Enhancing discharge preparation for parents following their infant's complex cardiac surgery: Evaluation of an e-learning programme for children's cardiac nurses

Abstract: (n=149)

Background: Parents going home with their infant following cardiac surgery for complex congenital heart disease, need to be appropriately prepared and educated by knowledgeable professionals.

Aim: To equip children's cardiac nurses with the knowledge, skills and understanding required to teach parents about going home with their infant

Methods: A mixed methods quality improvement project during 2018-2021

Results: Participants perceived that the e-learning: clearly explained the learning expectations and they effectively achieved the learning objectives (n=94, 96%); enhanced their knowledge and understanding of complex congenital heart disease (n=93, 95%); and developed their understanding of an early warning tool (n=96, 98%).

Conclusion: Participants perceived the e-learning had a positive impact on their understanding and awareness of complex CHD, behaviour, activity, performance, and practice of preparing these parents. Future work will focus on developing a parental e-learning resource, and translation for non-English speaking parents.

Keywords:

Heart Defects Congenital, Parents, Decision Making, Quality improvement, Education, Distance

Background:

In 2020, congenital heart disease (CHD) was the most prevalent congenital anomaly (66.6 per 10,000, 95% CI 64.5– 68.7) in England, with 1242 babies born with severe cardiac defects (Public Health England 2022). Over 3000 cardiac surgical procedures were conducted in children during 2021-2022 and approximately 2000 of these are on infants in their first year of life (National Institute for Cardiovascular Outcomes Research 2023, 2023a). For some of these infants with more complex CHD, such as functionally univentricular hearts, several stages of surgery are required and the first year of life remains a critical time (Crowe et al 2016). Some centres will discharge infants with a home monitoring programme between the first and second stage of surgery; however, this requires appropriate parental preparation to ensure that they are able to safely care for their infant at home (*authors 2023*). Several studies have identified that parents of infants with CHD going home after surgery (between 2009 and 2013), were concerned about recognising deterioration in their infant (Tregay et al 2016a, 2016b, Twaddell et al 2013, *authors 2023*); however, recognising signs of deterioration promptly is essential to initiate timely decisions and to know who to contact for appropriate advice and support (*authors 2023*, Tregay et al 2016a, Brown & Smith 2018).

Authors (2016) qualitative study, found that parents felt unprepared for their discharge home with their infant following their first stage of cardiac surgery, and fewer than a third of mothers felt they understood everything about their infant's heart condition at the time of discharge. Furthermore, parents perceived that local healthcare professionals (HCP) were unprepared and needed to be educated about caring for an infant with CHD, especially in an emergency (*authors* et al 2016); this has also been identified elsewhere (March 2017, Wray et al 2018a).

The findings from an online survey and discussion group with parents during 2011-2013 indicated a gap in parents' understanding of signs of deterioration in their infant following complex cardiac surgery for functionally univentricular and systemic shunt dependent cardiac

lesions (*authors* 2016). This resulted in the development of a parental early warning traffic light tool, called the XXXX, for infants going home following first stage cardiac surgery or cardiac intervention during their first year of life (*authors* 2016). The XXXX tool was tested in a feasibility study during 2013-2015 (*authors* 2018). The tool (*authors* 2016) is based on a traffic light system divided into green (low risk), amber (intermediate risk), and red (high risk). The clinical parameters (e.g., expected oxygen saturations) are individualised by the Consultant. Prior to discharge, parents are taught to assess their infant's activity level, skin colour, breathing, circulation, feeding, and weight and to decide actions based on the information in the green, amber, and red columns. The aim is to prepare parents at least 5 days before discharge, confirming that they understand how to assess their infant. They are taught to assess their infant daily at home using the tool, or at any other time if their infant's condition has altered. Parents are also taught to understand the significance of the signs, to record their findings in a daily diary, and to contact HCPs as guided by the tool. An assessment of green specifies that parents can "continue as normal"; any sign in amber triggers a phone call to the ward to discuss management; any sign in the red column signifies the infant is seriously ill and parents are directed to phone for an ambulance immediately (*authors* 2016).

A subsequent multi-centred evaluation of the XXXX tool during 2016-2018, demonstrated its usefulness in both tertiary and community settings for HCPs and parents to escalate their concerns (*authors* 2022). An updated version of the tool called XXXX was created from the evaluation findings (*authors* 2022). Furthermore, participants identified that robust and nationally agreed training for all staff using the XXXX tool was necessary to ensure successful and complete implementation (*authors* 2022). Based on these recommendations, the XXXX e-learning resource was developed during 2019, with the aim of equipping HCP with the knowledge, skills and understanding required to teach parents about going home from hospital, using the XXXX tool, to monitor their infant.

Simultaneously, in 2019, a service evaluation was undertaken at the original study site to ascertain the impact of parental telephone calls, as the team had discontinued using the XXXX tool due to concerns about their workload. The nature and number of telephone calls to cardiac services were evaluated along with a survey to explore children's cardiac nurses' experiences of taking telephone calls from parents of children with CHD (*authors* 2023; *authors* 2023). Safety issues were identified from the telephone call evaluation, with approximately a quarter of calls concerned with significant clinical events or problems that required timely review and intervention (*authors*). Participants suggested that safety could be improved using a tool to structure communication, assessment, decision making, and documentation of parents worries and concerns (*authors* 2023). The *authors* recommendations, therefore, were to implement the updated XXXX tool in this tertiary cardiac surgical centre and to provide education for all nursing and HCP staff in the cardiac unit to ensure requisite knowledge, understanding and consistent application of the XXXX tool in practice (*authors*). The recently developed XXXX tool e-learning resource was, therefore, made available to staff in this tertiary centre.

This paper follows the SQUIRE guidelines (Ogrinc et al 2016) to report on the quality improvement project undertaken to develop, implement and evaluate the e-learning resource.

Materials and Methods:

The plan, do, study, act (PDSA) Quality improvement (QI) design (figure 1) (NHSE/NHSI 2021) was used to design and develop ('plan' April 2018 – April 2019), implement e-learning resource ('do' May 2019), evaluate the e-learning resource ('study' February 2020 – July 2022), implement the new XXXX in practice ('act' June 2021).

Ethical approval was obtained from the University of XXX College of Health, Life and Environmental Sciences Research Ethics Panel (XXX). The project was funded by the XX Learning, Teaching and Student Experience Fund (2017/2018), which focuses on funding

opportunities to enhance employability, enterprise, and entrepreneurship for students. Furthermore, the project aligned to the aims of the Teaching Excellence Framework (OfS 2020) and Research Excellence Framework (Research England 2021), by engaging in research based and technology enhanced learning, as well as aiming to make a transformative contribution to the lives of our students, staff, and people of the region.

Planning phase:

Planning this collaborative project involved a team of academics, students, clinicians, technologists, and Little Hearts Matter (a National CHD charity), to design and develop the XXXX e-learning resource. The e-learning resource was designed using the principles of Bloom's Taxonomy (Armstrong 2010), recognising different learning theories and styles (Bastable 2008) with the following learning objectives:

- To enhance knowledge and understanding of complex CHD, to teach parents how to spot signs of clinical deterioration in their infant whilst at home (remember and understand)
- To develop an understanding of the tool, who it is for, what it does, and why it is used (understand)
- To learn how to apply the tool XXXX when teaching parents prior to discharge (apply)
- To learn how to use the tool XXXX to support decision making when taking telephone calls from families at home (analyse and evaluate)

The team began by creating a framework for the content of the e-learning resource based on the learning objectives and a storyboard for each of the proposed videos. Clinical simulation methodology was used for the videos, with scenarios being role-played by the design team for the healthcare professional and parent roles. Using simulation to demonstrate use of the tool XXXX within the videos mimicked the environmental, physical, social, and psychological complexity of implementation in a clinical environment, where a parent is taking home their

fragile infant for the first time (Cheng et al 2014; LeBlanc et al 2011). The learning technologist recorded and edited the videos and supported creation of the e-learning resource using the software 'Articulate360' https://360.articulate.com/.

Implementation (Do) Phase:

The aim of this phase was to implement the e-learning resource to enable consistent education of nurses and HCPs who were involved in the preparation of parents and families for their infant's discharge. The e-learning resource was piloted by XX Children's Nursing and Paramedic students (n=3) and a staged implementation strategy was planned for 2019-2020. The final version of the e-learning resource was uploaded as a SCORM package to modules within the XX student learning environment (Blackboard 9.1) and made freely available with a Commons Attribution Licence via the XXX website, without a means to track the number of people accessing the resource. Additionally, all children's cardiac nursing staff at the tertiary cardiac surgical centre (n=54) were given a 7.5-hour study day to undertake the XXXX e-learning between February 2020 and June 2021.

The e-learning resource was formally disseminated and publicised through the XXX newsletters, social media and presented at several national and international conferences. In December 2021, the project team were contacted by Health Education England for permission to include the XXXX e-learning resource in the Guide to Cardiovascular Disease (CVD) Training Resources, and is now also available via e-learning for healthcare.

Results

Evaluation (Study) Phase:

The objective of this phase was to evaluate the knowledge mobilisation occurring as a result of accessing the freely available e-learning resource by:

- Identifying which professional groups were accessing the e-learning resource and their geographical location to map implementation of the tool XXXX discharge strategy across the UK and potentially internationally.
- Identifying how they heard about the e-learning resource and why they had accessed it, to ascertain whether this was part of a planned implementation within their cardiac network or individual professional development.
- Ascertaining how they had accessed it e.g., laptop, desktop, tablet, smartphone to gather information about ease of access, usability, and flexibility.
- Ascertaining whether the e-learning resource had met their learning needs regarding the XXXX discharge strategy, whether there are any improvements required to the e-learning resource.
- Ascertaining whether using the e-learning resource had led to or would lead to change of behaviour and/or practice.

An online survey design was used. The questionnaire including quantitative and qualitative questions, was developed, and piloted by XX Children's Nursing and Paramedic students (n=3) for ease of access, speed and convenience, and the final version of the questionnaire was made available in JISC Online surveys (2019). The first question of the online survey asked participants to consent and was mandatory to continue with the questions. The URL link to the survey was embedded into the final page of the XXXX e-learning resource and the survey status was left open, as access to the XXXX e-learning tool is still freely available. Descriptive statistical analysis using Microsoft Excel was undertaken of the quantitative data and thematic analysis (Braun and Clarke 2006) of the qualitative data.

Ninety-eight responses to the evaluation survey were received between February 2020 and July 2022. Participants were nurses (n=49) Consultant Paediatric Cardiology (n=2); students

(n=39); other/not known (n=8). Most participants were from Birmingham (n=53) or Worcester (n=39) (table 1). All participants (100%) agreed that the e-learning resource clearly explained what they were expected to learn. Perceptions of the accessibility, usability, design of the e-learning resource are presented in figure 2. The perceived relevance of each section (learning outcome) for learning is presented in figure 3. The e-learning resource took a varied amount of time to complete, the shortest being 25 minutes and the longest being nine hours (mean [hours] 3.4, SD 2.3).

Half of participants (n=50, 51%) indicated that using the e-resource would lead to a change in behaviour or practice; a quarter of participants (n=25, 26%) did not answer this question. Four themes emerged regarding the impact of the learning on awareness, behaviour, and practice: parental education and improving parents' confidence, structuring telephone calls with parents, enhancing own knowledge and understanding, implementing the XXXX tool; example quotes are shown in table 2. The benefits of completing the e-learning resource included: the visual resources and simulation videos, learning at own pace, the structure, organisation of e-learning resource and availability of resources and improving knowledge (table 3).

The limitations of the e-resource were perceived as not being able to access some of the articles, too much information and although the e-learning resource was built to allow you to re-visit at any time and to skip to the section where you left off, one respondent said: "*When logged off laptop did not save and continue where left off*" (P40, nurse) and another said "*It doesn't save the progress if you need to turn your laptop off so had to do half of it all over again*" (P65, student) (table 3).

Act Phase

In collaboration with the cardiac surgeons, cardiologists and nurse managers in the tertiary cardiac surgical centre, a plan was created to implement the updated XXXX (*authors* 2022) in

2020, However, due to the COVID-19 pandemic implementation of the tool XXXX was postponed until June 2021. It has been used consistently since to prepare this group of parents of infants with complex CHD for discharge and home monitoring. A service evaluation of the implementation of the XXXX tool between 2021-2023, as well as parent and staff experiences, has recently been completed and will be presented in a separate paper.

Discussion

We believe that this is the first paper to report on the development and evaluation of an e-learning resource created to help nurses and HCPs to prepare parents for discharge from hospital with their infant after the first stage of complex cardiac surgery. The aim of the QI project, equipping nurses and HCPs with the knowledge skills and understanding of complex CHD, using the tool XXXX to teach parents about what is normal for their infant and using the tool XXXX to take telephone calls, was met.

This project adds to the current dearth of literature by being the first to specifically address the educational needs of children's cardiac nurses and how to adequately prepare parents for discharge with their fragile infant. Other published studies focus on educational elements of family-centred care within the hospital setting, rather than the transition from hospital to home. For example, Dean et al (2021) recognised a lack of consistency in the implementation of a model of family-centred care and undertook a clinical education project to increase nurses' knowledge and decrease perception of barriers of the model. The educational programme implementing the model, improved their understanding and helped them to integrate developmental care interventions for the infants in the cardiac centre. Another model of care was described by Shackleford et al (2023); they explored nurses' perceptions of a novel rooming-in programme for infants with complex CHD. The rooming-in programme was developed and implemented in response to a nursing evidence-based practice project

addressing caregiver knowledge and improved involvement of carers in their infant's care. Whilst Shackleford et al (2023) were not reporting an educational programme for the nurses, nurse outcomes were perceived to improve because of the rooming-in programme; increased caregiver confidence resulted in increased nurse confidence and satisfaction. Furthermore, using a teach-back method, improved nurses' confidence in knowing they had effectively taught care-givers vital skills before discharge. Likewise in our project, participants' qualitative feedback indicated a perceived improvement in knowledge, understanding and confidence by using the tool XXXX to structure their pre-discharge care of infants and their parents, and telephone communication.

Campbell (2015) recognised that providing education for nurses working in paediatric intensive care units (PICU) to develop and update skills and knowledge required to care for infants with CHD following open heart surgery is challenging. Campbell and colleagues undertook a learning needs assessment of each PICU nurse to individualise their education programme using classroom and simulation-based activities, with complex scenarios created for the most experienced nursing staff. Participants perceived the simulation environment as a safe way to learn new skills and practices, whilst having the opportunity to discuss any concerns or fears.

In our project, participants particularly liked the simulated scenarios presented as videos and perceived these to be beneficial in terms of learning how to teach parents to use the tool XXXX, as well as how to manage receiving a phone call from a concerned parent. The clinical simulation method enabled participants to consider how they could use the tool XXXX in practice, whilst demonstrating a consistent and effective approach to preparing parents for discharge. A strength of our QI project has been the inclusion of children's nursing students in the design and development of the e-learning resource. They had some awareness of parents' experiences without the depth of specialist cardiac knowledge and were, therefore, able to approach the video storyboarding from a different perspective to those in the design team with

many years of experience. Furthermore, making the e-learning resource available to a variety of healthcare professional students within their undergraduate and postgraduate courses has made a transformative contribution to their academic and clinical development.

The PDSA cycle is currently being repeated to include evaluation of the impact of the programme of change (re-implementation of the tool XXXX) at the tertiary surgical cardiac centre and its successfulness.

Limitations

Whilst the XXXX e-learning resource was communicated with all HCPs within one tertiary cardiac surgical centre, only nurses (n=54) at this centre were given study leave to complete and evaluate the e-learning resource. Of the total participants, n=47/98 (48%) were nurses from this centre and n=6/98 (6%) were from this centre but did not give their professional role. Nurses generally are the HCPs preparing parents for discharge with their infant, however, other HCPs could take telephone calls from parents and, therefore, were told about the e-learning resource to understand the tool XXXX and how it should be used. The e-resource has also been made available to university students on a variety of healthcare courses and has been independently accessed by nurses and doctors from other geographical locations.

~~Likewise,~~ Inclusion of the e-learning resource in academic modules by course teams was mainly focused on the Midwifery and Physician Associate courses. Communication with other course leaders (Children's Nursing, Advanced Practice and Paramedicine) to remind them of the resource has since taken place. There are some amendments needed to the XXXX e-resource and these are continually being reviewed and actioned based on feedback from users.

We were originally unable to track the number of people viewing the e-learning resource, and this meant that we could not calculate the evaluation survey response rate based on usage.

However, we have now identified a way to track access, and this will be useful for ongoing evaluation.

Conclusion

The aim of the QI project, equipping nurses and HCPs with the knowledge skills and understanding of complex CHD, using the tool XXXX to teach parents about what is normal for their infant and using the tool XXXX to take telephone calls, was met. Participants perceived the e-learning had a positive impact on their understanding and awareness of complex CHD, behaviour, activity, performance, and practice of preparing these parents.

There was evidence from the survey responses that the tool XXXX is being considered for implementation nationally and internationally, demonstrating wider reach and collaborations.

Recommendations

- Further educational preparation is needed for HCPs to ensure consistency of parental teaching and preparation about the XXXX tool.
- Parents' perceptions of their preparation for discharge using the XXXX tool, need further evaluation.
- Future work needs to focus on developing a parental version of the XXXX tool e-learning resource to ensure consistency of preparation.
- Future work needs to focus on translation of the tool XXXX for non-English speaking parents, as there is a high incidence of CHD in black and minority ethnic populations (Knowles et al, 2017) and educational, financial, and language barriers present challenges during discharge planning of parents (Wray et al, 2018b).

Implications for Practice

- These infants are particularly vulnerable to sudden cardiac events at home and parents are anxious about what to do and who to contact for advice.
- Parents going home with their infant following complex cardiac surgery need to be appropriately prepared, educated and empowered to care for their infant
- An e-learning resource can effectively increase nurses' and HCP' knowledge, skills and understanding required to teach parents about going home with their infant.
- Educating parents about how to assess and monitor their infant whilst at home, and the importance of timely and structured communication with HCPs if their infant's condition changes, is essential.
- The XXXX e-learning resource is freely available via xxxx or via the Guide to Cardiovascular Disease (CVD) Training Resources e-learning for healthcare

Acknowledgements:

XXX Children's Nursing Students, University of XX

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Reviewer: Suzie Hutchinson, Chief Executive, Little Hearts Matter

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Figure captions

Figure 1 PDSA cycle

Figure 2 Accessibility, usability, and effectiveness of the CHAT2 e-learning resource

Figure 3 Relevance of each CHAT2 e-resource section for learning