

Infant deaths in the UK community following successful cardiac surgery: building the evidence base for optimal surveillance, a mixed-methods study

Katherine L Brown,^{1*} Jo Wray,¹ Rachel L Knowles,² Sonya Crowe,³ Jenifer Tregay,¹ Deborah Ridout,² David J Barron,⁴ David Cunningham,⁵ Roger Parslow,⁶ Rodney Franklin,⁷ Nick Barnes,⁸ Sally Hull⁹ and Catherine Bull¹

¹Cardiac Unit, Great Ormond Street Hospital NHS Foundation Trust, London, UK

²Population Policy and Practice Programme, University College London Institute of Child Health, London, UK

³Clinical Operational Research Unit, University College London, London, UK

⁴Cardiac Surgery Department, Birmingham Children's Hospital NHS Foundation Trust, Birmingham, UK

⁵National Institute for Cardiovascular Outcomes Research, University College London, London, UK

⁶Faculty of Medicine and Health, University of Leeds, Leeds, UK

⁷Paediatric Cardiac Unit, Royal Brompton and Harefield Hospitals NHS Trust, London, UK

⁸Department of Paediatrics, Northampton General Hospital NHS Trust, Northampton, UK

⁹Primary Care Department, Queen Mary University of London, London, UK

*Corresponding author

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Scientific summary

Infant deaths after cardiac surgery

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Scientific summary

Background

Early postoperative outcomes for children undergoing paediatric cardiac surgery have improved over the last decade because of many small incremental adjustments to the patient journey. Furthermore, such early postoperative outcomes for paediatric cardiac operations are subject to considerable scrutiny, especially in the UK. In contrast, postdischarge outcomes for infants with congenital heart disease (CHD) have to date been much less well understood, as has the performance of health services and postdischarge processes that contribute to longer-term survival. The motivation for this project was to explore and understand both the risk factors for poor postdischarge outcome for infants undergoing cardiac interventions and the health-care processes underpinning them, and hence to make a series of recommendations for improvement, the original study questions being:

1. Can a suitable surveillance programme or complex intervention be designed with the objective of decreasing mortality associated with infant cardiac surgery, by averting unexpected deaths in the community, subsequent to discharge after 'successful' surgery?
2. Can linkage of individual data from existing routine sources including both clinical and social information, from National Congenital Heart Diseases Audit (NCHDA) and Paediatric Intensive Care Audit Network (PICANet), improve our understanding of why some infants die or collapse at home following cardiac surgery?
3. Can the parents of infants with heart disease and professionals involved in postdischarge care better inform the follow-up and surveillance processes for infants in the community who have undergone cardiac surgery and help to identify barriers that may be impairing their access to health care?

Methods

Systematic reviews

The following two systematic reviews of the literature were undertaken.

1. Unexpected deaths and unplanned readmissions in infants discharged home after major surgery for congenital anomalies: a systematic review of potential risk factors: protocol registration PROSPERO CRD42013003483.
2. A systematic review of non-invasive interventions for infants discharged from hospital after major surgery for congenital anomalies: protocol registration PROSPERO CRD42013003484.

Quantitative analysis of national audit data

Records for all UK infants undergoing intervention for CHD between 1 January 2005 and 31 December 2010 were identified from NCHDA and linked to those individuals' intensive care admission records in PICANet. The procedure- and admission-based data sets from the two national audits were converted into a patient-based data set. A total of 115 children who had an excluded catheter procedure only, 765 premature babies who had ligation of patent ductus arteriosus only and 24 transplant patients were excluded from the analysis. A further 505 patients with unknown life status were removed, leaving 7976 remaining patients.

Logistic regression was used to develop risk models for:

Outcome 1: out-of-hospital death or death following emergency admission within 1 year following discharge.

Outcome 2: the combination of out-of-hospital death within 1 year following discharge and emergency readmission to intensive care ending in either survival or death.

Classification and regression tree (CART) analysis was used to identify patient groups differentiated by outcome 2.

Qualitative analysis

Helpline staff interviews (HLIs): semistructured interviews were conducted with 10 congenital heart charity staff.

Online discussion forum (OF): 73 participants joined an OF hosted by the user group Children's Heart Federation.

Family interviews (FIs): semistructured interviews were conducted with 20 families that had either lost an infant post discharge following paediatric cardiac surgery or had an infant readmitted to intensive care as an emergency.

Health professional interviews (HPIs): semistructured interviews were conducted with 25 tertiary health professionals (HPs) and 13 primary and secondary care HPs.

Qualitative analysis of these study data was performed using the Framework approach.

Intervention development

An expert advisory group was established to review evidence and propose interventions for improving services. It comprised professionals from three tertiary cardiac centres, representatives from primary care, secondary care and patient groups, as well as academics from the disciplines of psychology, statistics, epidemiology and operational research. Three members are trained in quality improvement methodologies. The group met on five occasions (each for 2–3 hours) between March 2013 and June 2014. The suggestions for service improvement were discussed at a workshop consisting of parents that participated in the FIs.

Through a facilitated process at the final meeting, the group generated a list of evidence-based interventions for future implementation or evaluation.

Results

Systematic reviews

Despite a broad search strategy for both reviews, studies meeting inclusion criteria pertained only to patients with CHD, in particular complex single ventricle conditions. Studies were predominantly from the USA.

Systematic review 1

Fifteen studies were eligible for inclusion. Risk factors identified as having a significant association with higher mortality or unplanned readmission were non-white ethnicity, lower socioeconomic status, comorbid conditions, age at surgery, operative complexity and procedure type, and postoperative feeding difficulties.

Systematic review 2

Eight studies were eligible for inclusion. The interventions of interest were home monitoring programmes (HMPs). Control patients were based on historic patient data in all studies. A range of clinical outcome measures (1-year outcome, interstage mortality, detection of clinical deterioration) showed improvement with HMPs in different studies.

Quantitative data

Of the 7976 patients meeting inclusion criteria, 333 [4.2%, 95% confidence interval (CI) 3.7 to 4.6] died within their index admission period and were excluded from our analyses, leaving a final data set comprising 7643 infants discharged alive from their index admission for paediatric cardiac surgery. Of these, 246 (3.2%, 95% CI 2.8 to 3.6) experienced outcome 1 and 514 (6.7%, 95% CI 6.2 to 7.3) experienced outcome 2.

Using multiple logistic regression analysis, risk factors for death within 1 year following discharge (outcome 1) were identified as age at procedure, weight z-score, cardiac procedure, cardiac diagnosis, non-cardiac congenital anomaly, clinical deterioration, prematurity (< 37 weeks' gestation), ethnicity and length of stay (LOS) in specialist centre.

When additionally including emergency readmissions to intensive care (outcome 2), preprocedure clinical deterioration was not significant, whereas neurodevelopmental conditions and acquired diagnoses were. Model discriminations for outcomes 1 and 2 were very similar, with area under the receiver operating characteristic curves of 0.78 (95% CI 0.75 to 0.82) and 0.78 (95% CI 0.75 to 0.80), respectively.

The CART analysis identified six patient groups differentiated by outcome 2 and defined in terms of the following patient characteristics:

1. neurodevelopmental conditions (24% outcome 2)
2. no neurodevelopmental conditions; low-risk cardiac diagnosis [ventricular septal defect (VSD)/other]; congenital anomalies; LOS in specialist centre > 1 month (24% outcome 2)
3. no neurodevelopmental conditions; high-risk cardiac diagnosis [hypoplastic left heart syndrome (HLHS), other types of functionally univentricular heart (UVH) or pulmonary atresia (PA)] (15% outcome 2)
4. no neurodevelopmental conditions; low-risk cardiac diagnosis (VSD/other); no congenital anomalies; LOS > 1 month (9% outcome 2)
5. no neurodevelopmental conditions; low-risk cardiac diagnosis (VSD/other); congenital anomalies; LOS < 1 month (8% outcome 2)
6. no neurodevelopmental conditions; low-risk cardiac diagnosis (VSD/other); no congenital anomalies; LOS < 1 month (3% outcome 2).

Qualitative data

This information is presented as a synthesis of the four qualitative data sources listed in the methods.

Training and information for families pre-discharge

Information overload: it is difficult for families to understand and absorb all of the information they are given (FI and OF).

Poor timing: information is often rushed before discharge (FI and HPI).

Insufficient training on 'signs, symptoms, responses': these are often missed, vague or unstructured, and no written material is given to take away (FI and HPI).

Barriers for non-English speakers: there is limited access to interpreters and most resources are only available in English (HPI).

Some families miss out: limits to the availability of resources may influence the content of training and information provided (HPI).

Discharge and transferring to non-specialist services

Poor access to local support services: it is difficult for specialist centres to know what local and community services are available and how to contact them, particularly when links are not well established.

Community teams are often short of resources (HPI).

Inadequate planning: discharge may occur at short notice and the content of a discharge package may be strongly influenced by the availability and accessibility of local resources, leading to variation across the country in terms of who is offered what follow-up care (HPI).

Poor-quality discharge letters/summaries: these are often very delayed, do not reach all HPs, contain too much specialist information and terminology and often do not include basic information, what to look out for and how to respond (HPI).

Ad-hoc planning for high-risk patients: in some centres there is no protocol in place for identifying high-risk babies and the (extra) care that is offered to them (HPI).

Medical follow-up services

Problems with clinics: clinics are often full and running late. Outreach clinics may not incorporate paediatricians and specialist nurses (FI and HPI).

Inconsistent specialist support between clinics: many families (particularly high-risk ones) get regular calls from cardiac liaison nurses, but some do not and can find it hard to get in touch with them (FI and HPI).

Variability and resource challenges: there are not enough paediatricians with expertise in cardiology (PEC) and often newly trained or less-experienced community nurses/health visitors (HVs) attend visits. Infants must have a medical need to get a community nurse but it can be difficult to maintain regular home visits from HVs, as the baby may not be considered high priority (HPI).

No protocol for HMPs: there is a large variation between centres in the provision of HMPs and the content thereof. Community professionals may not know how to respond to changes in the infant's condition. Some families find HMPs to be helpful, others find them to be a distraction or too complicated (FI and HPI).

Feeding/weight gain: many families find this a very stressful aspect of care. Lack of support and conflicting advice between HPs and difficulty in using nasogastric tubes were cited as reasons. (FI.)

Non-medical support

Practical difficulties: families sometimes experience practical difficulties in the community that may not have been identified prior to discharge. These include child care for siblings, access to transport, financial difficulties due to long hospital stays, debts, loss of earnings and inability to return to work. Some families struggle to adhere to medication regimes and can experience difficulty getting prescriptions because general practitioners are not always clear as to what has been prescribed or what to do about off-licence medications (FI, HLI and OF).

Fear and isolation: parents often live in fear of an emergency and the worry of infection isolates them from other parents and support groups in their community (FI and OF).

Families lack confidence: some families lack the confidence to approach or challenge HPs, fail to ask questions during appointments for fear of appearing ignorant or incapable or lack the ability to articulate their concerns (particularly non-English speakers) (HLI, HPI and OF).

The strain of 'expert parenting'/lack of confidence in local services: many families have to pass on information about their child's condition to HPs that do not have specialist knowledge and sometimes (as the holders of knowledge) feel they are battling with local services. Many families take on an 'expert parent' role, which can be alienating and frightening (OF, FI and HPI).

Insufficient psychosocial support: support offered to families is often purely related to the medical needs of their child with no specific protocol for assessing their psychosocial needs and resources harder to get for social support unless they meet criteria for safeguarding (FI, HPI and OF).

Patient information

Poor sharing of patient information: there are very few shared electronic patient record systems across services. Information is often relayed through the families, although there is inconsistency in the extent to which HPs use red books, hand-held records, health booklets, etc. (FI and HPI).

Not flagged or fast-tracked: there is often no formal system for flagging (high-risk) babies or for enabling them to have quick access to services (FI and HP).

Accessing support when a baby is sick

Not knowing 'signs, symptoms, response': parents and all local HPs are often unclear on what signs and symptoms to look for and how to respond, with insufficient guidance from specialist centres (FI and HPI).

Families not taken seriously: families sometimes find it difficult to verbalise their concerns, lack the confidence to seek help or do not feel listened to by HPs when they do (FI and OF).

Failing to seek specialist advice: sometimes local HPs fail to notify the PEC or specialist centre of an incident (deterioration) or contact them when there is a concern (FI and HPI).

Conclusions: suggestions for health care improvement

The following are recommended by the working group.

- All infants may benefit from a nationally standardised structured discharge document available to HPs involved in their care.
- Infants in high-risk groups, with HLHS, UVH or PA, neurodevelopmental conditions and/or LOS > 1 month, would benefit from 'step-down' care, that is discharge via their local hospital.
- Home monitoring may be beneficial for all infants with a primary diagnosis of HLHS, UVH or PA.
- All families and HPs are likely to benefit from the same clear guidance on 'what is normal' for that child, signs and symptoms to look for, how to respond and important contact numbers, for example in the form of a traffic-light tool.
- A nationally standardised checklist in order to plan, deliver and audit the provision of training and information for all families prior to discharge may be helpful to HPs.
- Review of all postdischarge deaths of infants outside a specialist centre may be best placed at a mortality and morbidity conference held within the relevant network.
- Peer support with other families, for example through social media or charity support groups, is suggested for those being discharged with their infant.
- The wider report provides detail of proposed metrics for processes and outcomes for use on the care quality dashboard, including additional clinical outcome measures for national audit.

Conclusions: recommendations for research

These include:

- further research and national consensus building is required to establish the optimal protocol, components and inclusion criteria for HMPs (if beyond those proposed above), including an assessment of resource implications
- additional health-care evaluation is required of the best format, applications and effectiveness of the proposed traffic-light tool, as well as an evaluation of the proposed structured discharge document, discharge checklist and step-down care. Cultural and language barriers should form part of this evaluation
- further research to establish the statistical and analytical steps required for routine audit of relevant outcome measures for this population, in particular postdischarge mortality rates, which should incorporate adjustment for case mix.

Study registration

This study is registered as PROSPERO CRD42013003483 and CRD42013003484.

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