

Review

The patient journey to home after major cardiac surgery in infancy

Kate L. Brown*, Liz Smith

Charles West Division, Great Ormond Street Hospital NHS Foundation Trust, Great Ormond Street, London WC1N 3JH, UK



ARTICLE INFO

Keywords:
Pediatric cardiac
Surveillance
Community
Cardiology

ABSTRACT

Major technological advances in pediatric surgical and intensive care in recent decades, particularly for neonates, have resulted in the survival of children with previously life-threatening congenital heart defects (CHDs) including those with significant comorbidities. Despite these positive steps forward, many cardiac infants remain medically vulnerable after surgery hence the process of discharge home as well as the period early after discharge are crucial phases in the patient journey. In order to ensure children achieve the best outcomes and parents are adequately supported in caring for them, preparation for discharge and the post discharge care should incorporate a range of important initiatives. These should include consideration of the risk profile of patient and family, their information and training requirements, the family psychosocial support needs as well as support barriers such as language. There may be a requirement for specialist training and equipment to meet the particular needs of the child's condition. It is important to share information about the child with health professionals outside the tertiary centre, as well as guidance on how to handle deterioration in the child's condition and follow up arrangements. There is evidence that enhanced surveillance with home monitoring programmes is advantageous however these are not always consistently deployed. There is a need for improved access to understandable information for professionals based outside the tertiary centre and the development and testing of parent led early warning tools.

1. Introduction

Major technological advances in pediatric surgical and intensive care in recent decades, particularly for neonates, have resulted in the survival of children with previously life-threatening congenital heart defects (CHDs) [1] and those with significant comorbidities [2]. Despite these positive steps forward, many cardiac infants remain vulnerable after surgery, and one reason for this is that certain CHD types necessitate a series of staged procedures in early life, with more brittle circulation types (single ventricle circulation with shunt dependent pulmonary blood flow) being the standard in the youngest babies [3]. Furthermore, infants with CHD are more likely than healthy infants to have feeding difficulties, failure to thrive [4] and serious medical conditions affecting other organ systems [5] and this can further complicate matters. It is important to note that children with CHDs who survive past their first birthday are subsequently at lower mortality risk later during childhood [6,7].

Historically, great emphasis has been placed on quantifying and exploring risk factors that impact upon early post-operative and in-hospital mortality and on improving treatment strategies within hospital care, including surgical techniques and post-operative management approaches, resulting in net benefit to patients. Less attention has

been paid to the risks and care pathways post discharge, although recently these have attracted more attention. The most notable example of quality improvement activity in this area is the case of hypoplastic left heart syndrome (HLHS), where teams from the USA have reported the benefits of enhanced surveillance known as home monitoring programmes (HMP) [8]. In fact preparation for hospital discharge and the early post-discharge period is a phase in the patient journey with obvious importance to patients and families, when optimisation of the care package is vital in order to ensure best outcomes. This holds true for a wide range of diagnostic groups across the spectrum of infant CHD, all of who may be at some risk of adverse post discharge outcomes [9]. Hence it is important to consider elements and stages of relevant care pathways in order to optimally prepare patients and parents for discharge home.

During preparations for discharge from hospital of infants who have undergone a major heart intervention, the following aspects require attention: the patient and family risk profile based on medical and psychosocial factors, general information and educational requirements, psychosocial support, specialist training and equipment to meet the needs of the child's condition, sharing of information about the child with health professionals outside the tertiary centre, guidance on how to handle a deterioration in the child's condition and follow up arrangements.

* Corresponding author.

E-mail address: Katherine.Brown@gosh.nhs.uk (K.L. Brown).

2. Risk factors for adverse events post-discharge

In order to achieve optimal outcomes post-discharge and to offer targeted support to vulnerable infants and their families at home in the community, it is important to understand the risk factors for these late outcomes.

A recent systematic literature review from Tregay et al. [10] identified individual baseline patient and family factors that carried higher risk of late post-discharge adverse events in infant CHD including minority ethnic groups, lower socio-economic status and non-cardiac malformations or genetic syndromes. Socioeconomic deprivation, assessed through measures such as household income, family income below the national poverty threshold, deprivation index of the residential area, and Hispanic ethnicity were highlighted as risk factors for mortality and unplanned hospital readmission in the USA [11]. Preterm birth, low birth weight and non-cardiac malformations were risk factors for mortality in a range of studies [12,13]. When cardiac diagnosis and procedural factors were considered, studies suggested that infants with more complex conditions and those undergoing palliative procedures were at greater risk of both late death and readmission [14,15]. Specifically considering HLHS, those infants with more severe variants were at higher risk of mortality and unplanned readmission. In children with single ventricle (SV) circulations undergoing staged palliative operations, older age at first procedure was associated with higher mortality risk whereas younger age at the second stage Glenn procedure increased the risk of later adverse events [16]. Findings from the Single Ventricle Reconstruction (SVR) trial, in which patients with HLHS were randomised to

receive different surgical interventions, higher mortality rates after hospital discharge were observed within the group receiving a modified Blalock-Taussig shunt compared with a right ventricle-to-pulmonary artery conduit; this difference was no longer significant when there was moderate to severe post-operative atrio-ventricular valvar regurgitation [12].

A further very important characteristic linked to poorer post-discharge outcomes within several studies featured in the systematic review is post-operative feeding difficulties, which was consistently identified as a risk factor for late mortality and unplanned readmissions [14]. Post-operative feeding difficulties are more likely in children with severe heart disease, associated comorbidities and neurodevelopmental problems [4] therefore these are a very important indicator that an infant requires close medical and nursing supervision.

A recent population based study by Crowe et al. [9], of nearly 8000 infants undergoing an initial CHD intervention between 2005 and 2010 in England and Wales showed that 333 (4.2%) infants died before discharge and 246 (3.2%) infants died outside hospital or following an unplanned readmission to the pediatric intensive care unit (PICU) within the first year after intervention, and a further 268 (3.5%) infants survived an unplanned PICU readmission. Risk factors for these adverse outcomes included younger age at surgery, lower weight-for-age at surgery, palliative cardiac procedures, more complex cardiac diagnoses, presence of congenital anomalies, pre-procedure clinical deterioration, prematurity, ethnicity and prolonged duration of operative hospital admission. A technique called Classification and Regression Tree

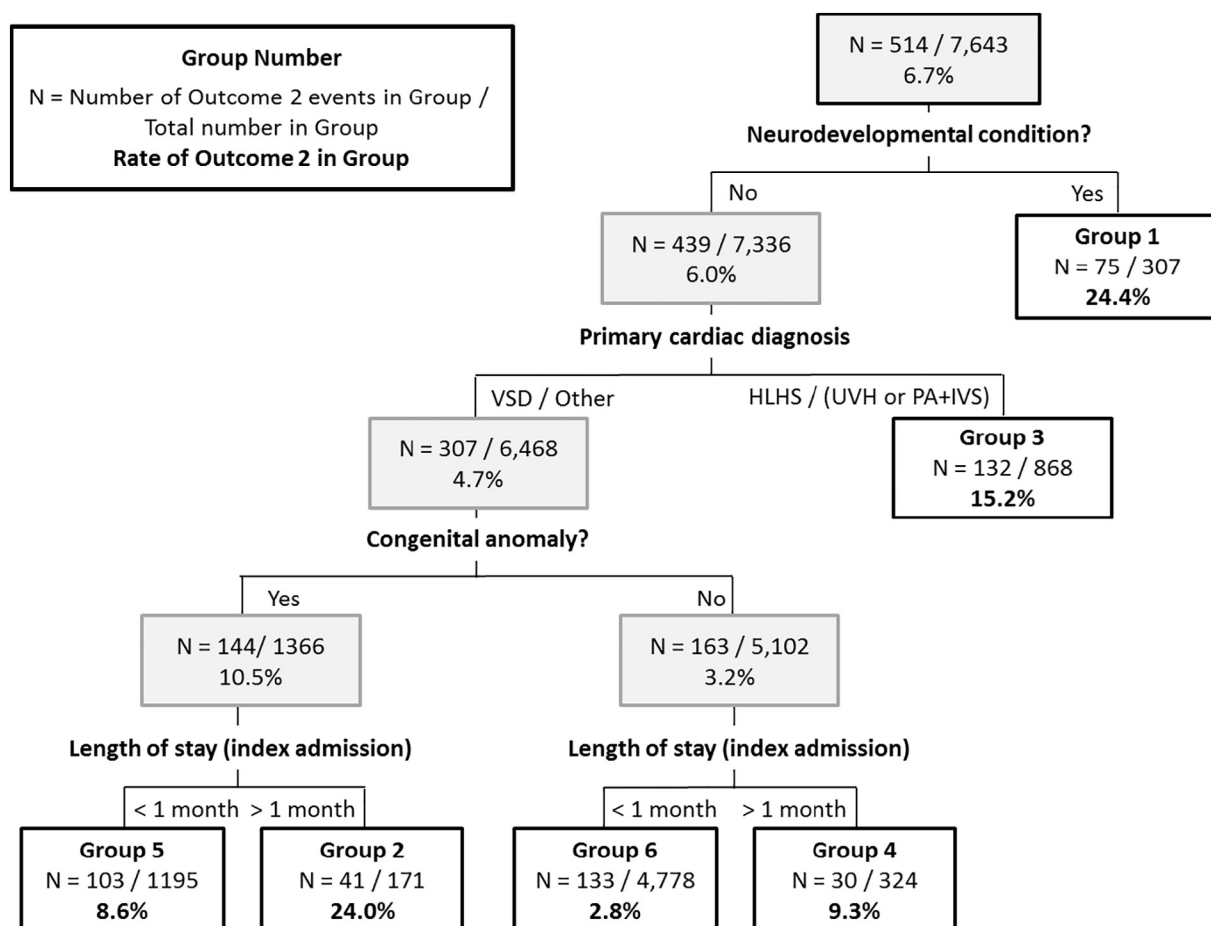


Fig. 1. Classification and regression tree analysis.

The figure shows a stratification tree generated by the classification and regression tree (CART) analysis in a population of infants after cardiac interventions from the UK, reproduced with permission from Crowe et al. [9] Outcome 2 refers to a combination of late post discharge deaths and unplanned readmissions to PICU. The number and rate of Outcome 2 events and the total number of patients is given for each node.

VSD ventricular septal defect, HLHS hypoplastic left heart syndrome, UVH univentricular heart not hypoplastic left heart syndrome, PA + IVS pulmonary atresia and intact ventricular septum.

Download English Version:

<https://daneshyari.com/en/article/8675331>

Download Persian Version:

<https://daneshyari.com/article/8675331>

[Daneshyari.com](https://daneshyari.com)