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The importance of early involvement of paediatric palliative care for patients with severe congenital heart disease

Sophie Bertaud¹, David F A Llovd^{1,2}, Joanna Laddie³, Reza Razavi^{1,2}

¹Division of Imaging Sciences and Biomedical Engineering, King's College London, The Rayne Institute, St. Thomas' Hospital, London, UK

²Department of Paediatric Cardiology, Evelina London Children's Hospital, Guy's & St Thomas' NHS Foundation Trust, London, UK

³Department of Paediatric Palliative Care, Evelina London Children's Hospital, Guy's & St Thomas' NHS Foundation Trust, London, UK

Abstract

Growing numbers of patients with severe congenital heart disease (CHD) are surviving into late childhood and beyond. This increasingly complex patient group may experience multiple formidable and precarious interventions, lifelong morbidity and the very real risk of premature death on many occasions throughout their childhood. In this paper, we discuss the advantages of a fully integrated palliative care ethos in patients with CHD, offering the potential for improved symptom control, more informed decision-making and enhanced support for patients and their families throughout their disease trajectory. These core principles may be delivered alongside expert cardiac care via non-specialists within pre-existing networks or via specialists in paediatric palliative care when appropriate. By broaching these complex issues early—even from the point of diagnosis—an individualised set of values can be established around not just *end-of-life* but also *quality-of-life* decisions, with clear benefits for patients and their families regardless of outcome.

Introduction

The Association for Children's Palliative Care (ACT, now integrated together with Children's Hospices UK into *Together for Short Lives*) gives a definition of children's palliative care as an 'active and total approach to care from the point of diagnosis or recognition, throughout the child's life, death and beyond'. It embraces a comprehensive and

Correspondence to: Sophie Bertaud.

Correspondence to, Dr Sophie Bertaud, Division of Imaging Sciences and Biomedical Engineering, King's College London, The Rayne Institute, 4th Floor, Lambeth Wing, St. Thomas' Hospital, Westminster Bridge Road, London SE1 7EH, UK; sophie.bertaud@kcl.ac.uk.

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multifaceted approach focused on enhancing the quality of life for the child/young person and support for the family, not simply limited to death or bereavement.¹

Paediatric palliative care services have traditionally had a limited role in children with severe congenital heart disease (CHD);² however, with an ever-growing and increasingly complex cohort of patients, more families face the possibility of multiple procedures and prolonged admissions throughout childhood, accompanied by periods of great apprehension and uncertainty. Earlier integration of palliative care would enable stronger support for children and their families, facilitating improved symptom control and better informed decision-making, as well as allowing families to accept, plan and prepare for the possibility of death. In this paper, we discuss the role of specialist palliative care teams in paediatric cardiology and outline the potential advantages—and barriers—to more cohesive integration of palliative care services for children with severe CHD.

An increasing patient population

The past few decades have seen an increase in prenatal detection of complex CHD,³ with a large percentage of patients with significant CHD now diagnosed antenatally.⁴ Total CHD birth prevalence is approximately 9 per 1000 live births, or 1.35 million newborns per year worldwide.⁵ Mortality from CHD continues to fall, following advances in surgical and interventional procedures for children with CHD, high-technology life-support strategies and the advances in the field of cardiac transplantation; however, CHD remains one of the leading causes of non-accidental death in childhood.⁶ Indeed, the majority of children who die from advanced cardiac disease die young with multiorgan failure while undergoing invasive support in an intensive care setting.^{6,7} Thus, clinicians, families and children are facing evermore complex decisions, not just in terms of delivering appropriate and timely treatments, but also in discussions regarding the end of life.

The current state of paediatric palliative care in the UK

In a recent publication using the English Hospital Episode Statistics data set (2000/2001–2009/2010), the prevalence of life-limiting conditions in children and young people in England was double the previously reported estimates at 32 per 10 000 population, identifying the escalating need for specialist paediatric palliative care services in the UK.⁸ Non-malignant diagnoses, including cardiovascular disease, represent a significant proportion of palliative care service needs (box 1). Despite this warning, the number of specialist tertiary centres and specialist palliative care consultants remains relatively small, and there is a wide variation geographically in the extent to which children have access to these services.⁹ However, many of the key components of a palliative care ethos simply involve a more holistic approach to the needs of the child or young person, and hence could quite reasonably be provided by existing paediatric and community teams in partnership with local authorities and the voluntary sector.¹⁰ In this circumstance, specialist paediatric palliative care would retain its specific roles, particularly in providing symptom control, end-of-life care and compassionate withdrawal of life-sustaining treatment, and there is clear guidance to inform referrals.¹¹

The potential roles of palliative care in children with CHD

In infants or children with severe congenital heart defects not amenable to intervention or those in whom treatment strategies have failed, the rationale for palliative care involvement is well recognised. However, paediatric palliative care also encompasses children with *life-limiting conditions*, in whom premature death is usual, but not necessarily predictable or imminent, and *life-threatening conditions*, in which there is a high probability of premature death, but also a chance of long-term survival to adulthood.¹⁵ Both definitions have increasing resonance within the paediatric CHD population.

ACT and the Royal College of Paediatrics and Child Health have categorised childhood conditions that may benefit from palliative care into four groups according to the expected disease trajectory, with the first two groups having particular relevance to children with CHD (table 1).¹¹⁶ The inclusion of a specific section on palliative care and bereavement in the National Health Service (NHS) England's current national review of CHD services offers further weight to the argument for a more cohesive approach.¹⁷

Barriers to stronger integration of palliative care

The disease trajectory for children with CHD is inherently unique and unpredictable, and clinicians involved in day-to-day care of the children with CHD tend to focus on improving outcomes by using aggressive interventions even in the final stages of advanced disease.¹⁸ This period is often marked by periods of acute decompensation requiring specialist treatment or further intervention, followed by periods of relative stability when end-of-life discussions can be difficult to broach.¹⁸ Paediatric cardiac intensive care unit (ICU) providers have cited unrealistic clinician expectations and differences between clinician and patient–parent understanding of prognosis as common barriers to conducting advanced care discussions.¹⁹ When the possibility of death more clearly presents itself, however, it may be too late: a study across two large American paediatric cardiology centres found that at end of life 86% of children were intubated and 46% were receiving mechanical circulatory support; 78% died during withdrawal of life-sustaining interventions and 16% during resuscitative efforts.⁶

A similar pattern is emerging in the rapidly increasing population of adult survivors with CHD.²⁰²¹ In a retrospective study of adult patients with CHD who died while admitted to hospital, it was found that although the majority of patients were known to be in the end stages of their disease, only a minority had documented end-of-life discussions prior to their terminal admission and most received continued aggressive medical therapy up to their demise.²⁰ The authors postulate several potential reasons for this reluctance to enter end-of-life discussions (box 2).

Timing of involvement of palliative care

Palliative care has been described as 'a continuum of care from provision of responsive services (eg, education, respite, transport and social services) to access to specialist services (eg, specialist paediatric palliative care teams, a paediatric palliative care consultant)',²² and early involvement has been shown to improve both overall quality of life and mood.²³ A

recent study demonstrated that patients receiving early palliative care in an adult oncology setting may even survive longer despite receiving less aggressive care at the end of life.²³

Even within ‘major’ forms of CHD (those requiring intervention within the first year of life),²⁴ there is important heterogeneity. For some conditions, such as transposition of the great vessels, despite undergoing neonatal cardiopulmonary bypass and a highly technical open heart procedure, early survival in most centres is well above 95%.²⁵ For others, such as those with a ‘single ventricle’ physiology (eg, hypoplastic left heart syndrome), the only available treatment strategies are by their nature palliative²⁶ and the argument for more holistic support from an early stage is far stronger—perhaps even before birth in those diagnosed antenatally.²

Ultimately the selection of patients, and degree of involvement of either specialist or ‘ground-level’ palliative care input, will be dictated by a multitude of factors involving both the patients and their families. Thus, the optimum timing for involvement of palliative care alongside other treatments in children with CHD will require a bespoke approach, and there may be conflicting views between healthcare professionals and families—or indeed between professionals themselves—on when that time should be. There are however several strong arguments for much earlier involvement of palliative care than is currently the case. Earlier contact with palliative care services may allow patients and families to be better equipped to choose the elements of a service they wish to access and when. Openly discussing what the future may hold may have important implications to decision-making: it has been suggested that families may opt for high-risk surgical or interventional procedures simply because they are unclear of the outcomes of a more conservative approach.¹⁸ There also appears to be little downside of early involvement: well-informed parents do not necessarily conceptualise cure-directed and symptom-directed care as mutually exclusive or alternative approaches,²⁷ and the act of raising these issues is not felt to be in conflict with the principle of ‘honouring hope’ for their loved one.²⁸

Indeed, the recent NHS England CHD consultation recommended that clinicians should use nationally approved paediatric palliative medicine guidance to plan palliative care from the point of diagnosis for very severe forms of CHD.¹⁷ *Together for Short Lives* highlights that parallel planning for life while also planning for deterioration or death allows a child’s full potential to be achieved and primes the mobilisation of services and professionals where necessary. Planning for the future at times of great uncertainty has been shown to be comforting for parents and children.²⁹

In some cases of complex CHD, particularly those who have undergone multiple interventions and treatments, the original prognosis and goals of therapy may begin to change. Professionals, families or patients may begin to question ‘whether continued life is too burdensome’ or come ‘to accept the inevitability of death’.³⁰ This watershed can be subtle, however. Pre-existing palliative care may provide a separate space to reflect on these feelings more openly. In the small number of children with CHD who deteriorate quickly and/or unexpectedly, the confrontation with death may be far more abrupt. Palliative care has become increasingly recognised as an integral part of the paediatric intensive care unit (PICU) service³¹ and is no longer equated with a withdrawal of all ‘care’ or abandonment of

the patient. Rather the application of palliative care in the context of a PICU is about a 'coherent and encompassing treatment strategy that makes sense to the patient, family and health team'³² and can be delivered in conjunction with specialist palliative care teams or independently by trained PICU staff.

Similarly, outside of the ICU, the resources to deliver the bulk of day-to-day palliative care exist in most local community teams, among children's community nurses and general paediatricians or general practitioners.¹¹ Stronger links between the specialist and non-specialist palliative care providers enable better choices, experiences and outcomes.¹⁰ In particular, the increasing recognition of adverse neurodevelopmental outcomes in children with CHD³³ means that paediatric disability services are playing an evermore crucial role in the lives of many CHD survivors.

Introducing end-of-life discussions

A key element of the UK national CHD consultation standards is for communication and end-of-life care discussions to be open, honest and accurate.¹⁷ In a study of bereaved parents of children who died with advanced cardiac disease, around two-thirds described the quality of life of their child during the last month of life as 'poor' or 'fair'. Breathing and feeding difficulties were perceived as the symptoms causing the most suffering in children under 2 years old, whereas it was fatigue and sleeping difficulties that principally affected older children. Despite this, the same study found that most parents only realised that their child had no realistic chance of survival a median of two days prior to death, with some not realising this until death was imminent, or even up to the time of death itself.⁶ Reluctance to approach end-of-life discussions therefore means that families are often poorly prepared, and their children ultimately suffer a death that differs significantly from both their own and their family's goals for the end of life, including preferences for treatment and location of care. Conversely, in a study of bereaved parents of children with cancer, a perception of high-quality care was associated with parents' feeling prepared for the circumstances surrounding the child's death,³⁴ reinforcing the recommendation to approach end-of-life discussions in a routine way, close to the time of diagnosis if appropriate, and to continue this dialogue throughout the illness trajectory.³⁵ There is also clear evidence that this is in keeping with children's preferences.³⁶⁻³⁹

Involving children and young people in decision-making is important to provide choice and control for the child and their family.⁴⁰ Paediatric Advance Care Planning is a simple, structured way of facilitating decision-making and provides a framework for healthcare professionals, patients and their families to document and reflect on discussions about what might happen in the future.⁴² In addition, tools such as this may be particularly useful for the increasing numbers of children surviving into adulthood, in whom effective transition may depend on a pre-emptive, flexible and individually tailored approach.¹⁰¹⁷

Discussion

While mortality continues to fall for many forms of CHD, those children that do not survive tend to die with highly technical medical support at the end of life, frequently undergoing cardiopulmonary resuscitation within 24 h of their death.⁶⁷ Early access to palliative care for

patients with CHD could encourage a more comprehensive approach to physical and emotional well-being—from the point of diagnosis in some cases—with the potential to improve the patient and family’s experiences, promote better decision-making and ultimately enhance quality of life for all of those affected.

To deliver this, clinicians looking after children with severe CHD require increased training in facilitating advance care planning and addressing both quality-of-life and end-of-life issues. They require guidance as to when to involve specialist palliative care teams and a greater understanding of the myriad roles these teams can play. A recent study from a UK tertiary hospital found that late or non-referral to the paediatric palliative care team may be as a result of other healthcare professional’s association of palliative care only with death and dying;⁴³ a misunderstanding that must be modified. Indeed, the ethos of this type of care does not always need to be delivered by specialist teams; rather, it provides a structured way of delivering appropriate clinical care in a more holistic and supportive way, and there is now an established movement to provide a stronger emphasis on teaching palliative and end-of-life care in paediatric settings. This does not necessarily require a hefty allocation of resources, but rather a shift in the bias of paediatric training such that palliative care is always conceptualised as part of the care paradigm:³⁰ in short, that palliative care is not at odds with delivering concomitant therapies directed at cure or long-term survival.

The trend now is for the lessons learned by palliative care physicians to be reclaimed by everybody.

Smith⁴⁴

Conclusion

Advances in the diagnosis and treatment of patients with CHD have resulted in increasing survival into childhood and beyond for this complex set of patients. By allowing these children and their families early and consistent access to both specialist and non-specialist palliative care services, they can develop the means to accept and prepare for the possibility of premature death, and gain better access to more robust support in life, including improved symptom control and better informed decision-making. We owe it to our patients to seek and understand their personal context, and to evaluate their condition in light of their and their family’s individualised moral preferences.

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Box 1**The importance of cardiology in children with palliative care needs**

- ▶ Of all children with a life-limiting diagnosis between 2000 and 2010, 3.8% were classified as circulatory.⁸
- ▶ In 2013, 102 children in the UK aged 28 days to 15 years died from diseases of the circulatory system.¹²
- ▶ At present, it is expected that, at best, 70% of the newborns with hypoplastic left heart syndrome will reach adulthood.¹³
- ▶ The current UK single-ventricle population is estimated at around 1700 children, with a significant increase predicted in the coming years.¹⁴

Box 2**Barriers to end-of-life discussions in severe congenital heart disease (CHD)²⁰**

- ▶ Clinicians find the provision of end-of-life and palliative care to be more distressing in younger patients.
- ▶ The nature of the CHD community is such that it prides itself on advances in life-prolonging measures and hence professionals avoid ‘do not resuscitate’ discussions and other similar anticipatory planning.
- ▶ Some patients are awaiting transplantation that by definition keeps hope alive.
- ▶ Recognition of the dying phase is difficult in patients with CHD, and it can be difficult to define prognosis.

Table 1
Childhood conditions that may benefit from palliative care¹¹⁶

Group 1	Life-threatening conditions for which curative treatment may be feasible but can fail. Palliative care may be necessary during periods of prognostic uncertainty and when treatment fails. There may be acute crises where palliative care input is required, but on reaching long-term remission or following a successful curative treatment, palliative care services are no longer needed.
Group 2	Conditions where premature death is inevitable. Includes conditions requiring long periods of intensive care aimed at prolonging life and allowing participation in normal childhood activities.
Group 3	Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years.
Group 4	Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death.
