**Title: Development of feeding information for infants with congenital heart disease**

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**Keywords:** congenital heart disease, infants, feeding, information, parents

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**Abstract**

**Introduction:**

Infants with congenital heart disease (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A search for existing material was carried out on six-electronic databases and an internet search for unpublished (grey) literature on feeding information for infants with CHD. Following the development of feeding information, semi-structured interview(s) with parents/healthcare-professionals were completed, focusing on whether the information was; i) easy to understand ii) relevant iii) provided sufficient information around feeding/feeding difficulties and iv) 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:**

23 unique articles were identified of which 5 studies were included. From the grey literature 4 web pages were reviewed. Twenty-two parents and twenty-five health care professionals were interviewed. All parents/healthcare-professionals felt 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.

**Word count: 249**

**Introduction**

Congenital heart disease (CHD) represents one third of all major congenital anomalies ([1](#_ENREF_1), [2](#_ENREF_2)), of which around 4,000 in England will require surgery per annum ([3](#_ENREF_3)). Although there have been significant improvements in the medical and surgical management of infants with CHD leading to improved outcomes ([1](#_ENREF_1), [3](#_ENREF_3)), there are still significant burdens to families of infants with CHD, particularly emotionally ([4](#_ENREF_4)).

Whilst most infants are in the normal range for weight at birth ([5](#_ENREF_5)), many experience growth failure during the first year of life before surgery ([6-8](#_ENREF_6)), increasing the risk of mortality ([9](#_ENREF_9), [10](#_ENREF_10)). Ensuring infants achieve optimal growth has emerged as a significant cause of parental stress ([11](#_ENREF_11), [12](#_ENREF_12)). In addition, parents report receiving conflicting messages (particularly around feeding e.g. what type of feed and food enrichment), from health care professionals, which can add to their distress ([11](#_ENREF_11), [13](#_ENREF_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](#_ENREF_14)). As part of the work completed for that study, parents reported they felt frustrated with the lack of written material around 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](#_ENREF_11), [13](#_ENREF_13)). The aim of this study was to develop feeding information to try and address this gap.

**Methods**

An iterative process of semi-structured interviews (as described by Kallo *et al*. ([15](#_ENREF_15))) was used to develop the feeding information for parents. In short we firstly; i) identified some of the key areas thought to be concerns for parents around feeding of infants with CHD by conducting a literature review and data synthesis ii) planned a semi-structured interview guide to be used as part of the iterative process with parents and health care professionals, iii) pilot tested the interview guide for parents and health care professionals with two dietitians not involved in paediatric cardiology, and iv) completed the interviews using the semi-structured interview guide making iterative changes to the parent information following each semi-structured interviews.

*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 (CINAHL), PsycInfo and Medline. Searches were also undertaken in PubMed, the Cochrane Library and 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 intensive care unit 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](#_ENREF_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 recommendations made were coded. Within the grey literature information relation to feeding advice, support and other recommendations were 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”* was developed and a recipe book *“For Babies who need to make the most out of every mouthful”.*

*Interviews with parents*

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, CK). A letter of invitation was sent along with a parent information-sheet. After initial contact was made (LM, ND, CK) contacted parents via telephone; 10 days after the invitation letter and parent information sheet was 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 ≥ 6 years of age were excluded. Interviews for parents focused on whether the feeding information developed was: i) easy to understand ii) relevant to the parents’ concerns iii) provided sufficient information around feeding/feeding difficulties and iv) whether there were any perceived gaps in the feeding information.

*Healthcare 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 i) perceived to be relevant for infants with CHD, ii) contained sufficient information relating to feeding and iii) whether there were any clinical gaps in the information. Health care professionals were identified by (LM, ND, 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 participants 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 was then repeated to ensure that iterative changes from each stakeholder group was 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 take 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](#_ENREF_16)).

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

As a final step, once the feeding information had been developed the parent feeding information developed was also information was circulated for review to members of the British Dietetic Association Paediatric Cardiology Interest Group who are all paediatric dietitians from tertiary Surgical Paediatric Cardiac Centres for further comments. Further iterative changes were made and the process was complete 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 out of the 23 being included ([11](#_ENREF_11), [17-20](#_ENREF_17)). From the grey literature search, 4 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](#_ENREF_21)), 24 descriptive codes were identified during the data extraction (Table 1). These were grouped into 8 sub-categories, which were distilled into 4 overarching interdependent categories from which the dietary material was developed: i) growth before surgery ([17-19](#_ENREF_17), [26](#_ENREF_26)), ii) how to feed your baby - experience of feeding ([11](#_ENREF_11), [17](#_ENREF_17), [19](#_ENREF_19), [20](#_ENREF_20)) iii) feeding problems and symptoms ([11](#_ENREF_11), [18](#_ENREF_18), [20](#_ENREF_20)), iv) additional information on enriching food ([20-25](#_ENREF_20)). In addition we incorporated information from the consensus nutritional pathway for infants with CHD before surgery, previously developed by our research group ([14](#_ENREF_14)).

**Parent and health care professional interviews**

Twenty-two parents and twenty-five health care professionals were interviewed; paediatric dietitians (n=12), paediatric cardiac nurse (n=5), doctor (paediatric cardiology/general) (n=5), Speech & Language Therapist (2), psychologist (n=1).

All parent interviews were conducted face-to-face by a single researcher (LM). Regarding the children of recruited parents, sixteen had undergone corrective surgery, four received palliative surgery, and two were awaiting surgical repair. Two interviews were conducted as small groups of three parents each; two interviews as mother and father and the remaining twelve 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 was not captured. No further changes were made to the parent information once thematic saturation was achieved. A total, fifty-five 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 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](#_ENREF_17), [26](#_ENREF_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 the limited feeding information available focused only on milk feeds and not complementary food. Parents felt 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 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 their infants were delayed e.g. > 6 months of age in starting complementary food either due to developmental delay or post-surgical complication such as vocal cord palsy, and so felt 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 it was important to include considerations around feeding readiness for infants, particularly those with developmental delay, which was included in the recipe book.

*Growth before surgery*

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

Parents also wanted it to be emphasized that breastmilk 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 breastmilk 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 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 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 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 gastrooesophageal reflux disease. Parents thought it would be useful to have a list of common feeding problems, so that when talking to Health care professionals it may validated parents descriptions of possible symptoms allowing for a discussion regarding possible medical management.

All parents (n=10) whose infants required naso-gastric tubes (NGTs) reported finding the whole experience very stressful. Many parents describe feeling completely overwhelmed and not wanting the responsibility of managing the NGT 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 a NGT for. Many parents were worried 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 they would have benefitted 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. While 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 centered around parent feedback and information needs, together with evidence from the literature and health care professionals opinion based on clinical experience. Parent reports of a lack of feeding information for infants with CHD, with some available information often being contradictory has been described elsewhere ([11](#_ENREF_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 was 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 NGT’s ([27](#_ENREF_27)), which are commonly used in with CHD ([28](#_ENREF_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](#_ENREF_29), [30](#_ENREF_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 around providing positive touch to improve oral feeding skills ([31](#_ENREF_31)).

The World Health Organisation amongst others, recommend the introduction of complementary food around 6 months of age ([32-34](#_ENREF_32)). The complementary feeding advice was developed based on evidence suggesting that growth in children with complex CHD benefits from early intensive nutrition support ([35](#_ENREF_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](#_ENREF_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 characterize the use of nut butters in this way on growth.

Concurrent with findings of other reports ([11](#_ENREF_11)), 84% of parents interviewed reported feeding difficulties amongst infants with CHD irrespective of the feeding method. Parents reported 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](#_ENREF_13)). Growth was a 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 infant 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 to also 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](#_ENREF_37), [38](#_ENREF_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](#_ENREF_39)), particularly as their use may also be associated with a worsening of gastrointestinal symptoms ([39](#_ENREF_39), [40](#_ENREF_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 naso-gastric 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](#_ENREF_20), [41](#_ENREF_41)). Some studies have suggested that parents of infants with CHD may provide fewer social and emotional interactions e.g. smiling, making eye contact, touching or singing when feeding compared to mothers of infants without CHD ([42](#_ENREF_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](#_ENREF_26)). In response to these findings parents felt encouraged by a section in our feeding information on providing positive touch ([31](#_ENREF_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 (HRQoL); factors which impact on HRQoL include, poor growth before surgery, the medicalisation of feed infants and becoming more of a carer than a parent ([17-19](#_ENREF_17), [26](#_ENREF_26), [43](#_ENREF_43)). In this study parents whose infants required a NGT reported finding the whole experience very stressful, as well as feeling completely overwhelmed by responsibility of managing the NGT 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 HRQoL in parents of children with CHD, these have usually focused on older children > 5 years ([44](#_ENREF_44), [45](#_ENREF_45)). Denniss *et al*. recently completed a cross sectional study assessing HRQoL in families with infants or young children CHD, with the aim of identifying factors that place mothers at greater risk of vulnerability. Lower child HRQoL was associated with children who had single ventricles, other physical comorbidity, feeding difficulties and greater levels of maternal psychological stress; in contrast maternal HRQoL was strongly associated with poorer family functioning, greater maternal psychological stress, difficult child temperament and child physical comorbidity ([43](#_ENREF_43)). Future work is required to better understand whether there are potentially modifiable factors of parental HRQoL through the use of feeding related parent information, improving growth through the use of nutrition care pathway ([14](#_ENREF_14)) and the support from a dietitian/ HCP before and following surgery particularly for infants who have feeding difficulties e.g. transition to textured complementary food and oral feeding.

**Limitations**

As part of this study were not able to quantify the type and prevalence of feeding difficulties, which is a limitation of this study. The feeding information developed 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 Dietitians 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, material thought to helpful included information regarding: the feeding journey, other infant feeding stories and advice about making the most out of every mouthful.

**ACKNOWLEDGEMENTS:**

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. To 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.

**COMPETING INTERESTS:**

None

**FUNDING:**

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

**CONTRIBUTORS STATEMENT:**

Authors made the following contribution to the manuscript: (1) Luise Marino formulated the original idea and wrote the initial patient information using the best available evidence, collated the parent information and drafted the manuscript. (2) Luise Marino, Tara Bharucha, Natalie Davies, Catherine Kidd, Ann-Sophie Darlington and Mark Johnson made iterative changes to the dietary information at various time points during the process. (3) Tara Bharucha, Trevor Richens, Anne-Sophie Darlington and Mark Johnson, contributed to revising the manuscript for important intellectual content, (5) and all authors provided final approval of the version to be submitted.

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