Cardiology in the Young

cambridge.org/cty

Development of feeding information for infants with CHD

Luise V. Marino[1,2,3], Mark J. Johnson[2,3], Natalie J. Davies[1], Catherine Kidd[1], Trevor Richens[4], Tara Bharucha[4] and Anne-Sophie Darlington[5]

[1]Department of Dietetics/SLT, University of Southampton, Southampton, UK; [2]NIHR Biomedical Research Centre Southampton, University of Southampton, Southampton, UK; [3]Neonatal Medicine, University of Southampton, Southampton, UK; [4]Paediatric Cardiology, University of Southampton, Southampton, UK and [5]University Hospital Southampton NHS Foundation Trust and School of Health Sciences, University of Southampton, Southampton, UK

Original Article

Cite this article: Marino LV, Johnson MJ, Davies NJ, Kidd C, Richens T, Bharucha T, and Darlington A-S (2019) Development of feeding information for infants with CHD. *Cardiology in the Young* **29**: 1165–1171. doi: 10.1017/S1047951119001665

Received: 23 April 2019
Revised: 8 June 2019
Accepted: 18 June 2019
First published online: 5 August 2019

Keywords:
CHD; infants; feeding; information; parents

Author for correspondence:
L. V. Marino, University Hospital Southampton NHS Foundation Trust, Southampton, JK S016 6YD, UK. Tel: + 44 (0) 23 8079 6000; Fax: 023 8120 3087.
E-mail: Luise.marino@uhs.nhs.uk

Abstract

Introduction: Infants with CHD often experience growth failure. Ensuring optimal growth before surgery is associated with improved outcomes and has emerged as a significant cause of parental stress. Parents have reported a perceived lack of accessible feeding information for infants with CHD. To address this gap, the aim of this study was to develop feeding information to better support parents. *Materials and methods:* A search for existing material on six electronic databases and an internet search for unpublished (grey) literature on feeding information for infants with CHD were carried out. Following the development of feeding information, semi-structured interview(s) with parents/health-care professionals were completed, focusing on whether the information was easy to understand, relevant, provided sufficient information around feeding/feeding difficulties, and whether there were any information gaps. Iterative changes were made to the information following each interview. The process was completed until thematic saturation was achieved. *Results:* A total of 23 unique articles were identified of which 5 studies were included. From the grey literature, four web pages were reviewed. A total of 22 parents and 25 health-care professionals were interviewed. All parents/health-care professionals felt that the feeding information developed provided sufficient information; however, many wanted information on how to introduce complementary food, particularly if weaning was delayed. *Conclusions:* This study describes the development of feeding information for infants with CHD. From parent interviews, gaps identified focused on the introduction of complementary foods and uncertainty regarding the feeding journey beyond surgery.

CHD represents one-third of all major congenital anomalies,[1,2] of which around 4000 in England will require surgery per annum.[3] Although there have been significant improvements in the medical and surgical management of infants with CHD leading to improved outcomes,[1,3] there are still significant burdens to families of infants with CHD, particularly emotionally.[4]

Whilst most infants are in the normal range for weight at birth,[5] many experience growth failure during the first year of life before surgery,[6–8] increasing the risk of mortality.[9,10] Ensuring infants achieve optimal growth has emerged as a significant cause of parental stress.[11,12] In addition, parents report that receiving conflicting messages (particularly around feeding, e.g., what type of feed and food enrichment), from health-care professionals, is one of the causes for their distress.[11,13] In order to improve growth amongst infants before surgery, we recently developed a consensus-based nutritional pathway providing a structured approach for the nutritional care of infants with CHD awaiting surgical palliation or repair.[14] As part of the work completed for that study, parents reported "feeling" frustrated with the lack of written material about feeding of their infants with CHD. They felt feeding information freely available for healthy babies did not address common symptoms their infants experienced, such as vomiting, feed refusal, and poor growth, leading to feelings of isolation.[11,13] The aim of this study was to develop feeding information to fill this gap.

Methods

An iterative process of semi-structured interviews (as described by Kallo et al[15]) was used to develop the feeding information for parents. In short, we first identified some of the key areas that thought to be concerns for parents about feeding of infants with CHD by conducting a literature review and data synthesis, planned a semi-structured interview guide to be used as part of the iterative process with parents and health-care professionals, pilot tested the interview guide for parents and health-care professionals with two dieticians not involved in paediatric cardiology, and completed the interviews using the semi-structured interview guide making iterative changes to the parent information.

© Cambridge University Press 2019. This is an Open Access article, distributed under the terms of the Creative Commons Attribution licence (http://creativecommons.org/licenses/by/4.0/), which permits unrestricted re-use, distribution, and reproduction in any medium, provided the original work is properly cited.

CAMBRIDGE UNIVERSITY PRESS

Literature review

As a first step, we complete a literature review of any existing feeding information for infants with CHD, as well as qualitative studies focusing on feeding issues amongst infants with CHD in the scientific literature, in order to identify areas for development. A search strategy was developed in consultation with an information specialist and included a number of key terms: "congenital heart disease" AND "feeding information" AND "diet" AND "infants" AND "parents" which were adapted for searching each database. NICE Healthcare Databases Advanced Search website (https://hdas.nice.org.uk/) was used as a tool for multiple searches within multiple databases including the Cumulative Index to Nursing and Allied Health Literature, PsycInfo, and Medline. Searches were also undertaken in PubMed, the Cochrane Library, and the NHS Evidence. Forward and backward citation searching was completed on studies describing dietary and feeding information for parents of infants with CHD. Studies were excluded if they focused primarily on nutrition and perioperative nutritional support, during admission to the ICU following surgery.

Data extraction for quantitative studies included the sample size, methodology, outcome measures, intervention, and recommendations. Data extraction for qualitative studies included methodology and information relating to any theoretical framework. Data synthesis was completed using an established thematic analysis approach.[16] Using this approach, the descriptive aspects about the population of interest were extracted into a data extraction form which included information about methodology, outcomes, and any coded recommendations made. Within the grey literature, information related to feeding advice, support, and other recommendations was coded. These codes were then grouped into a number of categories and then grouped again into sub-categories. The key overarching categories were then developed based on this. An information booklet entitled *Information on Feeding Infants with Congenital Heart Disease* and a recipe book *For Babies Who Need to Make the Most Out of Every Mouthful* were developed.

Interviews with parents

The inclusion criteria were parents of an infant/child with CHD that had required surgery in the last 5 years at Southampton Children's Hospital Regional Cardiac service. Prospective parents were identified by a paediatric cardiac liaison nurse and paediatric dietitians (LM, ND, and CK). A letter of invitation was sent along with a parent information sheet. LM, ND, and CK contacted parents via telephone, 10 days after the invitation letter and parent information sheet were sent. If parents confirmed their interest in participating they were invited to participate in small group or individual interviews (depending on parental availability) and preference. Informed consent was taken prior to the interview. Bereaved parents and parents of children with CHD $\geq$ 6 years of age were excluded. Interviews for parents focused on whether the feeding information developed was easy to understand, was relevant to the parents' concerns, provided sufficient information about feeding/feeding difficulties, and whether there were any perceived gaps in the feeding information.

Health-care professionals

Health-care professionals working in Paediatric Cardiology from Southampton Children's Hospital Regional Cardiac Service were also approached to be interviewed to gain their feedback on the information being developed and whether they felt the information was perceived to be relevant for infants with CHD, contained sufficient information relating to feeding, and whether there were any clinical gaps in the information. Health-care professionals were identified by LM, ND, and CK. A study information sheet was provided along, and if they confirmed their interest in participating they were then invited to attend a small group interview or individual interview, depending on their availability and preference. Informed consent was taken prior to the interview. Following informed written consent, patients were provided with copies of the parent feeding information for their comment.

Interviews

Up to 20 parental and 20 health-care professionals' interviews were planned or until thematic saturation was reached. The interviews were planned to be split into blocks of five parents, followed by five health-care professionals, which were then repeated to ensure that iterative changes from each stakeholder group were incorporated into the parental feeding information. This process was continued until thematic saturation was reached, and no new suggested changes were reported.

Parents were not specifically asked to provide information about their child's feeding experience, although all parents chose to elaborate. Detailed notes were taken by LM during each interview, which were used to make iterative changes following each interview. Revised feeding information was then used in subsequent interviews with parents and health-care professional groups, which continued until thematic saturation was reached. Charts of the interview notes were made including verbatim quotes to aid interpretation and ensure key themes were systematically reviewed.[16]

Review of feeding information by the British Dietetic Association Paediatric Cardiology Interest Group

As a final step, once the feeding information had been developed, the information was circulated for review to the members of the British Dietetic Association Paediatric Cardiology Interest Group who are all paediatric dieticians from tertiary surgical paediatric cardiac centres. Further iterative changes were made, and the process was completed when no further comments or new information was suggested by the Paediatric Group.

This study was approved by an NHS ethics committee (North West – Greater Manchester Central, reference 17/NW/0490).

Results

Dietary information search and development of feeding material for parents

The literature search identified 23 unique articles, and the full text of each study was reviewed as per the inclusion criteria and resulted in 5 studies.[11,17–20] From the grey literature search, four web pages describing feeding strategies were identified providing parent information. Using thematic analysis of the findings from the 5 studies and 4 web pages,[21–25] 24 descriptive codes were identified during the data extraction (Table 1). These were grouped into eight sub-categories, which were distilled into four overarching interdependent categories from which the dietary material was developed: growth before surgery,[17–19,26] how to feed your baby – experience of feeding,[11,17,19,20] feeding problems and

https://doi.org/10.1017/S1047951119001665 Published online by Cambridge University Press

Table 1. Development of codes, sub-categories and overarching themes

Initial coding (n=24)	Sub-categories (n=8)	Overarching themes/categories (n=4)
Meeting nutritional requirements Cardiac surgery Growth Morbidity Mortality Feed as focus	Growth Surgical outcomes	Growth before surgery[1-8]
Family atmosphere at mealtimes Scheduling of feeding Formula feeding Breastfeeding	Mealtimes Feeding	How to feed your baby - experience of feeding[1, 7, 9, 10]
Parental stress and anxiety Frustration Social isolation Strains/ stress Support Time taken to feed Fatigue Poor appetite Nasogastric tube feeds Vomiting Gastro-oesphagael reflux disease	Family functioning Insufficient and inconsistent support	Feeding problems and symptoms[2, 9, 10]
Feeding difficulties Lack of information and support Ways in which to increase calories	Feeding difficulties and symptoms Feeding experiences	Additional information on enriching food[4-8, 10, 11]

symptoms,[11,18,20] and additional information on enriching food.[20–25] In addition, we incorporated information from the consensus nutritional pathway for infants with CHD before surgery, previously developed by our research group.[14]

Parent and health-care professional interviews

In total 22 parents and 25 health-care professionals were interviewed: paediatric dieticians (n = 12), paediatric cardiac nurse (n = 5), doctor (paediatric cardiology/general) (n = 5), speech and language therapist (n = 2), and psychologist (n = 1).

All parent interviews were conducted face-to-face by a single researcher (LM). Regarding the children of recruited parents, 16 had undergone corrective surgery, 4 received palliative surgery, and 2 were awaiting surgical repair. Two interviews were conducted as small groups of three parents each; two interviews as mother and father, and the remaining 12 parents as individual interviews, at the parents' request. The majority of parents were white British (n = 18), with the remainder Asian/Asian British (n = 3) and mixed ethnicity (n = 1). Other demographics including age, socio-economic status, and educational attainment were not captured. No further changes were made to the parent information once thematic saturation was achieved. In total, 55 iterative changes were made to the feeding information.

All children (bar two – who were still waiting for a surgical date) underwent surgery between March, 2013 and May, 2018. Post-surgery, all children were discharged to home directly from the specialist surgical centre. Prior to surgery, half of the infants (n = 10) required nasogastric tube feeds to support adequate nutritional intake, three required a long-term feeding tube in the form of a percutaneous endoscopic gastrostomy with one needing a jejunal extension and had support from a variety of health-care professionals (Table 2).

Overarching themes

Common issues identified by parents such as growth before surgery and how to feed your baby have been described in the literature[17–19,26]; however, there was a new theme which included information on age appropriate complementary feeding advice.

Starting complementary food and ways in which to increase energy intake

A theme around commencing complementary food for infants was an aspect of infant feeds, to the authors' knowledge has not previously been described. Parents reported that the limited feeding information available focused only on milk feeds and not complementary food. Parents felt that introducing solids was often forgotten by health-care professionals, and they were not able to find any information about weaning, how to do and when to start complementary foods, and what to add to complementary food to enrich them. Parents reported that they are receiving conflicting advice about what to add into food to make them more nutrient and energy dense. Parents also reported that recommendations such as cream, oil, and butter often made their infants sick. Parents of some of the infants reported that their infants were delayed, e.g., >6 months of age in starting a complementary food either due to developmental delay or post-surgical complication such as vocal cord palsy and so felt that the information should reflect this. As a result of this feedback, we also developed a recipe book *For Babies Who Need to Make the Most Out of Every Mouthful*.

Health-care professionals, particularly speech & language therapists, felt that it was important to include considerations about feeding readiness for infants, particularly those with developmental delay, which was included in the recipe book.

https://doi.org/10.1017/S1047951119001665 Published online by Cambridge University Press

Table 2. Parent and patient demographics

ID	Relationship to child	Diagnosis	Age of child at time of session	Surgery - complete/ planned	Main feeding route as an infant	Feeding difficulties/ issues	Community support accessed?
1	Mother	Atrioventricular septal defect; Trisomy 21	8 month	Complete	NGT	Reflux, vomiting	Dietitian/ SLT/ community nurse
2	Mother	Cardiac fibroma	1 years	Complete	Bottle fed	None	Dietitian/ community nurse
3	Mother	Transposition of the great arteries, ventricular septal defect, pulmonary stenosis	1 year 1month	Complete	Bottle fed	None	Dietitian
4	Mother	Tetralogy of Fallot	3 month	Complete	Bottle fed	None	Community nurse
5	Mother	Chromosome 18 deletion, congenitally abnormal mitral valve with severe regurgitation	4 month	Complete	NGT	Reflux, vomiting	None
6	Father	Atrioventricular septal defect; Trisomy 21	8 month	Complete	Bottle fed	Reflux, vomiting	Dietitian/ SLT/ community nurse
7	Mother	Atrioventricular septal defect with moderate-to-severe AV valve regurgitation	2 years	Complete	PEG	Reflux, vomiting, feeding aversion, blended diet	Dietitian/ SLT/ community nurse
8	Mother	Double outlet right ventricle – fallot type	6 moths	Planned	PEG-J	Reflux, vomiting, feeding aversion	Dietitian/ SLT/ community nurse
9	Mother	Atrioventricular septal defect, Trisomy 21	4 months	Planned	NGT/ NBM	Reflux, vomiting	Dietitian/ SLT/ community nurse/ Neonates home team/ Physio/
10	Mother	Transposition of the great arteries	1 month	Complete	NGT/ Bottle fed	Vomiting tired on feeding NGT fed	Dietitian
11	Father	Coarctation of the aorta	1 month	Complete	NGT/ Bottle fed	Feeding - tiring	Dietitian
12	Mother	CHARGE association, 16Q 22.2 duplication, Coarctation repair, cleft lip – palate, epilepsy	6 months	Partially complete	PEG	Reflux/ vomiting/ FTT, CHARGE	Dietitian/ SLT/ Cleft nurse/ Physio/ LTV
13	Mother	Fontan – awaiting heart transplant	2 years	Partially complete	Bottle fed	Feeding difficulties poor growth	Dietitian/ SLT/ community nurse/ Physio/ OT
14	Mother/ father	Atrioventricular septal defect, Trisomy 21	6 month	Partially complete	Breast/ NGT	Feeding difficulties; reflux; poor growth	Dietitian/ SLT/ community nurse/ Physio/ OT
15	Mother	Ventricular septal defect	2 years	Complete	Bottle fed	diarrhoea; poor growth; CMPA	Dietitian/ SLT/ community nurse
16	Mother	Transposition of great artieries	5 years	Complete	Bottle fed	Constipation	None
17	Mother	Coarctation of the aorta, ventricular septal defect, mitral stenosis	1 year	Complete	Bottle fed	Feeding difficulties; reflux; poor growth	Dietitian/ SLT/ community nurse/ Physio/ OT
18	Mother	Tetralogy of Fallots	2 months & 2 years	Complete	Bottle fed / NGT	Feeding difficulties; reflux; poor growth	Dietitian/ SLT/ community nurse
19	Mother /father	Ventricular septal defect	3 years	Partially complete	Bottle fed / NGT	FTT proctocolitis CMPA	Dietitian/ nurse/ community nurse

NG = naso gastric tube; PEG = percutaneous endoscopic gastrostomy; PEJ = percutaneous endoscopic jejunostomy; FTT = failure to thrive; CMPA = cow's milk protein allergy; T21 = trisomy 21; OT = occupational therapy; SLT = Speech and Language Therapist; CHARGE = coloboma, heart defects, choanal atresia, genital abnormalities, and ear abnormalities

https://doi.org/10.1017/S1047951119001665 Published online by Cambridge University Press

Growth before surgery

Parents reported that they had looked "on-line" regarding their baby's medical diagnosis before their baby's birth. However, several parents reported that they had been unable to find information relating to feeding and felt unprepared for how difficult feeding and achieving optimal growth would be, and they would have appreciated realistic antenatal feeding information to allow them to set their expectations about the infant's feeding journey. Some parents also wanted information to explain the different types of infant feeds and the possible need for them.

Parents also wanted it to be emphasised that breast milk is good for babies and where possible to "keep breastfeeding"; however, parents also acknowledged that a high-calorie milk may be required as well. Health-care professionals suggested the information should provide reassurance that there were ways in which weight gain could be achieved with the use of energy-nutrient-dense infant formula in addition to breast milk or infant formula.

How to feed your baby – experience of feeding

A section was included within the feeding information encouraging parents to provide positive touch including skin-to-skin contact where possible. Parents thought that this section was very useful and would have felt encouraged to do this, particularly during periods of critical illness following cardiac surgery for staged procedures.

Health-care professionals felt that it was important to include information that would prevent feeding difficulties later, including concepts such as positive touch, milk on dummies to provide taste experiences for enterally fed infants, and helping parents to form a secure bond and attachment with their infant.

Feeding problems and symptoms

Parents describe a perception of not "being listened to", or having their concerns dismissed regarding some of their infant's feeding symptoms, or what common symptoms might indicate, such as gastro-oesophageal reflux disease. Parents thought that it would be useful to have a list of common feeding problems, so that when talking to health-care professionals, it may validate parents' descriptions of possible symptoms allowing for a discussion regarding possible medical management.

All parents (n = 10) whose infants required nasogastric tubes reported finding the whole experience is very stressful. Many parents describe feeling completely overwhelmed and not wanting the responsibility of managing the nasogastric tubes and the feeds. Parents also felt that they would have benefited from information on what happens if their baby does not consistently meet their feeding target and how long they might require nasogastric tubes. Many parents were worried that their infant would lose the ability to feed orally and felt that parent information should have a section on how this could be maintained. Some parents found the whole cycle of feeding followed by vomiting/aspirating exhausting and describe days as being long and hard. Some parents felt that they would have benefited from being given realistic expectations about feeding and told that some days may be better than others.

Health-care professionals' focus was more on the severe life-threatening symptoms, which should prompt parents to seek urgent medical attention and contact emergency services, for example, increased work of breathing, being quieter than usual, change in an infant's colour. Whilst parents felt this was useful, their focus was more on feeding symptoms.

Discussion

This study resulted in the development of feeding information for parents of infants with CHD entitled *Information on Feeding Infants with Congenital Heart Disease* based on an iterative process centred around parent feedback and information needs, together with evidence from the literature and health-care professionals' opinion-based on clinical experience. Parents report of a lack of feeding information for infants with CHD, with some available information often being contradictory has been described elsewhere.[11] Parents expressed a strong need for both a trusted evidence-based source of dietary information to which they can refer during their infant's feeding journey and a tool to aid communication with health-care professionals.

To our knowledge, the introduction of complementary food as a feeding concern for parents of infants with CHD is something new. Parents reported that weaning infants onto solid foods were often forgotten by health-care professionals, with a lack of available written information about weaning and when to start complementary food in infants with CHD. Parents reported conflicting advice about what to add to enrich food and some infants were delayed in starting complementary food due to developmental delay or concerns regarding feeding readiness and felt the information should reflect this. There are reports of infants experiencing difficulties in transitioning from a liquid to solid diet, particularly following the prolonged use of nasogastric tube's,[27] which are commonly used in with CHD,[28] to ensure an adequate intake. In our cohort, 50% of infants had a feeding tube of some form, with parents reporting varying degrees of feeding difficulties. Infants with CHD may also have delayed feeding skill acquisition or feeding regression, which may arise from watching parents or family members eat, vocal cord palsy following surgery or feeding aversion either due to limited opportunity to take milk or food by mouth or as a result of painful experiences involving the oral cavity during the perioperative period.[29,30] To support the weaning section within the feeding information we have also developed a recipe book for weaning *For Babies Who Need to Make the Most of Every Mouthful*, as well as providing parents with tips about providing positive touch to improve oral feeding skills.[31]

The World Health Organisation amongst others recommends the introduction of complementary food around 6 months of age.[32–34] The complementary feeding advice was developed based on evidence suggesting that growth in children with complex CHD benefits from early intensive nutrition support,[35] making use of energy-nutrient-dense formulas/food. Enriching weaning food is typically done with fat such as cream, butter, and oil. However, this approach may delay gastric emptying and many parents anecdotally report made their infants/children feel sick. In more recent times, nut butters have been used to enrich food, based on the concept of Ready to Use Therapeutic Foods in severe acute malnutrition.[36] Nut butters are a nutrient-energy-dense food source with which low-calorie weaning foods such as vegetables and fruit can be enriched. All of the parents and health-care professionals included in this study found nut butters to be an acceptable food source with which to enrich their infant's diet as it was a common food item within individual(s) food cupboards. Future work will look to characterise the use of nut butters in this way on growth.

Concurrent with findings of other reports,[11] 84% of parents interviewed reported feeding difficulties amongst infants with CHD irrespective of the feeding method. Parents reported that they found a lack of feeding information challenging, particularly as the advice they were given by various health-care professionals was often inconsistent, as reported elsewhere.[13] Growth was a

https://doi.org/10.1017/S1047951119001665 Published online by Cambridge University Press

significant concern for many of the parents, and routine weight checks completed by their local health-care professionals were a focus for the week, being either a high or low point; depending on whether their infants had gained weight, health visitors were seen as supportive, though often growth patterns were not understood and wrongly interpreted. Parents wanted information which both provided reassurance and acknowledged the unique growth pattern their infant with CHD may follow. Parents also wanted to be able to use this information to inform discussions with their local team, reduce conflicting messages, and also to validate their infant's growth trajectory.

In common with other studies, many parents reported gastrointestinal symptoms, particularly those relating to reflux, vomiting, and early satiety.[37,38] Some parents reported having a complicated relationship with the use of nutrient-energy-dense feeds used to improve growth in infants with CHD,[39] particularly as their use may also be associated with a worsening of gastrointestinal symptoms.[39,40] Many parents wanted information to affirm their infants were experiencing symptoms related to the feeding itself.

Half of the infants (n = 10) had a nasogastric or long-term feeding tube to either top up bottle feeds or as the sole route of feeding, which is similar to rates seen in other studies.[20,41] Some studies have suggested that parents of infants with CHD may provide fewer social and emotional interactions, for example, smiling, making eye contact, touching, or singing when feeding compared to mothers of infants without CHD.[42] One such study noted that infants with CHD exhibit significantly more stress signals, such as disengagement cues, including splayed fingers or hand to head actions compared to healthy infants.[26] In response to these findings, parents felt encouraged by a section in our feeding information on providing positive touch,[31] and wished they had known about that earlier as they felt this would have helped them and their infants particularly during periods of critical illness following cardiac surgery.

Parents of children with CHD are reported to have lower parental health-related quality of life; factors which impact on health-related quality of life includes poor growth before surgery, the medicalisation of feed infants, and becoming more of a carer than a parent.[17–19,26,43] In this study, parents whose infants required a nasogastric tubes reported finding the whole experience very stressful, as well as feeling completely overwhelmed by responsibility of managing the nasogastric tubes and the feeds. Parents reported finding the whole cycle of feeding followed by vomiting exhausting and described days as being long and hard. Although a number of studies have been completed considering health-related quality of life in parents of children with CHD, these have usually focused on older children > 5 years.[44,45] Denniss et al recently completed a cross-sectional study assessing health-related quality of life in families with infants or young children with CHD, with the aim of identifying factors that place mothers at greater risk of vulnerability. Lower child health-related quality of life was associated with children who had single ventricles, other physical comorbidity, feeding difficulties, and greater levels of maternal psychological stress; in contrast, maternal health-related quality of life was strongly associated with poorer family functioning, greater maternal psychological stress, difficult child temperament, and child physical comorbidity.[43] Future work is required to better understand whether there are potentially modifiable factors of parental health-related quality of life through the use of feeding-related parent information, improving growth through the use of nutrition care pathway[14] and the support from a dietician/Health Care Professionals (HCP) before and following surgery, particularly for infants who have feeding difficulties, for example, transition to textured complementary food and oral feeding.

Limitations

Part of this study was not able to quantify the type and prevalence of feeding difficulties, which is a limitation of this study. The feeding information as part of this study was developed using the opinions of parents and health-care professionals from a single institution, although the opinion of paediatric dieticians from a national group was sought. It remains to be tested whether this approach has a positive impact on both the growth of infants with CHD and measures of parental stress, and future work should consider this within a research setting.

Conclusions

This study describes the development of feeding material for infants with CHD. From parent and health-care professionals' interviews, materials thought to be helpful included information regarding the feeding journey, other infant feeding stories, and advice about making the most out of every mouthful.

Author ORCIDs. L. V. Marino 0000-0002-1257-121X

Acknowledgements. The authors would like to thank members of the British Dietetic Association: Paediatric Cardiology Interest Group for their assistance and support with this project; Jason Beyers, Bristol Children's Hospital, Graeme O'Connor, Great Ormond Street Children's Hospital, Amber Greene, Leicester Children's Hospital, David Hopkins, Yeovil Hospital, Shelina Meah, St. Mary's Imperial College London, Ruth Hornby, Oxford Children's Hospital, Oxford, Emma Gentles, Glasgow Children's Hospital, Glasgow. Dr Rosan Meyer, Senior Honorary Lecturer, Imperial College London. The authors would like to thank the following health-care professionals at Southampton Children's Hospital including Paediatric Cardiac Liaison Nurses Gill Harte, Colette Cochran, Katy Stimson, Cate Anson, Doreen Macphail, Dr Victoria Clarke, Dr Abigail Sharpe, Dr Alex Snell, SLT; Lowri Daniels, Julia Robinson, and for all of the parents for their time and invaluable contributions.

Financial Support. This report is an independent research arising from an Integrated Clinical Academic Clinical Lectureship, Luise Marino – ICA-CL-2016-02-001 supported by the National Institute for Health Research and Health Education England. The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the National Institute for Health Research, the Health Education England, or the Department of Health and Social Care.

Conflicts of Interest. None.

Contributors Statement. The authors made the following contribution to the manuscript: L.V.M. formulated the original idea and wrote the initial patient information using the best available evidence, collated the parent information, and drafted the manuscript; L.V.M., T.B., N.J.D, C.K., A.S.D., and M.J. made iterative changes to the dietary information at various time points during the process; T.B., T.R., A.S.D., and M.J. contributed to revising the manuscript for important intellectual content; and all authors provided final approval of the version to be submitted.

Ethical Standards. The authors assert that all procedures contributing to this work comply with ethical standards and have been approved by the the NHS ethics committee (North West - Greater Manchester Central, reference 17/NW/0490).

https://doi.org/10.1017/S1047951119001665 Published online by Cambridge University Press

References

1. van der Linde, D, Konings, EE, Slager, MA, et al. Birth prevalence of congenital heart disease worldwide: a systematic review and meta-analysis. J Am Coll Cardiol 2011; 58: 2241–2247.
2. Townsend, N, Bhatnagar, P, Wickramasighe, K, Williams, J, Vujcich, D, Rayner, M. Children and Young People Statistics 2013. London: British Heart Foundation Health Promotion Research Group, 2013.
3. Petersen, S, P.V., Rayner, M. Congenital Heart Disease Statistics. London: British Heart Foundation Health Promotion Research Group 2003.
4. Connor, JA, Kline, NE, Mott, S, Harris, SK, Jenkins, KJ. The meaning of cost for families of children with congenital heart disease. J Pediatr Health Care 2010; 24: 318–325.
5. Hehir, DA, Rudd, N, Slicker, J, et al. Normal interstage growth after the norwood operation associated with interstage home monitoring. Pediatr Cardiol 2012; 33: 1315–1322.
6. Marino, LV, Magee, A. A cross-sectional audit of the prevalence of stunting in children attending a regional paediatric cardiology service. Cardiol Young 2016; 26: 787–789.
7. Toole, BJ, Toole, LE, Kyle, UG, Cabrera, AG, Orellana, RA, Coss-Bu, JA. Perioperative nutritional support and malnutrition in infants and children with congenital heart disease. Congenit Heart Dis 2014; 9: 15–25.
8. Vaidyanathan, B, Nair, SB, Sundaram, KR, et al. Malnutrition in children with congenital heart disease (CHD) determinants and short term impact of corrective intervention. Indian Pediatr 2008; 45: 541–546.
9. Eskedal, LT, Hagemo, PS, Seem, E, et al. Impaired weight gain predicts risk of late death after surgery for congenital heart defects. Arch Dis Child 2008; 93: 495–501.
10. Mitting, R, Marino, L, Macrae, D, Shastri, N, Meyer, R, Pathan, N. Nutritional status and clinical outcome in postterm neonates undergoing surgery for congenital heart disease. Pediatr Crit Care Med 2015; 16: 448–452.
11. Tregay, J, Brown, K, Crowe, S, Bull, C, Knowles, R, Wray, J. "I was so worried about every drop of milk" – feeding problems at home are a significant concern for parents after major heart surgery in infancy. Matern Child Nutr 2017; 13.
12. Davis, D, Davis, S, Cotman, K, et al. Feeding difficulties and growth delay in children with hypoplastic left heart syndrome versus d-transposition of the great arteries. Pediatr Cardiol 2008; 29: 328–333.
13. Tregay, J, Wray, J, Crowe, S, et al. Going home after infant cardiac surgery: a UK qualitative study. Arch Dis Child 2016; 101: 320–325.
14. Marino, LV, Johnson, MJ, Hall, HJ, et al. The development of a consensus-based nutritional pathway for infants with CHD before surgery using a modified Delphi process. Cardiol Young 2018; 28: 938–948.
15. Kallio, H, Pietila, AM, Johnson, M, Kangasniemi, M. Systematic methodological review: developing a framework for a qualitative semi-structured interview guide. J Adv Nurs 2016; 72: 2954–2965.
16. Srivastava, A, Thomson, SB, Framework analysis: a qualitative methodology for applied policy research. JOAAG 2009; 4: 7.
17. Clemente, C, Barnes, J, Shinebourne, E, Stein, A, et al. Are infant behavioural feeding difficulties associated with congenital heart disease? Child Care Health Dev 2001; 27: 47–59.
18. Lobo, ML. Parent-infant interaction during feeding when the infant has congenital heart disease. J Pediatr Nurs 1992; 7: 97–105.
19. Idesoe, Y, Obata, F, Ishikawa, Y. Difficulties mothers have when feeding their infants who have Congenital Heart Disease. JJSE 2006; 43: 6.
20. Medoff-Cooper, B, Naim, M, Torowicz, D, Mott, A. Feeding, growth, and nutrition in children with congenitally malformed hearts. Cardiol Young 2010; 149–153.
21. Association, AH. Feeding Tips for Your Baby with CHD, 2019. Retrieved January 18, 2019, from: https://www.heart.org/en/health-topics/congenital-heart-defects/care-and-treatment-for-congenital-heart-defects/feeding-tips-for-your-baby-with-chd
22. Org, HT. Feeding Problems and Congenital Heart Disease, 2014. Retrieved January 18, 2018, from: http://www.healthtalk.org/peoples-experiences/heart-disease/parents-children-congenital-heart-disease/feeding-problems-and-congenital-heart-disease
23. Count, S. Feeding a Baby Who Has Congenital Heart Disease, 2019. Retrieved January 18, 2019, from: http://www.secondscount.org/pediatric-center/pediatric-detail?cid=c14b51c7-e10b-4aec-ae36-636aff48990 c.
24. Physicians, A.A.o.F. Congenital Heart Disease: How to Care for Your Baby and Yourself. Retrieved January 18, 2019, from: https://familydoctor.org/how-to-care-for-your-baby-and-yourself/
25. Federation, C.s.H. Feeding Children with Heart Conditions, 2014. Retrieved January 19, 2019, from: http://www.chfed.org.uk/how-we-help/information-service/caring-for-heart-children/feeding-children-with-heart-conditions/.
26. Lobo, ML, Michel, Y. Behavioral and physiological response during feeding in infants with congenital heart disease: a naturalistic study. Prog Cardiovasc Nurs 1995; 10: 26–34.
27. Duff, AJ, Wolfe, SP, Dickson, C, Conway, SP, Brownlee, KG. Feeding behavior problems in children with cystic fibrosis in the UK: prevalence and comparison with healthy controls. J Pediatr Gastroenterol Nutr 2003; 36: 443–447.
28. Hill, G, Silverman, A, Noel, R, Bartz, PJ. Feeding dysfunction in single ventricle patients with feeding disorder. Congenit Heart Dis 2014; 9: 26–29.
29. Ross, ES, Browne, JV. Developmental progression of feeding skills: an approach to supporting feeding in preterm infants. Semin Neonatol 2002; 7: 469–475.
30. Kerzner, B. Clinical investigation of feeding difficulties in young children: a practical approach. Clin Pediatr (Phila) 2009; 48: 960–965.
31. Indramohan, G, Pedigo, TP, Rostoker, N, Cambare, M, Grogan, T, Federman, MD. Identification of risk factors for poor feeding in infants with congenital heart disease and a novel approach to improve oral feeding. J Pediatr Nurs 2017; 35: 149–154.
32. West, C. Introduction of complementary foods to infants. Ann Nutr Metab 2017; 70: 47–54.
33. Fewtrell, M, Bronsky, J, Campoy, C, et al. Complementary feeding: a position paper by the European Society for Paediatric Gastroenterology, Hepatology, and Nutrition (ESPGHAN) Committee on Nutrition. J Pediatr Gastroenterol Nutr 2017; 64: 119–132.
34. WHO Working Group on the Growth Reference Protocol and the WHO Task Force on Methods for the Natural Regulation of Fertility. Growth of healthy infants and the timing, type, and frequency of complementary foods. Am J Clin Nutr 2002; 76: 620–627.
35. Vogt, KN, Manlhiot, C, Van Arsdell, G, Russell, JL, Mital, S, McCrindle, BW. Somatic growth in children with single ventricle physiology impact of physiologic state. J Am Coll Cardiol 2007; 50: 1876–1883.
36. Manary, MJ, Ndkeha, MJ, Ashorn, P, Maleta, K, Briend, A. Home based therapy for severe malnutrition with ready-to-use food. Arch Dis Child 2004; 89: 557–561.
37. Cavell, B. Gastric emptying in infants with congenital heart disease. Acta Paediatr Scand 1981; 70: 517–520.
38. Hehir, DA, Easley, RB, Byrnes, J. Noncardiac challenges in the cardiac ICU: feeding, growth and gastrointestinal complications, anticoagulation, and analgesia. World J Pediatr Congenit Heart Surg 2016; 7: 199–209.
39. Zhang, H, Gu, Y, Mi, Y, Jin, Y, Fu, W, Latour, JM. High-energy nutrition in paediatric cardiac critical care patients: a randomized controlled trial. Nurs Crit Care 2019; 24: 97–102.
40. Cavell, B. Effect of feeding an infant formula with high energy density on gastric emptying in infants with congenital heart disease. Acta Paediatr Scand 1981; 70: 513–516.
41. Shine, AM, Finn, DG, Allen, N, McMahon, CJ. Transition from tube feeding to oral feeding: experience in a tertiary care paediatric cardiology unit. Ir J Med Sci 2019; 188: 201–208.
42. Barnard, K Nursing child assessment feeding scales. In: Nursing Child Assessment Feeding Scales. University of Washington, School of Nursing, Seattle, 1978.
43. Denniss, DL, Sholler, GF, Costa, DSI, Winlaw, DS, Kasparian, NA. Need for routine screening of health-related quality of life in families of young children with complex congenital heart disease. J Pediatr 2019; 205: 21–28.e2.
44. Abassi, H, Gavotto, A, Picot, MC, et al. Impaired pulmonary function and its association with clinical outcomes, exercise capacity and quality of life in children with congenital heart disease. Int J Cardiol 2019; 285: 86–92.
45. Shackleford, JL, Kelley, SJ, Spratling, R. Applying the self-determination theory to health-related quality of life for adolescents with congenital heart disease. J Pediatr Nurs 2019; 46: 62–71.

https://doi.org/10.1017/S1047951119001665 Published online by Cambridge University Press