two reporters [5]. Parents expecting a complete repair of their child’s cardiac lesion and normal lifespan were more likely to report ‘a lot’ of suffering at the end-of-life [5]. Discrepancies were noted in how well families were prepared for the way in which the child died. Many physicians (43%) felt that the family was prepared, while parents described not feeling prepared for the way in which their child died [5], again exemplifying the need for adequate communication.

### 3. Parental Grief

The death of a child forever impacts the family that is left behind. When considering parents, extended family members, and grandparents, it has been estimated that nearly 19% of the adult U.S. population has experienced the death of a child [6]. Bereaved parents report many negative consequences including anxiety, guilt, depressive symptoms, overall poorer well-being, and more health problems [7–9]. Studies have shown that more profound grief is experienced when parents lose a child than when an adult loses a spouse or parent [10,11]. Some studies have demonstrated similar intensity of grief between men and women while others have demonstrated that mothers experience more intense and persistent grief than fathers when grief was studied over one year; grief being most severe in the first six months after the loss of a child [8,9]. While grief may be the most intense closer to the time of the child’s death, some studies have shown that grief may last for up to nine years after the child’s death [12–14]. Some suggest that while grief may evolve over time, it remains ever-present throughout the parent’s lifetime [15,16]. Marital discord is also more common in bereaved parents [7,8].

Theories have been proposed for the powerful grief experienced by parents that have lost a child. Loss of a child prior to the death of a parent disrupts the natural order of death, as parents expect that their child will outlive them [17]. Feelings of parental failure have also been implicated in this complex grief response. Parents may feel that they have not succeeded in their role of protecting their child and this feeling may vary based on the mechanism of the child’s death [17]. A third proposed theory is interruption in the family structure. The once familiar and comfortable household reverts to instability and discomfort, requiring reorganization of roles and responsibilities within the family unit [17].

For some children in the intensive care unit, families and health care providers determine that the most appropriate path of care is to withdraw life-sustaining therapies. In one anonymous questionnaire study of families of children who died after the withdrawal of life-sustaining therapies, the health care provider initiated the conversation about withdrawal of these therapies in 90% of cases, although, more than half of the parents of these children had considered that route of care prior to the conversation being initiated by the health care provider [18]. In this same study, factors most important in deciding whether to withdraw life-sustaining therapies from their child included: the child’s quality of life, chance for improvement, and perception of the level of the child’s pain [18]. Over half of the parents in this study reported having little control in the final days of their child’s life and nearly a quarter would have made decisions differently [18]. In a prospective qualitative study, factors influencing parental decisions on withholding life sustaining therapies included prior experiences with death and end-of-life decision making for others, perceptions of the child’s will to survive, observations of the child suffering, their need to protect and advocate for their child, and financial resources to meet the needs of

long term care for the child [19].

### 4. What Do Grieving Parents Need?

Parental needs during time of bereavement in a highly technological unit such as a cardiac intensive care unit are multifaceted and intensely spiritual. Children are unique and differ from adult patients at the end of life beyond their physical differences. They are at different development levels, have different psychological needs, and have varied relationships with family members [20]. While critically ill in an intensive care unit, additional challenges include their inability to communicate, altered behavior due to their underlying illness in conjunction with sedation and analgesic agents, and their altered appearance. A systematic literature review [20] sought to identify strategies to improve end-of-life care in the Pediatric Intensive Care Unit (PICU). Similar in milieu and technologic supportive devices, these findings can likely be extrapolated to children at the end-of-life in the cardiac intensive care unit. Truog et al. (2006) suggest that there are six domains of high quality, family-centered care. These domains were identified as: support of the family unit, communication with the child and family about treatment goals and plans, ethics and shared decision making, relief of pain and symptoms, continuity of care, and, finally, grief and bereavement support [20]. (Table 1).

Parents seek truth from health care providers and yearn for continued connection to their child [21]. Themes identified for maintaining a connection to their child include mementos, memorials, support groups, charitable work, and organ donation, when appropriate [21]. The environmental needs of parents of dying children also becomes important; an evaluation shows parents remembering the intensive care unit rooms, waiting areas, access to services for parental self-care (e.g. showering, eating), access to their child, ability to participate in their child’s care, and access to individuals who provide personal and professional support [21]. Memories of the unit after the child’s death are impacted by both the physical space and support offered.

Many surveys, studies, and interviews have been conducted to discover what exactly families need and desire from health-care professionals during the bereavement process. Although there is a lack of data specific to pediatric congenital heart disease, there are several studies looking at parental needs and desires in the pediatric population. One study by Garstang et al. addressed this specific question and while this study dealt specifically with *unexpected deaths*, it found three main themes that seemed to resonate with most: the ability for parents to say goodbye to their child, the desire for information and understanding surrounding the cause of death, and support from the professionals involved [22].

These three tenets have been supported by multiple other studies. In review of the literature, the majority of parents expressed a desire to see their child’s body after death, giving them time to say goodbye and lessening their grief [22–25]. In fact, parents were shown to regret not seeing the body when asked at a later date. Merlevede et al. also showed the importance parents placed on receiving information regarding the circumstances surrounding their child’s death; knowing the

**Table 1**  
Strategies for improving family experiences during end of life care in children.

Align information sharing from clinical team to family needs and interests
Tailor communication style to the needs/preferences of the family
Facilitate parental control over decision making for their child
Engage nursing to assist in decision making for the child
Facilitate access to their child
Increase opportunities for family participation in child’s care
Assure parents that treating pain is a priority and how it will be assessed and treated
Increase access to health care providers; e.g. email, journaling, ‘office hours’ at bedside
Encourage staff acts of kindness and commemoration during the bereavement process

Adapted from Truog et al. (2006). Crit Care Med.

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