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Palliative care for children with complex cardiac conditions: survey results

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ABSTRACT

Objective To explore perspectives of paediatric cardiac and palliative care professionals on providing palliative care to children with complex cardiac conditions.

Design A national survey including closed-ended and open-ended questions as well as clinical scenarios designed to capture referral practices, attitudes towards palliative care, confidence delivering key components of palliative care and perspectives on for whom to provide palliative care. Responses to closed-ended questions and scenarios were analysed using descriptive statistics. Open-ended responses were analysed thematically.

Participants Paediatric cardiac and palliative care professionals caring for children with complex cardiac conditions in the UK.

Results 177 professionals (91 cardiac care and 86 palliative care) responded. Aspects of advance care planning were the most common reasons for referral to palliative care. Palliative care professionals reported greater confidence than cardiac colleagues with such discussions. Clinicians agreed that children with no further surgical management options, comorbid genetic disorders, antenatal diagnosis of a single ventricle, ventricular device in situ, symptomatic heart failure and those awaiting heart transplantation would benefit from palliative care involvement.

Conclusions Components of palliative care, such as advance care planning, can be provided by cardiac care professionals alongside the disease-directed care of children with complex cardiac conditions. Further research and training are needed to address confidence levels in cardiac care professionals in delivering components of palliative care as well as clarification of professional roles and parent preferences in delivery of family-centred care for children with complex cardiac conditions.

INTRODUCTION

Approximately 15%–20% of children with major heart conditions have high-risk complex cardiac conditions.¹ While survival rates for these children have improved,^{2,3} not all have a successful outcome.^{4–7} Death is more likely to occur in the first year of life, commonly in high-acuity settings following withdrawal of intensive therapies.^{5,8} Parents report significant suffering of their child at their end of life and may only realise their child was dying within their last 24 hours.⁴ Those who survive their first year do so with complex morbidity⁹ and ongoing possibility of early death.^{10,11}

Given these risks, there is an increasing call to provide palliative care alongside disease-directed

What is already known on this topic?

- Despite improved operative survival rates, children with complex cardiac conditions have a high burden of morbidity and risk of death in childhood.
- Palliative care delivered in parallel to disease-directed care is recognised as beneficial.
- The specific roles for palliative and cardiac care professionals delivering key components of palliative care to children with complex cardiac conditions are unclear.

What this paper adds?

- Children antenatally diagnosed with single ventricle disease, no surgical options, ventricular device in situ, comorbid disorders, heart failure or awaiting transplantation should have palliative care involvement.
- Identification of cardiac care professionals' self-reported lack of confidence in conducting advance care planning discussions with parents.
- Support for development and study of parental views of packages of care integrating principles of palliative care into care for children with complex cardiac conditions.

management.^{11–13} By planning disease-directed and palliative care in parallel, clinicians can better address parental concerns, improve parental well-being and broaden the focus of parent–clinician discussions.^{14–20} Specifically, palliative care professionals (PCPs) can support complex decision-making, particularly regarding advance care planning, and improve the quality of life for children with complex cardiac conditions and their families throughout the illness,^{10,11,13} not just at the end of life.

In the UK, children with complex cardiac conditions receive care in 1 of 16 paediatric cardiac centres, 11 with cardiac surgical facilities,²¹ including 2 with cardiothoracic transplant programmes. PCPs, predominantly nurses, largely provide direct care in community and hospice settings. Most medical PCPs are paediatricians or general practitioners with special interests in palliative care.²²

Despite increasing interest in incorporating palliative care into the care of children with complex cardiac conditions, referrals remain low^{4,23} and the

specific role of PCPs in this context remains largely unexplored. This study addresses this gap through an examination of current referral practices, attitudes, confidence levels and perspectives of cardiac care professionals (CCPs) and PCPs who provide palliative care to children with complex cardiac conditions.

METHODS

Study design

This national cross-sectional e-survey study was registered at the Great Ormond Street Hospital National Health Service Foundation Trust and was exempt from research ethics committee review. Deidentified data with no institutional-based linkage were collected.

Inclusion criteria

CCPs and PCPs, regardless of discipline, who care for children with complex cardiac conditions in the UK.

Recruitment

An invitation and secure email link were distributed to members of the: Paediatric Intensive Care Society Study Group, British Congenital Cardiac Association, Congenital Cardiac Nurses Association, Association for Paediatric Palliative Medicine and Royal College of Nursing's Children's Palliative Care Special Interest Group. Snowball sampling was encouraged. The survey remained open from 20 June 2018 to 31 August 2018.

The survey

The survey aimed to identify current practices, attitudes, confidence and perspectives of participants on providing palliative care to children with complex cardiac conditions. The survey (online supplemental file 1) was divided into six parts: (1) non-identifiable participant demographics, (2) palliative care referral practices, (3) attitudes towards palliative care and its key components, (4) confidence delivering key components of palliative care, (5) palliative care involvement in clinical scenarios, (6) open-ended questions exploring the appropriate time for referral, barriers to discussing goals of care when a child may have a poor outcome and additional comments regarding palliative care involvement.

Questions and topics included items used in previous surveys,^{8 24 25} new items, as well as clinical scenarios developed using existing literature¹⁰ in consultation with PCPs and CCPs. The surveys were hosted on SurveyMonkey.²⁶

Data analysis

Quantitative analysis

Descriptive analysis was performed using SPSS.²⁷ Data related to current referral practices were discrete response choices that were summarised according to percentage of either PCP or CCP who selected each response option. Data from questions related to attitudes towards palliative care and its key components, confidence delivering the key components and palliative care involvement in clinical scenarios were obtained from a 4-point Likert scale. These data, predominantly presented graphically, were summarised according to the proportion of responses made by PCPs or CCPs. A two-sided Mann-Whitney U test with continuity and tie corrections, with p value set at ≤ 0.05 , was used to test differences between responses of each group—PCPs and CCPs. We then dichotomised these data to analyse level of agreement/disagreement or confidence within each group. When considering the views of participants, we used an a priori level of 75% to indicate overall agreement/disagreement or confidence in each statement or activity. Statistical details

Table 1 Participant demographics

Characteristic	PCPs (n=86)	CCPs (n=91)	P value
Female	74 (87.1%)	72 (79.1%)	0.368
Clinical role			0.010
Nurse	37 (43.5%)	59 (64.8%)	
Doctor	46 (54.1%)	30 (33%)	
Other	2 (2.4%)	2 (2.2%)	
Specialty			
Hospital-based team	19 (22%)	–	
Community-based team	8 (9.3%)	–	
Children's hospice	25 (29.1%)	–	
>1 listed affiliation	11 (12.8%)	–	
Cardiology	–	37 (40.7%)	
Intensive care	–	46 (50.5%)	
Cardiac surgery	–	2 (2.2%)	
Other	14 (16.3%)	6 (6.6%)	
No response	9 (10.5%)	0	
Seniority*	63 (76.8%)	58 (65.9%)	0.130
Years in current position			0.124
<1	9 (11.5%)	7 (7.9%)	
1–3	19 (24.4%)	17 (19.1%)	
4–6	14 (17.9%)	20 (22.5%)	
7–9	15 (19.2%)	8 (9.0%)	
>10	21 (26.9%)	37 (41.6%)	
Conducts prenatal consultations	37 (47.4%)	11 (12.4%)	<0.001
Institution has separate cardiac ICU	27 (34.6%)	61 (68.5%)	<0.001

*Band 7 (senior clinical nurses, nurse managers) or higher or consultant position. CCPs, cardiac care professionals; ICU, intensive care unit; PCPs, palliative care professionals.

of results not presented graphically are in the text. Supporting numerical data are available in online supplemental file 2.

Qualitative analysis

Responses to open-ended questions were analysed thematically with reference to closed-ended questions and clinical scenarios thereby capturing both a priori themes from the survey and literature as well as newly emerging themes. Qualitative data analysis was managed in NVivo.²⁸

RESULTS

Participants

Two-hundred and one professionals commenced the survey. Thirteen did not go beyond the initial screening questions, eight did not answer any survey questions and three did not identify as PCPs or CCPs. Of the 177 included professionals, 86 identified as PCPs and 91 as CCPs. Demographics are described in [table 1](#).

Current palliative care referral practices

The most commonly reported reasons for referral of children to PCPs were for: assistance with preferred place of death discussions, advance care planning, symptom management, death/dying discussions or to aid parental decision-making ([table 2](#)).

There was no overall agreement among either CCPs or PCPs on whether referrals of children with complex cardiac conditions to palliative care were untimely.

Attitudes towards palliative care and its key components

There were significant differences between CCPs and PCPs not only in their views and attitudes towards palliative care, but also

Table 2 Reasons for referral to palliative care

Cited reason	Reported by cardiac care providers	Reported by palliative care providers
Preferred place of death discussions	73/74 (98.6%)	51/72 (70.8%)
Advance care planning discussions	70/74 (94.6%)	42/72 (58.3%)
Symptom management	67/74 (90.5%)	45/72 (62.5%)
To discuss death/dying issues with parents	64/74 (86.5%)	37/72 (51.4%)
Assist with parental decision-making	58/74 (78.4%)	33/72 (45.8%)
To discuss anticipated outcomes	54/74 (73%)	32/72 (44.4%)
Interprofessional conflict	47/74 (63.5%)	21/72 (29.2%)
Do-not-attempt resuscitation discussions	43/74 (58.1%)	32/72 (44.4%)

in its key components and impact on parental hope (figure 1). Both CCPs and PCPs reported that palliative care extended beyond the end of life phase (statement 1), the last weeks of life (statement 2) and could be instituted even when management had not yet been decided (statement 5).

While CCPs disagreed among themselves on the acceptability (statement 3) and impact of introducing palliative care on parental hope (statement 4), they agreed on its value as a support to clinicians (statement 9), when there was disagreement among professionals (statement 6) and in managing symptoms (statement 8).

Confidence in delivering key components of palliative care

Both CCPs and PCPs reported confidence in: discussing ‘goals of care’ (statement 1) and concerns over ‘death and dying’ (statement 3), ‘caring for a deteriorating child over hours to days’ (statement 4) and ‘providing care during the ‘end of life period’ (statement 8). PCPs were more confident than CCPs in the first three of these activities and also more confident in discussions around preferred place of death (statement 6). There was, however, no difference in confidence between PCPs and CCPs in providing care during the ‘end of life period’ (statement 8) (figure 2).

While PCPs reported confidence in discussing resuscitation with 16-year-old children, CCPs did not. Neither PCPs nor CCPs expressed confidence discussing resuscitation with 12-year-old children ($p < 0.001$ for both).

Both CCPs and PCPs reported similarly low levels of confidence in prognostication ($p = 0.27$). For both, this was the area of lowest reported confidence.

Palliative care involvement in clinical scenarios

CCPs and PCPs agreed that children with: no further surgical options (scenario 1), an antenatal diagnosis of single ventricle disease (scenario 2), a ventricular assist device in situ (scenario 3), a comorbid genetic condition (scenario 4), symptomatic cardiac failure from myocardial dysfunction (scenario 5) and those awaiting cardiac transplantation (scenario 11) should be referred to palliative care (figure 3). Of these, PCPs were more likely than CCPs to agree that babies diagnosed antenatally with single ventricle disease (scenario 2) and those with a comorbid genetic condition (scenario 4) should be referred to palliative care.

While there was lack of agreement among CCPs about whether a child with a prolonged intensive care unit stay (scenario 6), neonate with single ventricle disease proceeding to surgery (scenario 10) and those with lack of professional consensus over the treatment plan (scenario 12) should be referred to palliative care, there was no significant overall difference in these responses between PCPs and CCPs.

Although neither group agreed on palliative care involvement for a planned ventricular assist device (scenario 9), implantable cardiac defibrillator (scenario 8) or for a child receiving extra-corporeal membrane oxygenation (scenario 7), CCPs were more likely to agree with the statement that palliative care should be involved for a child being planned for a ventricular assist device.

PCPs were ranked by both CCPs and PCPs as the choice for assistance after a colleague in the same team, but before a clinical ethics panel in cases of disagreement about resuscitation status, or in cases where withdrawing artificial nutrition/hydration, further cardiac surgery, or tracheostomy insertion and long-term ventilation were being considered.

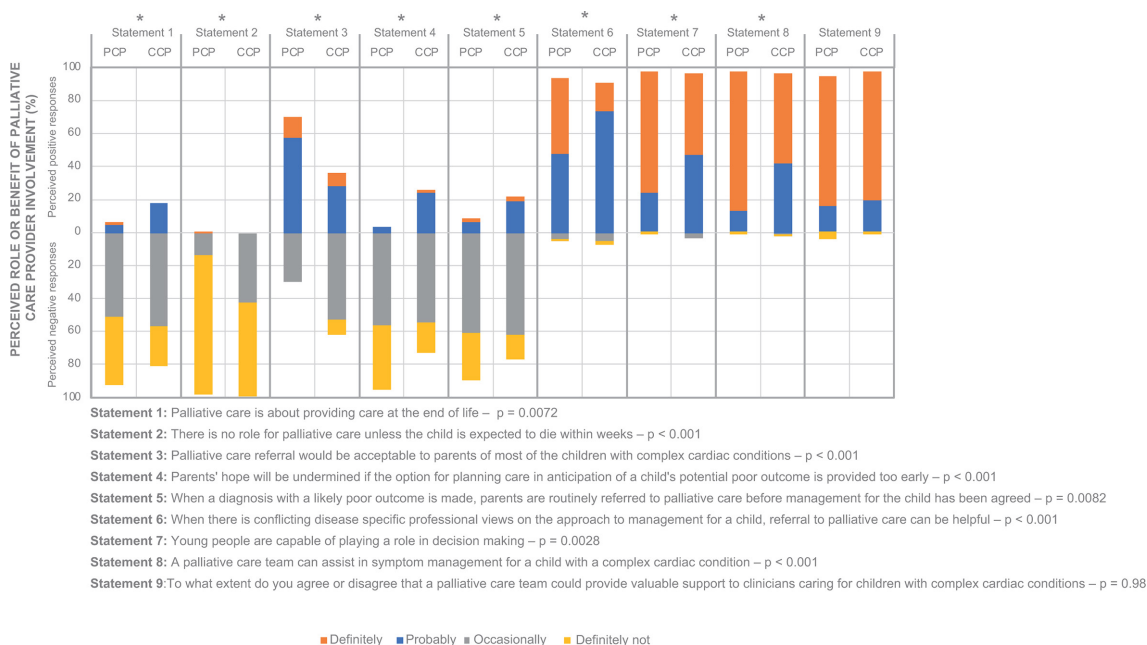


Figure 1 Attitudes towards palliative care. CCP, cardiac care professional; PCP, palliative care professional.

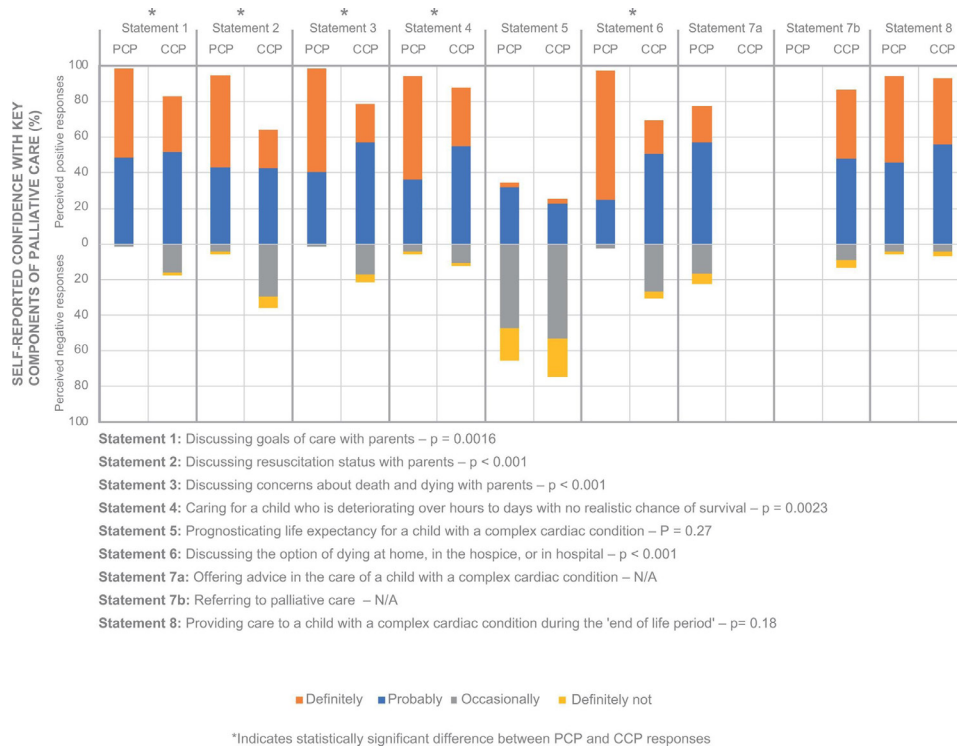


Figure 2 Self-reported confidence in delivering key components of palliative care. CCP, cardiac care professional; N/A, not applicable; PCP, palliative care professional.

Qualitative analysis

One-hundred and thirty-seven participants (69 of 91 (75.8%) CCPs; 68 of 86 (79%) PCPs) responded to one or more of the open-ended questions; elaborating on their responses to closed-ended questions regarding attitudes to palliative care, confidence in delivering palliative care and when to refer to PCPs.

Additional information not directly touched on in closed-ended questions included: (1) foregrounding quality of life as an indicator for referral; (2) nature of uncertainty and (3) management of parental hope.

While the term 'quality of life' did not appear in the survey (as meaning is variously interpreted²⁹), it was raised by both

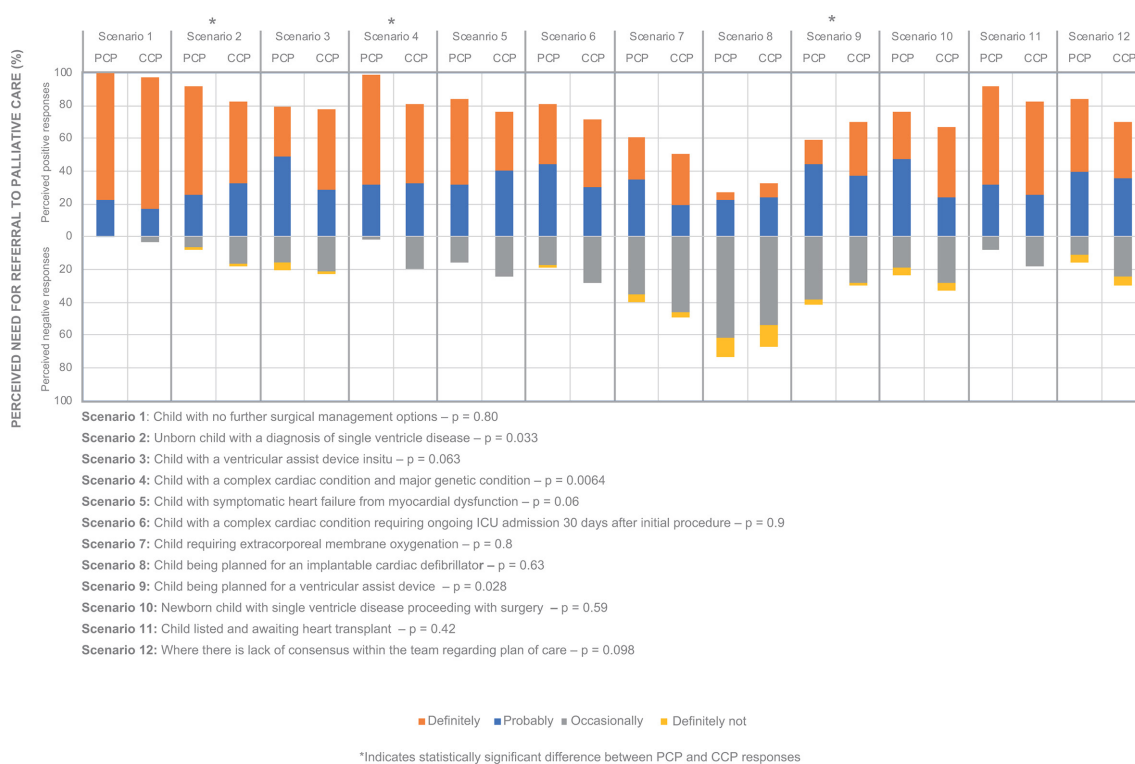


Figure 3 Referral practices related to clinical scenarios. CCP, cardiac care professional; ICU, intensive care unit; PCP, palliative care professional.

CCPs and PCPs as an indicator for referral. For example, referring a child *‘ideally when [the child] becomes unstable/quality of life is in question’* (CCP, <1-year experience in current role) or *‘at the point of diagnosis ... selling all the positive benefits about focusing on having the best life they can rather than approaching it from the end of life care perspective’* (PCP, 7–9 years of experience in current role).

The nature of uncertainty, particularly around surgery, as an indicator for referral to PCPs, was made more explicit in some responses. For example, in CCPs’ statements, while there was support for earlier referral, this was defined as when there were *‘no further surgical options’* (CCP, 4–6 years of experience in current role) or *‘at the point where treatment has ‘failed’* (CCP, >10 years of experience in current role). PCPs remarked on surgery, but more broadly, including risk and the future as in *‘when there is uncertainty about the future or [the child is] facing potentially risky surgery’* (PCP, 1–3 years of experience in current role).

Management of hope also figured in CCPs’ comments on referral, which should occur *‘as early as possible PROVIDING it is managed carefully with the families and that they are helped to see that this is not saying that we are giving up on their child’* (CCP, 4–6 years of experience in current role).

DISCUSSION

This study revealed significant agreement between CCPs and PCPs on when children with complex cardiac conditions should be referred to PCPs. There was also strong agreement on the roles of PCPs and their contributions to enhancing care. Given this strong support for referral to PCPs and specific indicators for doing so both in this study and others,^{4 8 10–13 24 30–32} why do we repeatedly see calls for earlier and greater referral to palliative care not only for children with complex cardiac conditions, but also for other life-threatening conditions?^{14 19 24 31 33–35}

We would suggest the solution to this conundrum lies in reframing the question from: *How can we achieve earlier and greater referral to palliative care?* to: *How can we achieve the benefits of palliative care in the face of conscious and unconscious individual and institutional barriers?* These barriers often establish a dichotomy between ‘fixing’ the child versus supporting best quality of life. Previous studies indicate that while parents prefer palliative care principles and practices integrated into their child’s treatment,^{36–39} they do not necessarily want to receive those services from PCPs. They prefer to receive them from their treating teams.

Building on CCPs and PCPs’ shared vision of which children would benefit, we would recommend integrated models of care for children with complex cardiac conditions such as that described by Moynihan *et al*⁴⁰ enhanced by PCPs providing an educative and supportive role to CCPs in such aspects of care as advance care planning. We hypothesise that with such an approach, CCPs will gain greater confidence in delivering essential components of palliative care as well as better management in face of deterioration and death. Moreover, parents will be able to have advance care planning conversations with those they want to—the treating team.^{36 37} Not inconsequentially such an approach may also enhance clinicians’ skills in other areas of practice including talking with parents and children about less charged issues, as well as reducing the risk of overwhelming the availability of palliative care resources.

Strengths and weaknesses/limitations of the study

This study was robust, involving senior multidisciplinary professionals matched in seniority in both groups, capturing

perspectives of those with valuable experience. Reflecting the field, the survey also included all potential providers of palliative care. As a national survey, the findings extend beyond practices and perspectives within a single institution.

To reach the greatest number of professionals, participants were recruited through national organisations and snowball sampling was encouraged. However, given this strategy, we cannot report the response rate. We recognise the potential biases within the sample, based on gender, given significant differences in medical and nursing respondents, limited number of cardiac surgical respondents and those from non-medical/nursing backgrounds. We agree that professionals who are interested in this area may have been more likely to participate, and note that those with different attitudes towards palliative care may not be represented in our sample. We acknowledge the implications that this lack of inclusion might have on planning service model innovations, and as such, hope future research will capture the variety of perspectives of individuals within institutions. In addition, we encourage further study of interpretations of quality of life, content of advance care planning discussions and how these might fit within cardiac treatment plans.

Aware of the inherent limitations in exploring perspectives through a survey, we used 4-point Likert scales, removing the neutral option, ensuring a more definitive response. The disparity in overall number of responses to closed-ended questions with multiple options and no requirement to rank responses was addressed through open-ended questions which provided opportunities for elaboration and clarification of closed responses. Finally, the survey was unique in inclusion of clinical scenarios which identified how CCPs applied their perspectives in practice and provided opportunities for PCPs to specify which children they could offer the most help with.

CONCLUSION

This study provides evidence-based guidance for integration and delivery of palliative care to children with no further surgical management options, comorbid genetic disorders, an antenatal diagnosis of a single ventricle, ventricular device in situ, symptomatic heart failure from myocardial dysfunction and those listed and awaiting heart transplantation. Further research and training are needed to address confidence levels in cardiac care professionals in delivering components of palliative care as well as clarification of professional roles and parent preferences in delivery of family-centred care for children with complex cardiac conditions.

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