Place, Age, and Mode of Death of Infants and Children With Hypoplastic Left Heart Syndrome: Implications for Medical Counselling, Psychological Counselling, and Palliative Care

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Abstract / A review of outcomes of hypoplastic left heart syndrome at a pediatric hospital 1985-2004 identified 154 deaths among 206 children (75%). Of 134 surgically treated, 82 (62%) died: 68 (83%) in intensive care, six (7%) in the operating theatre, three (4%) during transport from home, two (2%) on the cardiac ward, one (1%) at home, one (1%) in the emergency department, and one (1%) elsewhere. Seventy died after stage one Norwood surgery (median age: 13 days), three died after second stage surgery (ages: 3, 4, and 20 months), two died after third stage surgery (ages: 1.2 and 3.5 years), two died after heart transplantation (ages: 4.6 and 15 years), and five died after non-Norwood surgery. All 72 infants treated without surgery died: 68 died at a median age 3 days; 57 (79%) in intensive care, three (4%) on the ward, and 12 (17%) elsewhere. Discussion involves strategies to support parents and staff at diagnosis, and before and after a child’s death.

Résumé / L’examen des dossiers de 206 enfants atteints du syndrome d’hypoplasie du cœur gauche et soignés dans un hôpital pédiatrique a révélé qu’entre 1983 et 2004, 154 de ces enfants (75%) étaient morts. Des 134 enfants ayant subi une opération, 82 (62%) sont morts soit 68 (83%) en soins intensifs, 6 (7%) dans la salle d’opération, 3 (4%) en route vers l’hôpital, 2 (2%) dans le service de cardiologie, 1 (1%) à la maison, 1 (1%) dans le service d’urgence, et 1 (1%) ailleurs. Plus spécifiquement, 70 sont morts après la première intervention chirurgicale de Norwood vers l’âge moyen de 13 jours, 3 sont morts âgés de 3, 4 et 20 mois après une deuxième chirurgie de Norwood, 2 sont morts âgés de 1,2 et 3,5 ans après une troisième chirurgie de Norwood, 2 sont morts âgés de 4,6 et 15 ans après une transplantation cardiaque, et 5 sont morts suivant un type de chirurgie autre que celle de Norwood. Tous les 72 enfants qui n’ont pas subi d’opération sont morts ainsi: 68 à l’âge de moyen de 3 jours; 57 (79%) aux soins intensifs, 3 (4%) dans l’unité de cardiologie et 12 (17%) sont morts ailleurs. En conclusion on propose certaines stratégies afin de pouvoir aider les parents et le personnel lors du diagnostic et, par le suite, avant et après la mort de l’enfant.

INTRODUCTION

The management of children with congenital heart disease has radically changed. Children who were previously deemed inoperable can now receive satisfactory correction or palliation (1,2). One of the most serious malformations is hypoplastic left heart syndrome (HLHS) (3). The diagnosis can be made in utero by fetal ultrasonography, but is sometimes made after birth when the infant rapidly deteriorates after several days of apparent normality.

Infants born with HLHS die, almost without exception, within days or weeks unless surgery is undertaken. Parents have three options when the condition is diagnosed before the infant’s birth. The first option is termination of pregnancy, the second is continuance of pregnancy and palliative treatment after birth, the third is surgery in the newborn period. Although medical and surgical techniques have advanced, the prognosis is guarded. Mortality is high despite surgery and surviving infants are prone to many complications (2), which include cognitive and neuromotor difficulties (2,4,5). Surviving children and all parents are prone to psychosocial problems (4–7). In spite of optimal care, HLHS
infants and children can die suddenly at any stage before or after surgery (6).

Surgery involving a three-staged reconstruction of the heart has been offered at our institution since 1983. The first stage, a Norwood or Sano procedure performed within days of the infant’s birth, enables the single pumping chamber (right ventricle) to pump blood to both the systemic and pulmonary circulations. Although this gives short-term survival, the ventricle eventually fails. The second stage operation, a bilateral cavo-pulmonary shunt (BCPS) at 3 to 6 months of age, decreases the work of the ventricle by diverting some venous blood return directly to the lungs, thus bypassing the heart. The third stage (Fontan operation), at approximately 3 to 6 years of age, diverts all venous return directly to the lungs, thus reducing cardiac work considerably.

Although most deaths in pediatric hospitals occur in intensive care units (ICU) (8), we have not accurately determined previously when and where all children with HLHS have died at our institution. The aim of this study was to determine the places of death of these patients, their ages at death, and the stages of surgery attained.

The parents’ experience has not been studied. Although this study does not include the experiences of parents, the outcomes of their children are relevant for their medical counselling and psychological assistance. Finally, the requirements for palliative care of the newborn infant or older child are considered.

METHOD

We examined the medical records of children born from 1983 to 2004 and recorded for each child their place of death, their age, and the stage of surgery attained.

RESULTS

HLHS was the diagnosis in 206 infants treated in the period 1983–2004. Surgery was undertaken in 134 infants, and was not in 72.

Of the 134 infants who had surgery, 82 (61%) died. Of those who died after surgery, 68 (83%) died in the ICU, six died in the operating theatre (7%), three were pronounced dead on arrival at the emergency department from home (2%), two died in the cardiac ward (2%), one died at home (<1%), one died in the emergency department (<1%), and one was transferred to another hospital for palliative care at the age of 3.5 years (<1%).

Seventy died after stage one Norwood or Sano surgery at a median age of 13 days; three
died after stage two surgery aged 3, 4, and 20 months; two died after third stage surgery aged 1.2 and 3.5 years; two died after transplantation aged 4.6 and 15 years (Figure 3); and five died after other types of cardiac surgery.

Of the eight children who died outside the ICU or operating theatre, all died suddenly and usually as a result of a minor illness, such as a viral infection, with the exception of one who deteriorated over a number of days in the ward.

Of the 72 infants who did not have surgery, 57 (79%) died in the ICU, 12 (17%) were transferred to another site at the request of parents (it is not known where they died), and three (4%) died in the cardiac ward.

The survival of 68 of these infants was a median of 3 days (range 1–39 days).

The survival of the total of 206 infants born with HLHS to the end of 2004 was 52 (25%) at a median age of 1.9 years (range: 1 month–16 years).

In another study of these 206 infants at our institution, we found that, of 178 infants considered fit for surgery, 68 (38%) had a prenatal diagnosis and 110 (62%) did not. Of the 72 infants who did not have surgery, palliative care was chosen by parents for 49 (68%). When the diagnosis was made prenatally, 96% of infants underwent surgery, whereas when the diagnosis was made post-natally, 47% underwent surgery (9).

DISCUSSION

The results highlight the frailty of these infants and children. Without surgery they quickly die. For example, most infants in this study died after the first stage of surgery, before they reached the second stage, and died in the ICU (70/129; 78%). At that time, the infants were critically ill and in the immediate post-operative phase requiring invasive life-supportive treatment. In this state, it is impractical or not possible, even when death is inevitable, to transfer them to a hospice facility or to home because medical staff are attempting to save their lives or because the withdrawal of life-saving machinery would result in a rapid death. Consequently, it can be difficult to judge when palliative care is appropriate. This is frequently the case with other pediatric cohorts during the transition between life-sustaining treatments and palliative care (10). The circumstances and deaths of HLHS infants and children mandate parental support.

Medical Counselling and Informed Consent

Counselling parents, who are shocked and distressed after their infant’s diagnosis, is de-
ing repeatedly about the source of trauma). If parents have traumatic symptoms, they cannot engage in higher order thinking (17) and so they may have difficulty with comprehension. The parents who are most vulnerable at this time are those whose infant was not diagnosed \textit{in utero} because these parents will have had no preparation.

Parents will experience limitations in medical knowledge when they attempt to learn about HLHS because there is restricted data about long-term outcomes. Surgery for HLHS has only been performed in the last 25 years, with high mortality rates (18), and there is no information on the psychosocial and family impact.

The doctor needs to establish an empathetic relationship with the parents. Parents are likely to have confidence in the doctor if they feel that he/she wants what is best for their family (19), speaks openly, and conveys warmth and respect. Small acts of human kindness are valuable at any time, but when kindness comes from a doctor, it can be most powerful; parents are vulnerable because their infant’s life is at stake, and doctors can determine life and death. The doctor needs to be aware of the enormous loss for the parents of the “wished for” child and the resulting sadness. It can be supportive if the doctor acknowledges the emotions experienced by the parents and even convey her or his own feelings where appropriate. This communication conveys the mutual humanity in the doctor-parent relationship, and can indicate empathy and deepen trust. Parents will be more prepared to make a decision about their infant’s treatment if they receive comprehensive information conveyed with support and sensitivity.

The timing of decision making is an issue for these parents. When feasible, parents may need information conveyed in a staged process in a comfortable environment to enable them to assimilate material and to have time for reflection, communication with their family, and their own research. Parents whose infant is diagnosed after birth have very little time to make a decision (possibly one day). It may be helpful to have another doctor, such as an intensive care specialist, who has experience in treating these infants, present at the meeting with the parents. The parents may also wish to have someone of their choice at the meeting. In addition, nursing and allied health professionals who can discuss the choices of treatment also have a role in supporting the parents.

Parents require information about survival and treatment. They also require information about morbidity. The medical priority may be focused upon saving the life of the infant without a consideration of the long-term impact on the child and the family. Although surgery for this condition is relatively new and advancing, there is significant morbidity (3–7). For example, a recent small study of outcomes among HLHS children found that six of nine school-aged children needed special assistance at school, four had attention-deficit/hyperactivity disorder (ADHD), and their mean composite intelligence quotient was 87 (range: 52–111) (4). In spite of the possibility of morbidity, some parents will prefer a child with significant morbidity rather than no child at all.

Parents may wish to consider the psychosocial and family impact. In spite of the lack of information about HLHS and effect on the family, studies of parents of children with other disabilities have drawn attention to the many family stresses, for example healthcare- and treatment-related needs, anxiety, family disruption, and concern about the child’s future (1,21) and siblings (1,22,23). However, in a study of long-term outcomes of HLHS patients, all parents reported that their child brought them many positive experiences (4).

At this institution, the depth and quality of communication received by parents were not evident because medical records were not explicit. At another institution, in a study of ten mothers of children with HLHS (age range: 2.5–6 years), nine felt they had decided on surgery independently, one thought the doctor had decided for her (18). Although these numbers are very small, even if one mother felt that the doctor alone made the decision about surgery, this may be unacceptable, because parents have the primary relationship with the child over the duration of a child’s life. A later study of parents’ experiences (11 mothers, four fathers) after their infant’s birth at a different institution found that five parents felt the attitudes of both doctors and nurses had been unsatisfactory, information was unbalanced, and there had been a lack of support (4). These studies suggest there is potential for improved counselling.

In a previous study at this institution, we found that, if the diagnosis was made post-natally, most parents (68%) chose palliative care rather than surgery. These results would seem to negate the findings that, where there is uncertainty, people choose options that may extend life (19). However, this figure included infants for whom surgery was not offered because they were too ill (9).

In summary, doctors need a range of skills to assist parents at diagnosis. They should build
a trusting relationship, have good communication skills and have extensive knowledge about HLHS, parental stress and shock, and allow parents time to contemplate before choosing a course of treatment.

Counselling Beginning at Diagnosis

All parents of children with HLHS are likely to be exposed to many different stresses. Parents whose child has congenital heart disease have complex psychosocial stresses (1) including the psychosocial problems of their children. In one study, 20% of children born with congenital heart disease were found to have severe psychosocial problems (1). Parents may have long-lasting traumatic reactions as a result of the diagnosis (11,13,14,24,26). Parents may also experience cumulative trauma and grief effects in response to their child’s condition or treatment, for example, in witnessing their child’s open chest after surgery, or being present during their child’s cardiac arrest, or their appearance on extracorporeal membrane oxygenation (ECMO). Readily available counselling may reduce their stress. It has been recommended that all families whose child has other forms of congenital heart disease need social and psychological support (1). This support could facilitate decision making, mobilize resources, promote attachment, assist the family’s coping, and reduce the possibility of longer term psychopathology and complicated bereavement.

Psychological Counselling After the Child’s Death

As this study has illustrated, the mortality rates of infants and children with HLHS are high. Family counselling is desirable. Engel considered that the pain caused by bereavement is as physiologically traumatic as the pain of a severe wound or burn (25). However, even this metaphor is insufficient because a person so harmed may receive some relief from their pain with analgesics, which is not the case in response to death. All bereavement may be painful, but parental grief after a child’s death is the most difficult grief of all (17) and disrupts the anticipated cycle of life where children outlive their parents. Reactions to the death may involve shock, anxiety, depression, guilt, anger, somatic complaints, loss of energy, psychosomatic reactions, social difficulties, and existential challenges concerning meaning, faith, and assumptions about life (24). Parents of HLHS patients may erroneously believe that they have been responsible in some culpable way for their child’s cardiac malformation, which could add to their distress.

Recently, a new syndrome—a form of complicated grief termed “traumatic grief”—has been proposed (27,28). Traumatic grief shatters a parent’s worldview such that he/she has symptoms of both grief and trauma. Traumatic grief is a nosologic entity and has its roots in attachment behaviour, separation distress, and traumatic distress. Although grief is well recognized after loss, there is a high risk of parents developing traumatic grief after the death of their child (17).

Other members of the family can also develop psychological trauma. This may happen in response to the child’s death or in response to living with a family member who is traumatized (29). These family members may require support within or outside of the hospital.

When a parent experiences both loss and grief, it constitutes an “intensely distressing, possibly catastrophic personal experience (30, p.179).” Smeding wrote: “Child loss is a descriptive of a life-shattering experience for families (31, p.230),” while Dyregrov et al. said, “The loss of a child is one of the most stressful situations a family can face (24, p.1).” The loss of an infant or a child shatters the parents’ hopes and dreams. Counselling may help these parents.

Parents of HLHS children often have had little preparation for their child’s death. Such parents include those whose infant had not been diagnosed before birth; parents whose infant or child has died soon after surgery; and parents whose child has died suddenly in the ward, in an operating theatre, in the emergency department, or in the ICU. The parents who are prone to the greatest psychopathologic risk are those whose child has collapsed at home. In these circumstances, they have witnessed their child dying and, at the same time, sought medical assistance and perhaps attempted resuscitation. It is also worth noting that these bereaved parents may have complicated bereavement patterns because of their responses to both the illness and to the death of their child.

Parents whose child has died experience enduring psychological responses (24,26), as illustrated by a longitudinal study over 12 to 15 years of mothers and fathers after the loss of a child (26). This study found that two-thirds of parents experienced intense enduring psychological effects 12 to 15 years after their child’s death, and also revealed that there were gender differences in the level of distress of parents at different times. In the earlier years after
the child's death, mothers had higher levels of distress (anxiety, depression, trauma, and poorer health) compared with fathers, whereas in the later years, fathers had higher levels of distress compared to mothers. It is unclear why this may be the case, but the authors suggested that it may be because women are more inclined to seek help than are men, and men may feel a need to be "strong" and support their wives. A further possibility is that the mothers talked about how they felt and worked through their grief. Further research is needed in order to understand parents' needs and the gender differences.

The wider family may also suffer. A sibling has not only had to cope with their brother or sister's death, but also with the experience of living with them. Studies of siblings of children with other disabilities have found that they may have unresolved feelings of distress and isolation, which may manifest as behavioural disturbances, school failure, and psychosomatic complaints (23). Siblings may have felt burdened prior to their brother or sister's death. Girls particularly have, for example, assumed adult caregiver roles within the family, at the expense of their own needs (23). Some siblings have felt the burden of parental expectation to compensate for the lack of achievement of the disabled sibling (23). Studies of risk factors for vulnerability to later mental and physical diseases found that a chronically ill sibling is a risk factor, and siblings who live with a brother or sister with a congenital heart disease are likely to bear many stresses (1). However, there are compensating protective factors for children, such as supportive caregivers, social support, and self-esteem (33). The availability of professional support may assist children emotionally.

**Palliative Care**

Although there are many definitions of palliative care, most include the central tenets outlined in the World Health Organization (WHO) definition, which are to optimize quality of life until death and to eliminate any notion that palliative care involves euthanasia. Carers should understand that palliative care is an active treatment (34), not merely a withdrawal of life-sustaining measures, and includes sensitive family-centred care, and attention to physical, emotional, and spiritual issues. It involves a continuum of care which includes bereavement support. Palliative care is distinct from terminal care where patients are in need of end-of-life support when there is a progressive decline.

Palliative care should be integrated into regular care in some situations at an early stage, in order to build trust. Professionals then have the time to assist the family with the many issues which accompany life-limiting illness. Time spent on palliation could reduce later grief responses. Since there is a continuing emotive bond between parents and a deceased child over the parents' lifetime (35), good palliative care could assist parents to establish a healthy bond before death. The child's dying, as painful as it is, can also become a powerful experience for the family, as joy and sorrow are interwoven.

Palliative care within pediatric hospitals has not been fully embraced (36) as it is often seen as the domain of older adults with incurable malignancies (37). Pediatric palliative care has specific differences from adult palliative care (34,39). These include a heterogeneous patient population, physiological factors, developmental issues, and parental involvement in caregiving and decision making (39).

Palliative care is an appropriate option for HLHS infants, but parents are likely to require education to understand what it entails. Some parents may fear that nontreatment represents a parental failure because "not all has been done for the child." They may need reassurance that palliation is an acceptable intervention when mortality is high, morbidity is serious, and care of these children is intense, demanding, and psychosocially costly for the family. Parents may choose palliation for their child at different times. Some parents, whose infant is diagnosed in utero, may proceed with the pregnancy and then choose palliative care after birth. Parents may be confronted with high morbidity, lack of success after surgery, or treatment too burdensome to be in the child's best interests. In these circumstances it is also appropriate to choose palliation.

It can be difficult to discern when palliative care professionals should be consulted, unless parents have made a clear decision about discontinuing treatment. Both the American Academy of Pediatrics (AAP) (36) and the WHO (40) support a model of palliative care that is "applicable early in the course of illness, in conjunction with other therapies that prolong life" (40). The AAP goes further, stating that an appropriate choice of action is one in which the "components of palliative care are offered at diagnosis and continued throughout the course of the illness, whether the outcome ends in cure or death" (38). This is a reasonable guide if a newborn infant has a condition which is clearly incompatible with life. However, with HLHS patients, outcomes are uncertain, even though
many children survive surgery and live active lives in spite of the fact they are never cured. Consequently, parents may be confused about whether they should be preparing for the death of their child or whether they should expect their child to live for many years. The early involvement of palliative care personnel could add to the parents’ confusion or they could feel that it is inappropriate. These parents should be informed that these specialists also want what is best for their family.

Added to these uncertainties is the difficulty for medical staff to foresee when a child may die, because deterioration can occur suddenly. At other times, however, in the ICU, survival or nonsurvival can be predicted due to certain indices, for example, the number of times the infant has required ECMO. Morbidity is also difficult to predict. ICU specialists have a number of options in relation to palliative care. They could inform parents that the involvement of the palliative care staff does not mean that their child is expected to die, but that death is a possibility. The parents could be told that the palliative care professionals routinely see all HLHS families as a matter of course, at an early stage. An alternative is that the palliative care professionals are involved only when the infant or child is clearly going to die. A further option is that the palliative care specialists do not see the parents and the child themselves, but the principles of this care are incorporated in routine care, and palliative care specialists are in the background for advice and support.

Currently, in our institution's ICU, some aspects of palliative care are routinely instigated. Extended family care is provided and parents can plan what they need for their child if life-sustaining support is to be withdrawn (if there is sufficient preparation time). Families usually hold their dying child and spend time with their child after death, for as long as desired. Nonetheless, the usual environment in the ICU and in the cardiac ward is not ideal for a dying patient, and our institution is developing facilities with a private room for families within the ICU. Private home-like areas can be important for expressions of intimacy, for grief, and for different cultural and religious rituals in a multicultural society. Similarly, this area may also protect other children and families who may feel disturbed or embarrassed by exposure to a dying child or a religious observance.

The ICU is not the only location for palliative care for HLHS children, even though most die within the ICU. When there is more time and warning before a child dies (for example, when parents have decided against surgery, or when a child progressively develops heart failure and parents do not wish to proceed with further treatment), palliative care could occur in other settings such as a ward within the hospital or in a specifically designed hospice for children. Parents may prefer home care, but this option involves planning, expertise, and support (10).

Palliative Care: Implications for Health Professionals

The period when a child is dying is very stressful for everyone involved, including staff. Delivery of sensitive care should involve sharing the emotional burden of the child’s dying. Empathy is at the heart of this support—when parents believe it is absent, their grief is intensified (41). The expression of empathy is not an all-or-none phenomenon. It should develop in response to the relationship with the child and the family. However, empathy can bring awareness of the difficult juxtaposition of intimacy with the family and the family’s need for respectful distance.

Health professionals should bear in mind that there is an intrinsic power differential between them and the parents. Although the traditional model of care is one where health professionals are the experts (34), it is important to empower parents and the child (where appropriate) to make decisions about their own needs. Staff may also learn from patients and their families. If families are well supported during their child’s dying, they may feel that, although this time was stressful and painful, it was also enriching. This may also be the case for health professionals who witness expressions of love and of family resourcefulness, which can be most satisfying.

Proper care of families requires that health professionals be attuned to family needs, including those of siblings. There are many family requirements, but the attitudes of professionals are the most important. Communication, verbal and nonverbal, is the principal determinant of high-quality care, and entails an attitude of presence, openness, and good listening skills (42).

Since this is challenging work, it may be helpful to offer education and opportunities for reflection to health professionals. These professionals may also need to think about self-care and to discern their own feelings of vulnerability, which are readily aroused in these situations. Finally, health professionals may also experience personal benefit and reward in their assistance of dying children and their families.
CONCLUSIONS AND FUTURE DIRECTIONS

Of children who die with HLHS, most die as infants after the first stage of surgery within the ICU, but children with this condition may die suddenly at any time. There is a need to offer comprehensive medical information to parents at diagnosis, sensitively delivered, so that they can make informed decisions about treatment. This could be combined with the availability of psychological counselling from the time of diagnosis until after a child’s death. Although all parents of children with HLHS may have experienced psychological trauma, parents whose child has died suddenly, outside the ICU, are also likely to have traumatic grief. Palliative care remains an option for children born with HLHS at time of diagnosis, or at some time after unsuccessful surgical treatment. Staff could require education about this specialty and support. Finally, further study of parents whose children have HLHS or have died with HLHS may provide worthwhile insights into their needs and improve professional services.

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