Clinical Nutrition ESPEN xxx (xxxx) xxx

Contents lists available at ScienceDirect

Clinical Nutrition ESPEN

journal homepage: http://www.clinicalnutritionespen.com

# Feeding difficulties in young paediatric intensive care survivors: A scoping review

K. Morton [a, e, *, 1], L.V. Marino [b, d, e, 1], J.V. Pappachan [a, c], A.S. Darlington [b]

[a] Paediatric Intensive Care Unit, University Hospital Southampton NHS Foundation Trust, UK
[b] School of Health Sciences, University of Southampton, UK
[c] Faculty of Medicine, University of Southampton, UK
[d] Department of Dietetics/ SLT, University Hospital Southampton NHS Foundation Trust, UK
[e] NIHR Southampton Biomedical Research Centre, University Hospital Southampton NHS Foundation Trust, UK

## ARTICLE INFO

*Article history:*
Received 6 September 2018
Accepted 31 January 2019

*Keywords:*
Feeding difficulties
Paediatric intensive care
Children
Survivor

## SUMMARY

*Background:* Although feeding difficulties are commonly described amongst children with chronic diseases, those admitted to a paediatric intensive care unit (PICU) represent a mix of previously healthy children as well as those with pre-existing diseases. There is, however, a lack of evidence describing the prevalence and type of feeding difficulties amongst healthy children who survive a period of critical illness and the subsequent impact on growth and family life. The aim of this work was to complete a scoping review of evidence describing feeding difficulties amongst PICU-survivors.

*Method:* Six electronic databases were searched from January 2000–October 2018. NICE Healthcare Databases Advanced Search website (https://hdas.nice.org.uk/) was used as a tool to complete multiple searches within multiple databases, including the Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycInfo and Medline. Any studies considering feeding difficulties amongst previously healthy children following discharge from PICU or those which explored the parental/caregiver experiences were included.

*Results:* As the initial search yielded only one study which fulfilled the inclusion criteria, the criteria was extended to include studies relating to feeding difficulties (post-discharge) amongst otherwise healthy ex-preterm infants (born $< 37$ weeks gestational age) and infants/children with chronic diseases where feeding difficulties were described following a PICU admission. A review team screened and extracted the data of published qualitative and quantitative studies, using content analysis techniques. Of the 9622 articles identified from the searches, 22 full-text studies were reviewed with seven studies included. Four overarching categories represented the results: prevalence of feeding difficulties; risk factors and predictors for developing feeding difficulties; parental/carer experience and emotional response to feeding difficulties; and challenges in accessing feeding support.

*Conclusions:* The results of this scoping review suggest there are gaps in the research, particularly those exploring the prevalence of feeding difficulties amongst previously healthy children and the negative impact this may have on family life. Future research should focus on addressing the extent of the problem and identifying risk factors, in addition to the potential development of toolkits for health care professionals to better support parents.

---

* Corresponding author. Paediatric Intensive Care Unit, University Hospital Southampton NHS Foundation Trust, Southampton, S016 6YD, UK.
*E-mail address:* Kathryn.morton@uhs.nhs.uk (K. Morton).

[1] joint first author.

https://doi.org/10.1016/j.clnesp.2019.01.013

Please cite this article as: Morton K et al., Feeding difficulties in young paediatric intensive care survivors: A scoping review, Clinical Nutrition ESPEN, https://doi.org/10.1016/j.clnesp.2019.01.013

**What we know**

- Feeding difficulties are common amongst children with chronic diseases.
- Feeding difficulties amongst children with chronic diseases can result in poor growth causing significant parental distress.
- Children admitted to PICU represent a mix of previously healthy children as well as those with pre-existing diseases.

**What this study adds**

- As part of this scoping review we identified four overarching categories; prevalence of feeding difficulties; risk factors and predictors for developing feeding difficulties; parental/carer experience and emotional response to feeding difficulties; and challenges in accessing feeding support.
- There is a paucity of evidence describing feeding difficulties amongst previously healthy paediatric intensive care survivors.
- Future research should focus on describing the prevalence and type of feeding difficulties following a PICU admission, particularly amongst otherwise healthy children, in addition to developing consensus for defining feeding difficulties in this cohort.

## 1. Introduction

Fussy eating at some stage during early childhood is common [1,2], with up to 17% of three year olds noted to having a poor appetite and 12% described as picky eating [3]. A degree of neophobia and pickiness is considered to be developmentally appropriate and in most cases usually has no impact on growth [4]. Eating is a complex learned behaviour, which occurs during infancy and involves sufficient developmental maturation, behavioural state and the coordinated process of sucking, swallowing and breathing. This then advances into chewing and texture control [5].

Feeding difficulties are well described in children with chronic diseases [6–11] including cystic fibrosis [9], gastrointestinal disorders [10], food allergy [8] and congenital heart disease (CHD) [11]. Maurer et al. described feeding difficulties amongst 22% of children at 2 years of age, who had undergone surgery for CHD as a neonate, representing a long-term problem for children and their families. Feeding difficulties were defined as the need for a nasogastric tube post-discharge, inadequate food intake for age and poor growth [7], all of which may result in parental distress [12,13].

The objective of nutritional support during critical illness is to preserve life, maintain and improve cell function and aid recovery [14]. The majority of nutritional support is delivered as enteral feeding via a nasogastric tube or post pyloric tube [15]. Most centres have incorporated the concept of early enteral feeds, aiming to commence feeds within 12–24 hrs of admission [16,17] in order to meet nutritional requirements [18]. During a PICU admission it is common for children to spend a large proportion of their admission being unable to eat or drink orally, either due to having an endotracheal tube (ETT) in-situ to facilitate mechanical ventilation or as a result of being unable to consume sufficient nutrients due to their clinical condition [15]. This may impact on feeding skill acquisition and the development of successful eating skills due to lack of observed mealtimes [1,19], with subsequent long-lasting effects throughout childhood [20,21]. In some infants and young children, feeding skill regression leads to significant infant and child distress around feeding or mealtimes, resulting in disordered feeding behaviours and adding to parental stress [1,2].

It is possible that similar associated feeding difficulties experienced by adults ICU survivors, such as dysphagia [22,23], may also occur amongst previously well children following an admission to PICU. Risk factors for adult dysphagia and feeding difficulties include ETT intubation for longer than 48 hrs, in addition to ICU associated malnutrition and muscle weakness [23–26]. Furthermore, survivors of adult critical care report significant changes to their ability to eat, with reduced appetite, altered taste and food preferences lasting up to 3 months post ICU discharge [22].

Children admitted to PICU represent a mix of previously healthy children as well as those with pre-existing diseases [27]. The aim of this work was to complete a scoping review of evidence in order to: i) describe what is currently known about the prevalence, predictors for and type of feeding difficulties amongst previously healthy paediatric intensive care survivors; ii) identify what is known about parental/caregiver experience of feeding following a PICU admission; and iii) to identifying any gaps in the research.

## 2. Methods

A scoping review was conducted in order to identify the key concepts that underpin this area of research [28]. Scoping reviews do not seek to answer a specific research question like systematic reviews or meta-analyses do [29,30]. Instead, scoping reviews examine a broader area of literature, aiming to describe what is currently known and identify gaps in the research knowledge base using a rigorous and transparent methodology [31] on a particular topic of interest [32].

A full scoping review protocol was written using an *a priori* approach and was used to define the research questions centred on three hypotheses: i) previously healthy young children who require mechanical ventilation are at risk of developing feeding difficulties following an episode of critical illness; ii) there are risk factors associated with the development of feeding difficulties for young survivors of PICU and iii) feeding difficulties in young survivors of PICU affect parental feeding experiences. The scoping review protocol included aims and objectives, in addition to an inclusion/exclusion criteria for study selection, the proposed methods for data extraction and a content analysis approach. Feeding difficulties were defined using definitions proposed by Kernzer et al. [1,2] which included; prolonged mealtimes, food refusal, disruptive and stressful mealtimes, dysphagia, aspiration, gagging, altered taste, pain, and growth failure.

Any study using qualitative and quantitative design, that considered feeding difficulties following PICU discharge or studies which explored the parental/carer experience of feeding an otherwise healthy child following a PICU admission were included. Systematic literature reviews and meta-analyses were excluded. Using this searching protocol, an initial search identified only one study which fulfilled the inclusion criteria. As this was a scoping review exercise, the criteria was subsequently broadened to include studies investigating feeding difficulties post-discharge amongst otherwise healthy ex-preterm infants (born < 37 weeks gestational age) and infants/children with chronic diseases where feeding difficulties were described following a PICU admission. Studies were included if they were; published in the English language; based on human subjects and published between January 2000 and October 2018. Over the last two decades, our feeding practices in PICU have changed and PICU mortality rates have significantly declined, emerging a new population of critically ill survivors.

Please cite this article as: Morton K et al., Feeding difficulties in young paediatric intensive care survivors: A scoping review, Clinical Nutrition ESPEN, https://doi.org/10.1016/j.clnesp.2019.01.013

Therefore, a date limitation of January 2000 was set to ensure that all research papers reporting all nutritional outcomes in young PICU survivors were found. Any studies that were completed in other healthcare settings (e.g. ward or community environment) were considered not to be in scope of this review. For the purposes of this review, young PICU survivors were defined as children between the ages of 0–5 years of age. The reviewing team (KM, LVM) agreed to exclude opinion pieces, editorials and congress abstracts as part of the iterative process as advocated by Aksey and O'Malley [29].

A search strategy was developed in consultation with an information specialist and included a number of key terms. The strategy included key terms: “paediatric intensive care” (intensive care, critical care, recovery, survivor) AND “feeding difficulties” (oral aversion, feeding problem, feeding difficulty, food restriction, tube feeding, enteral feeding, oral phobia, deglutition, dysphagia and nutrition) AND “disordered eating” (feeding behaviours, feeding patterns, nutrition disorders) AND “survivorship” (graduates, post-discharge, rehabilitation) 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 exploring feeding difficulties amongst PICU survivors.

Returned study titles and abstracts were reviewed independently by the reviewing team according to the inclusion criteria, which revealed a large number of articles outside the scope if this review and duplicate articles. The same reviewing team conducted the full text screening.

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 content analysis approach [33]. Using this approach, the descriptive aspects about the population of interest, methodology, outcomes and any recommendations made 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.

## 3. Results

A total of 9622 articles were initially screened identifying one study looking at feeding difficulties in young survivors of Neonatal Intensive Care (NICU) and/or PICU [34]. Following the broadening of the inclusion criteria to include feeding difficulties amongst ex-preterm infants/NICU graduates, and infants with chronic diseases where feeding difficulties were associated with a PICU admission, a further six articles met the inclusion criteria (Fig. 1). Two studies had a prospective design and three used retrospective methods. There were two qualitative descriptive studies, one of which used qualitative phenomenological research design based on grounded theory principles. The studies were most commonly completed in United States of America (n = 6) [34–39] and Australia (n = 1) [40] (Supplementary File: Table 1). Parental/caregiver experience of feeding was the focus of two of the studies, with the remainder considering feeding outcomes on discharge from hospital [34,40]. Study sample sizes varied amongst studies and study design, and all were single-centre designs. The age of child participants ranged from pre-term infant <37 weeks gestational age to 36 months and 25 to 46 years-of-age for parents/caregivers. Four of the seven articles focused on feeding abilities/difficulties amongst infants with CHD following cardiac surgery [35,36,38,39]. Two papers presented feeding difficulties in infants in the NICU, with one of these describing the characteristics of poor feeders and identifying the long term feeding outcomes for pre-term infants [37]. The other paper describes parental experiences of infant feeding in the NICU [34]. The final paper reported feeding difficulties amongst young NICU and PICU survivors, which included premature infants and/or those with congenital birth defects including CHD [34].

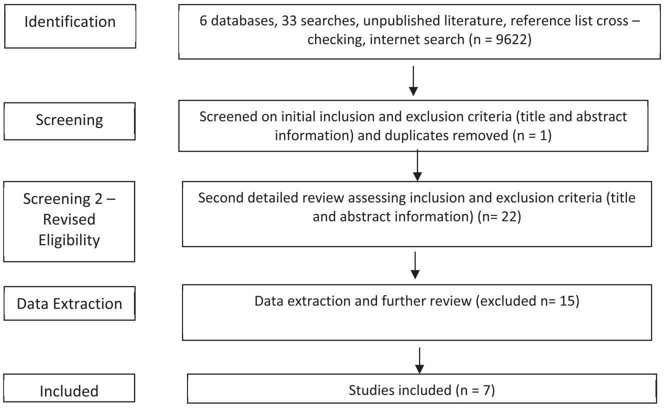

**Fig. 1.** PRISMA diagram showing search results. N, number of citations.

Using content analysis of the findings from the seven papers, 50 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: prevalence of feeding difficulties; predictors and risk factors for developing feeding difficulties; parental/carer experience and emotional response to feeding difficulties and challenges in accessing feeding support (Fig. 2).

## 4. Category 1: prevalence of feeding difficulties

### 4.1. PICU survivors

In a small qualitative study interviewing parents of young children who had survived a critical illness, Lutz et al. [36] found that children experienced a combination of behavioural, relational, mechanical and physiological problems. Parents reported oral aversion in toddlers, with several requiring long-term NGT feeding, with feeding difficulties persisting, reoccurring, or worsening following discharge home [36]. Although this study described feeding difficulties in young survivors of intensive care, the children in this study were not however previously healthy children, but rather included premature infants and/or those with congenital birth defects including CHD.

### 4.2. NICU survivors

The prevalence of feeding difficulties amongst NICU graduates varied considerably [35–38]. Specific feeding difficulties experienced by preterm infants at 36 weeks gestational age was explored by Swift et al. [40] where 44% of infants had difficulty latching to the breast, 89% experience fatigue during a feed which included an inability to attempt suckling. Other difficulties included a liquid loss due to poor lip seal around the breast/bottle (22%), ineffective feeding due to short suck-burst techniques (56%), unusual swallowing noises (44%) and experienced feeding intolerance including vomiting and reflux (44%). Furthermore, parents of NGT fed infants,

Please cite this article as: Morton K et al., Feeding difficulties in young paediatric intensive care survivors: A scoping review, Clinical Nutrition ESPEN, https://doi.org/10.1016/j.clnesp.2019.01.013

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

| Initial coding (n = 50) | Sub-categories (n = 8) | Overarching themes/categories (n = 4) |
|---|---|---|
| Ability to feed orally | Prevalence and longevity | Prevalence of feeding difficulties [35–38] |
| Prevalence | | |
| Time taken to feed | | |
| Meeting nutritional requirements Cardiac surgery | | |
| Specific feeding difficulties | Feeding difficulty definitions and assessments | Risk factors and predictors for developing feeding difficulties [6,34–41] |
| Acute vs. chronic | | |
| Feeding assessments | | |
| Growth | | |
| Oral programme | | |
| Nasogastric tube feeds | | |
| Loss of skill acquisition | | |
| Endo tracheal tube intubation | | |
| Mechanical ventilation | | |
| Gastro-oesophageal reflux disease | | |
| Parental distress | Clinical/procedural interventions | Parental/Carer experience and emotional response to feeding difficulties [35-39, 41] |
| Prematurity | Missing feeding experiences | |
| Endotracheal tube intubation and mechanical ventilation/respiratory support | Missing developmental milestones | |
| Severity of illness | | |
| Cardiac surgery | | |
| Predictors of feeding difficulty | | |
| Length of parenteral and enteral feeding | | |
| Expression of breastmilk | | |
| Breastfeeding focus | | |
| Scheduling of feeding | | |
| Feeding intervention | | |
| Specialist feeding intervention | | |
| Unhelpful | | |
| Privacy | | |
| Degrading | | |
| Mealtimes | | |
| Feeding aversion | | |
| Frustration | Family functioning | Challenges to access support for feeding difficulties [34,37,40,41] |
| Fatigue | Misunderstood | |
| Feed as focus | Insufficient and inconsistent support | |
| Failure at parental competence | | |
| Social isolation | | |
| Opinions not valued | | |
| Lack of information and support | | |
| Feeding inconsistency | | |
| Frustration | | |
| Bonding | | |
| Strains/stress | | |
| Support | | |
| Sensitive staff | | |
| Taking baby home | | |
| Lack of extended family/friend support | | |
| Nursing ownership | | |
| Health complications | | |
| Maternal competence | | |

reported dissatisfaction with long term NGT feeding as they felt their infant did not derive any enjoyment from feeding [37]. Those being fully orally fed at hospital discharge ranged from 55% up to 93% within the literature [35–38].

Definitions of feeding difficulties amongst the studies included oromotor readiness for feeding from a bottle up to 120 ml/kg [35], time to reach goal feeds including oral feeds [36], and ability to effectively latch to the breast, co-ordinated swallow, liquid loss and fatigue on feeding [40].

### 4.3. *CHD infants*

Feeding difficulties in infants with CHD who survived an admission to intensive care mirrored those found in preterm infants, such as prolonged time to reach feeding goals, prolonged time to transition to oral feeds, in addition to the continued requirement for NGT feeds in some infants [30,32,34]. Feeding difficulties were often defined as the ability of infants to feed entirely orally, by bottle, breast or both, with almost a half of infants not being able to do this at hospital discharge [36].

## 5. Category 2: risk factors and predictors for developing feeding difficulties

### 5.1. *PICU survivors*

In the studies found in this scoping review, there were no risk factors or predictors specifically identified for previously well PICU survivors.

### 5.2. *NICU survivors*

Risk factors associated with the development of feeding difficulties included the duration of ETT intubation and mechanical ventilation and/or respiratory support, all of which had a negative effect on oral feeding ability [35–39,41]. The risk of not feeding

Please cite this article as: Morton K et al., Feeding difficulties in young paediatric intensive care survivors: A scoping review, Clinical Nutrition ESPEN, https://doi.org/10.1016/j.clnesp.2019.01.013

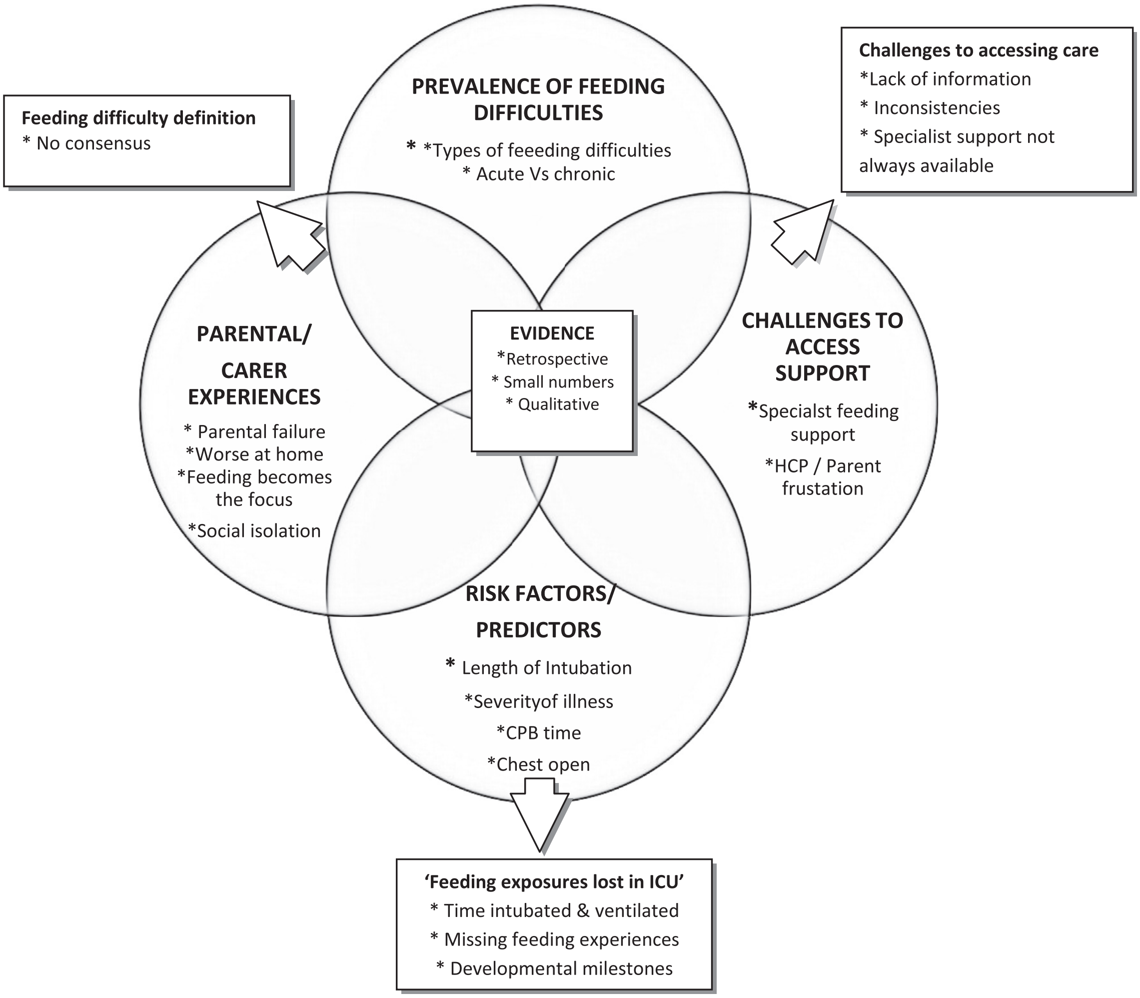

**Fig. 2.** Overarching themes and interdependent relationships.

orally at discharge increases by 10% for each day of mechanical ventilation and ETT intubation [38]. Preterm infants who experienced multiple oral interventions including oral ETT intubation as part of a NICU stay, required longer periods of NGT feeds post discharge and had poorer oral motor skills, compared to those who had little or no oral medical interventions [37].

### 5.3. *CHD infants*

Additional risk factors for feeding difficulties in infants undergoing cardiac surgery included the type of cardiac surgery, specifically aortic arch repair, length of cardio-pulmonary bypass time and post-op chest open [35,36,38,39], in addition to withholding of feeds and the presence of gastro-oesophageal reflux disease [39]. Furthermore, the time taken (days) to start oral feeding and time taken (days) to reach full volumes of oral feeds for infants following cardiac surgery, were also reported as risk factors for feeding difficulties [37,38,40,41].

## 6. Category 3: parental/carer experience and emotional response to feeding difficulties

### 6.1. *PICU survivors*

At home following discharge from intensive care, parents describe feeding as becoming the central focus of family life, which results in family tension, stress and social isolation for families. This left families feeling alone and misunderstood by others around them, adding to their burden and sense of responsibility [34].

### 6.2. *NICU survivors*

Feeding as a source of parental distress for families of NICU graduates was frequently reported in the qualitative papers [37,40]. Parents of critically ill preterm infants describe emotional fatigue around feeding their baby and question whether they know their baby well enough to understand their feeding cues. Many parents describe feeling that health care professionals knew their baby better, undermining their confidence and ability in how to feed and care for their baby [40]. At the time of hospital discharge, feeding becomes the overwhelming focus, with many parents feeling ill prepared for the complex preparation of certain feeds and the time required to dedicate to feeding, with feeds taking up to 60 min [34]. This is in addition to the lack of progression with oral feeding and feeding skill acquisition [40]. Isolation and violated expectations, with insufficient support is a commonly shared experience by all parents [34,40].

At home, parents describe feeding as becoming the central focus of family life, which results in family tension, stress and social isolation for families. This left families feeling alone and misunderstood by others around them, adding to their burden and sense of responsibility [34]. The impact of feeding difficulties was

Please cite this article as: Morton K et al., Feeding difficulties in young paediatric intensive care survivors: A scoping review, Clinical Nutrition ESPEN, https://doi.org/10.1016/j.clnesp.2019.01.013

reported to continue for a long time, with some parents reporting no enjoyment at mealtimes even at 12 months of age [35,37].

## 7. Category 4: challenges in accessing feeding support

Some parents view anticipated feeding progress and feeding perceptions between parents, health care professionals and between health care professionals in varying medical domains, positively. However, there were also frustrations felt by parents and health care professional alike, around issues of communication and lack of collaboration, resulting in conflict and parents feeling unheard [34,37,40]. Many parents and health care professionals also describe a number of barriers to accessing specialist feeding support and appropriate interventions or information which could be parent or health care professional led. For parents who were able to access specialist feeding clinics, many cite the difficulties and expense of attending multiple clinic appointments, often at centres far away from where the family live. This particularly impacted on working families and many parents felt these programmes of care did not meet their child's needs. Other families received inadequate support due to caseload constraints of local services. They concluded that parents would benefit from “sensitive, respectful collaboration” and also “anticipatory guidance and pre-discharge education by nurses" on topics as developmental changes affecting feeding, paediatric nutrition needs, and specific feeding techniques and speciality items, such as “nipples” [36].

## 8. Discussion

The purpose of this scoping review was to examine the available evidence on what is known about the prevalence, risk factors for and type of feeding difficulties amongst previously healthy young PICU survivors as well as parental/caregiver feeding experiences. Using a content analysis approach in reviewing the data, we identified 50 descriptive codes within the seven studies. From this, a further 8 sub-categories were formed resulting in 4 overarching interdependent categories identified. The categories as discussed in the results were; the prevalence of feeding difficulties; predictors and risk factors for developing feeding difficulties; parental/carer experience and emotional response to feeding difficulties and challenges in accessing feeding support.

In this review, we were not able to identify any specific data relating to the prevalence of feeding difficulties amongst previously healthy PICU survivors. One qualitative study interviewing parents of young children who had survived intensive care, suggested that feeding difficulties reoccurred, persisted or worsened once home. It is, however, important to note that within this cohort of 11 children, seven were previously preterm or low birthweight and four had a congenital or genetic disorder [34]. As such, it is unclear as to how many of these children had some degree of feeding difficulty prior to their PICU admission and whether this was further exacerbated by a period of critical illness [36–39]. As reported in the reviewed studies, up to 40% of preterm infants may have long term feeding difficulties [38–41] and similar numbers seen in infants with congenital heart disease [36,43,44]. It is important to note that preterm infants and those with chronic diseases represent a unique population group and as such, the pathology of feeding difficulties amongst these children may differ from those in previously healthy PICU survivors.

The terminology used to describe feeding difficulties in this scoping review differs from those used to describe food refusal in the general paediatric population [6,42], as it is centred around the acquisition of feeding skills in a primarily preterm infant population [37,40,41]. There is some overlap with the general paediatric population and children with chronic disease paediatric population relating to the introduction of complementary food mealtimes and feeding skill acquisition. For example, amongst the non-PICU population, childhood feeding disorders can arise as a result of a concurrent disease, behavioural problems or as a combination of both [7,10,23,25]. Levin et al. [45] proposed a screening criteria for diagnosing infantile feeding disorders which includes 5 domains; i) nocturnal feeding – dream feeding infant or young children whilst they are asleep, ii) persecutory feeding – repeated unsuccessful attempts to feed an infants, iii) forced feeding – forcing an infant to eat or drink, iv) mechanistic feeding – feeding at prescribed times e.g. clockwork feeding, ignoring feeding cues and v) conditional distraction – feeds or meals are only taken with distractions [42].

We found limited evidence considering the impact of a PICU admission on feeding amongst children with prior age appropriate feeding skills and patterns of eating [43]. PICU survivors may experience a similar regression of feeding skill and inability to progress onto age appropriate textured complimentary foods as has been described in the general paediatric literature amongst children who are NG fed [44] and those who had delayed introduction of complementary food [4,45]. Although this has not been described and would require further investigation.

With regards to predictors of and risk factors for, an admission to intensive care is associated with multiple physical and environmental stressors, often involving many painful oral cavity experiences such as insertion and use of ETTs and NGTs, oral suctioning procedures and repeated mouth care. Evidence from adult intensive care reports increased risk of dyphagia and reduced ability to orally feed at discharge amongst adults who are intubated for longer than 48 hrs [23–26]. A similar association is seen in younger children with CHD who, following cardiac surgery, are at risk of developing feeding difficulties, specifically vocal cord palsy and subsequent dysphagia [46]. Risk factors associated with this are cardio pulmonary bypass time, high-risk surgery [47–49] and open-chest post operatively, all of which are seen as contributing factors to post-operative feeding difficulties [35–37]. Due to the associated increase in intubation times, these procedures could reduce feeding exposure, delay the transition to oral feeding and prevent infants from meeting feeding developmental milestones whilst intubated and ventilated [35–38,40].

Bedside programmes that include aspect of positive touch have been reported amongst infants with CHD, but not extended to the wider PICU population. Positive touch programmes encourage parents and health care professionals to complete a set of exercises around the infant's face and mouth with the aim of reducing oral aversion and improving oral intake following ETT intubation and intensive care admission [39].

Parental experience around feeding describes feeding difficulties amongst preterm infants including parental distress, social isolation and a loss of enjoyment of feeding and mealtime further down the line [34]. This phenomenon has also been described amongst infants with CHD, with parents describing a lack of support, loss of being a parent, acting more like a carer for their infant and inconsistent and conflicting messages from health care professionals [12,13]. Parents of young PICU and NICU survivors expressed the need for more guidance around feeding during and after hospitalisation, and identified an important gap in discharge education for families, specifically on how to promote feeding skill acquisition or skill retention. Parents also felt that their opinions were not always appreciated both in hospital and after discharge, which added to their distress [34,41].

With regards to feeding support, several articles reported that health care professionals, alongside parents, are fundamental in providing early assessment of feeding ability and therefore assessment and planning of additional support and early intervention for feeding difficulties [34,38]. However, there is

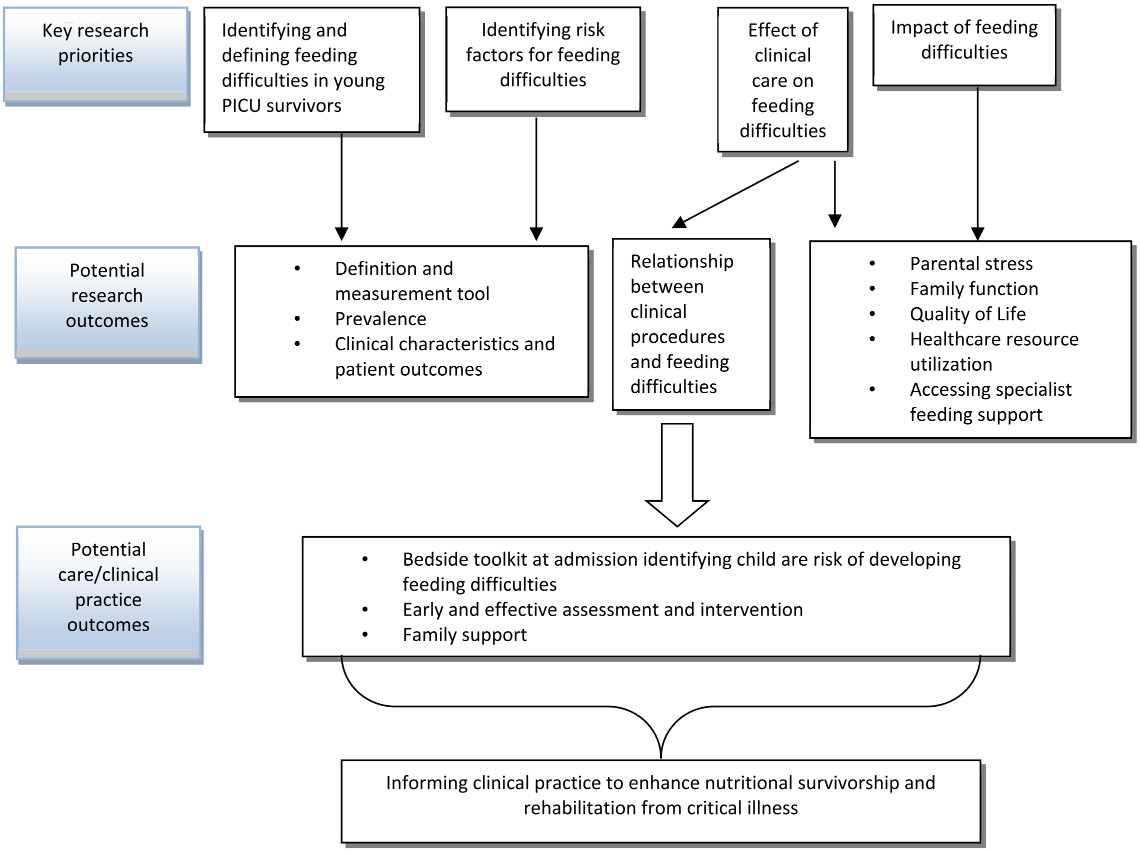

**Fig. 3.** Key research and care priorities.

considerable variation with regards to the ability to access support with many parents reporting a significant burden of having to attend appointments and traveling long distances to see health care professionals [37]. In other work involving parents of infants with CHD, those who were provided with feeding support before surgery had improved psychosocial well-being [50]. However, the link between feeding information and expectation setting around feeds was not fully established. Further work is required in all of these areas to ensure that any programmes of work or information packages are accessible, feasible and sustainable for a large group of parents and health care professionals.

### *8.1. Limitations*

This is a scoping review to present the current range of evidence specific to feeding difficulties in young survivors of intensive care. The results should not be generalised beyond this paper other than about the quality of the available evidence. A significant issue within this review was the lack of evidence regarding the prevalence and range of feeding difficulties amongst previously healthy children, which is why the literature included in this scoping review explores what is known about feeding difficulties amongst preterm infants and infants with chronic disease. Given this, it was not possible to synthesis results or reliably estimate prevalence and impact.

### *8.2. Future research and care priorities*

Given our lack of understanding around the current extent or type of feeding difficulties that previously well children may experience, appropriately identifying, diagnosing and managing ongoing feed/food refusal and poor oral intake represents a considerable challenge amongst this cohort of PICU survivors and is likely to hinder early diagnosis [2,6,51]. Several key areas for future research and care priorities are evident from this scoping review process (Fig. 3). There is a need for a consensus around the definition of feeding difficulties in young previously healthy PICU survivors, in order for health care professionals to apply in clinical practice. Further research is needed considering the type and duration of feeding difficulties as an outcome in the previously healthy PICU population, and to investigate the benefit of early assessments at PICU admission, identifying those children at risk of developing feeding difficulties. This can then be applied into clinical practice at the bedside, as a total body of work improving survivorship and rehabilitation from critical illness. Future research should also investigate the impact of feeding difficulties in young PICU survivors on family functioning and health care utilisation, including community input, hospital readmissions and the long -term effect on growth and development. In addition, work should consider factors that influence PICU clinical care, specifically at reducing intubation times and the effect that non-invasive ventilation may have on feeding difficulties.

In the future, the development of health care professional and parent information including training packages around feeding and the prevention of feeding difficulties during a PICU stay [19,21,48] should be considered with the aim of increasing parental coping skills and quality of life during and after a PICU admission.

## 9. Conclusion

This scoping review found no evidence relating to the prevalence or risk factors for developing feeding difficulties amongst

Please cite this article as: Morton K et al., Feeding difficulties in young paediatric intensive care survivors: A scoping review, Clinical Nutrition ESPEN, https://doi.org/10.1016/j.clnesp.2019.01.013

previously healthy children who survive a PICU admission. The review identified limited and varying evidence describing the prevalence of feeding difficulties in the neonatal and paediatric ICU population amongst children with chronic/congenital diseases or co-morbid diseases of prematurity. The impact of feeding difficulties on parents and family life was evident amongst NICU graduates and those with CHD, although there is a paucity of high quality evidence, with the published studies dominated by retrospective, single-centre, small sample sized designs, limiting the generalisability and transferability of the results to previously well children admitted to PICU. There was also a lack of consensus within the definitions of feeding difficulties which may hinder the development of a program of care for previously healthy PICU survivors at risk of feeding difficulties. Further research needs to be undertaken that identifies common key features of feeding difficulties in young previously healthy survivors of PICU, its prevalence and impact of family life and health care utilisation.

## Conflict of interest

None.

## Acknowledgements

None.

## Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.clnesp.2019.01.013.

## Funding

This report is the result of 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, Health Education England or the Department of Health. Kathryn Morton was supported by an Internship arising from an Integrated Clinical Academic Clinical Lectureship: ICA-CL-2016-02-001 supported by the National Institute for Health Research and Health Education England.

## Statement of authorship

Authors made the following contribution to the manuscript [1]: KM, LVM formulated the original idea [2], KM completed the database search [3] KM, LVM completed the data extraction and analysis [4] KM drafted the manuscript [5] ASD, JVP, LVM reviewed and revised the manuscript for important intellectual content [6], and all authors provided final approval of the version to be submitted.

## References

[1] Kerzner B. Clinical investigation of feeding difficulties in young children: a practical approach. Clinical Pediatrics 2009;48(9):960–5.

[2] Kerzner B, Milano K, MacLean Jr WC, Berall G, Stuart S, Chatoor I. A practical approach to classifying and managing feeding difficulties. Pediatrics 2015;135(2):344–53.

[3] Richman N, Stevenson JE, Graham PJ. Prevalence of behaviour problems in 3-year-old children: an epidemiological study in a London borough. J Child Psychol Psychiatry 1975;16(4):277–87.

[4] Wright CM, Parkinson KN, Shipton D, Drewett RF. How do toddler eating problems relate to their eating behavior, food preferences, and growth? Pediatrics 2007;120(4):e1069–75.

[5] Thoyre SM. Developmental transition from gavage to oral feeding in the preterm infant. Annu Rev Nurs Res 2003;21:61–92.

[6] Levy Y, Levy A, Zangen T, Kornfeld L, Dalal I, Samuel E, et al. Diagnostic clues for identification of nonorganic vs organic causes of food refusal and poor feeding. J Pediatr Gastroenterol Nutr 2009;48(3):355–62.

[7] Maurer I, Latal B, Geissmann H, Knirsch W, Bauersfeld U, Balmer C. Prevalence and predictors of later feeding disorders in children who underwent neonatal cardiac surgery for congenital heart disease. Cardiol Young 2011;21(3):303–9.

[8] Meyer R, Rommel N, Van Oudenhove L, Fleming C, Dziubak R, Shah N. Feeding difficulties in children with food protein-induced gastrointestinal allergies. J Gastroenterol Hepatol 2014;29(10):1764–9.

[9] 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(4):443–7.

[10] Haas AM, Maune NC. Clinical presentation of feeding dysfunction in children with eosinophilic gastrointestinal disease. Immunol Allergy Clin North Am 2009;29(1):65–75 [ix].

[11] Hill G, Silverman A, Noel R, Bartz PJ. Feeding dysfunction in single ventricle patients with feeding disorder. Congenit Heart Dis 2014;9(1):26–9.

[12] 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. Mater Child Nutri 2016.

[13] Tregay J, Wray J, Crowe S, Knowles R, Daubeney P, Franklin R, et al. Going home after infant cardiac surgery: a UK qualitative study. Arch Dis Child 2016;101(4):320–5.

[14] Powell-Tuck J. Nutritional interventions in critical illness. Proc Nutr Soc 2007;66(1):16–24.

[15] Mehta NM, Skillman HE, Irving SY, Coss-Bu JA, Vermilyea S, Farrington EA, et al. Guidelines for the provision and assessment of nutrition support therapy in the pediatric critically ill patient: society of critical care medicine and American society for parenteral and enteral nutrition. Pediatr Crit Care Med J Soc Crit Care Med World Feder Pediatr Inten Crit Care Soc 2017;vol. 18(7): 675–715.

[16] Briassoulis GC, Zavras NJ, Hatzis MT. Effectiveness and safety of a protocol for promotion of early intragastric feeding in critically ill children. Pediatr Crit Care Med 2001;2(2):113–21.

[17] Meyer R, Harrison S, Sargent S, Ramnarayan P, Habibi P, Labadarios D. The impact of enteral feeding protocols on nutritional support in critically ill children. J Hum Nutr Diet 2009;22(5):428–36.

[18] Zamberlan P, Delgado AF, Leone C, Feferbaum R, Okay TS. Nutrition therapy in a pediatric intensive care unit: indications, monitoring, and complications. JPEN J Parenter Enter Nutr 2011 Jul;35(4):523–9.

[19] Ross ES, Browne JV. Developmental progression of feeding skills: an approach to supporting feeding in preterm infants. Semin Neonatol : SN 2002;7(6): 469–75.

[20] Horner S, Simonelli AM, Schmidt H, Cichowski K, Hancko M, Zhang G, et al. Setting the stage for successful oral feeding: the impact of implementing the SOFFI feeding program with medically fragile NICU infants. J Perinat Neonatal Nurs 2014;28(1):59–68.

[21] Ross ES, Philbin MK. Supporting oral feeding in fragile infants: an evidence-based method for quality bottle-feedings of preterm, ill, and fragile infants. J Perinat Neonatal Nurs 2011;25(4):349–57. quiz 58-9.

[22] Merriweather JL, Salisbury LG, Walsh TS, Smith P. Nutritional care after critical illness: a qualitative study of patients' experiences. J Hum Nutr Diet : the official journal of the British Dietetic Association 2016;29(2):127–36.

[23] Skoretz SA, Flowers HL, Martino R. The incidence of dysphagia following endotracheal intubation: a systematic review. Chest 2010;137(3):665–73.

[24] Leder SB. Incidence and type of aspiration in acute care patients requiring mechanical ventilation via a new tracheotomy. Chest 2002;122(5):1721–6.

[25] Tolep K, Getch CL, Criner GJ. Swallowing dysfunction in patients receiving prolonged mechanical ventilation. Chest 1996;109(1):167–72.

[26] Macht M, Wimbish T, Clark BJ, Benson AB, Burnham EL, Williams A, et al. Postextubation dysphagia is persistent and associated with poor outcomes in survivors of critical illness. Crit Care 2011;15(5):R231.

[27] O'Brien S, Nadel S, Almossawi O, Inwald DP. The impact of chronic health conditions on length of stay and mortality in a general PICU. Pediatric critical care medicine : a journal of the society of critical care medicine and the world federation of pediatric intensive and critical care societies 2017;18(1):1–7.

[28] Peters MD, Godfrey CM, Khalil H, McInerney P, Parker D, Soares CB. Guidance for conducting systematic scoping reviews. Int J Evid Based Healthc 2015;13(3):141–6.

[29] Arksey HOML. Scoping studies: towards a methodological framework. Int J Soc Res Methodol: Theor Pract 2005;8(1):19–32.

[30] Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. Implement Sci : ISCUS 2010;5:69.

[31] Mole L, Kent B, Abbott R, Wood C, Hickson M. The nutritional care of people living with dementia at home: a scoping review. Health Soc Care Community 2018;26(4):e485–96.

[32] Crilly TJA, Ferlie E. Research utilisation and knowledge mobilisation: a scoping review of the literature 2012. 6 June 2018. Available from: https://repository.royalholloway.ac.uk/file/b8101c3b-4572-c3ea-57ea-73b46830629f/9/Jashapara_Research_utilisation_2010.pdf.

[33] Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. (1049-7323 [Print].

[34] Lutz KF. Feeding problems of NICU and PICU graduates: perceptions of parents and providers. Nborn Infant Nurs Rev : NAINR. 2012;12(4):207–13.

[35] Jadcherla SR, Wang M, Vijayapal AS, Leuthner SR. Impact of prematurity and co-morbidities on feeding milestones in neonates: a retrospective study. J Perinatol : official journal of the California Perinatal Association 2010;30(3): 201–8.

[36] Kogon BE, Ramaswamy V, Todd K, Plattner C, Kirshbom PM, Kanter KR, et al. Feeding difficulty in newborns following congenital heart surgery. Congenit Heart Dis 2007;2(5):332–7.

[37] Hawdon JM, Beauregard N, Slattery J, Kennedy G. Identification of neonates at risk of developing feeding problems in infancy. Dev Med Child Neurol 2000;42(4):235–9.

[38] Einarson KD, Arthur HM. Predictors of oral feeding difficulty in cardiac surgical infants. Pediatr Nurs 2003;29(4):315–9.

[39] 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: 149–54.

[40] Swift MC, Scholten I. Not feeding, not coming home: parental experiences of infant feeding difficulties and family relationships in a neonatal unit. J Clin Nurs 2010;19(1–2):249–58.

[41] Ross ESBJ. Feeding outcomes in preterm infants after discharge from the neonatal intensive care unit (NICU): a systematic review. Nborn Infant Nurs Rev 2013;13(2):87–93.

[42] Levine A, Bachar L, Tsangen Z, Mizrachi A, Levy A, Dalal I, et al. Screening criteria for diagnosis of infantile feeding disorders as a cause of poor feeding or food refusal. J Pediatr Gastroenterol Nutr 2011;52(5):563–8.

[43] Davis AM, Bruce A, Cocjin J, Mousa H, Hyman P. Empirically supported treatments for feeding difficulties in young children. Curr Gastroenterol Rep 2010;12(3):189–94.

[44] Mason SJ, Harris G, Blissett J. Tube feeding in infancy: implications for the development of normal eating and drinking skills. Dysphagia 2005;20(1): 46–61.

[45] Coulthard H, Harris G, Emmett P. Delayed introduction of lumpy foods to children during the complementary feeding period affects child's food acceptance and feeding at 7 years of age. Matern Child Nutr 2009;5(1):75–85.

[46] Matisoff AJ, Ari P, Zurakowski D, Espinel AG, Deutsch N, Reilly BK. Risk factors associated with the development of acquired airway disease after congenital heart surgery: a retrospective cohort study. Seminars in cardiothoracic and vascular anesthesia. 2018. 1089253218772848.

[47] Lal DR, Gadepalli SK, Downard CD, Ostlie DJ, Minneci PC, Swedler RM, et al. Perioperative management and outcomes of esophageal atresia and tracheoesophageal fistula. J Pediatr Surg 2017;52(8):1245–51.

[48] St Pierre A, Khattra P, Johnson M, Cender L, Manzano S, Holsti L. Content validation of the infant malnutrition and feeding checklist for congenital heart disease: a tool to identify risk of malnutrition and feeding difficulties in infants with congenital heart disease. J Pediatr Nurs 2010;25(5):367–74.

[49] Pereira Kda R, Firpo C, Gasparin M, Teixeira AR, Dornelles S, Bacaltchuk T, et al. Evaluation of swallowing in infants with congenital heart defect. Int Arch Otorhinolaryngol 2015;19(1):55–60.

[50] Lawoko S. Factors influencing satisfaction and well-being among parents of congenital heart disease children: development of a conceptual model based on the literature review. Scand J Caring Sci 2007;21(1):106–17.

[51] Chatoor I. Feeding disorders in infants and toddlers: diagnosis and treatment. Child Adolesc Psychiatr clin N Am 2002;11(2):163–83.

Please cite this article as: Morton K et al., Feeding difficulties in young paediatric intensive care survivors: A scoping review, Clinical Nutrition ESPEN, https://doi.org/10.1016/j.clnesp.2019.01.013