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Pediatric Feeding Disorder

Prevalence of Feeding Problems and Parents' Experiences

KAJSA LAMM

DEPARTMENT OF HEALTH SCIENCES | FACULTY OF MEDICINE | LUND UNIVERSITY



"SO I CAN FEEL SO-
MEWHERE, WELL, CORRECT
ME IF I'M WRONG BUT
IT FEELS LIKE THERE IS...
YOU CAN DEAL WITH NEW
HEARTS AND OPERATE ON
BRAINS AND SUCH, BUT
**TEACHING A CHILD
TO EAT IS BLOODY
ROCKET SCIENCE...**
IT'S LIKE "I CAN CHANGE
YOUR HEART, COME ON IN
TOMORROW AND WE'LL FIX
IT", BUT WE CAN'T GET OUR
CHILD TO EAT, IT'S IMPOS-
SIBLE. DO YOU SEE WHAT I
MEAN?" MOTHER 8

"AT THE CHCC THEY SEE THE-
SE GROWTH CHARTS... BUT
THEY CAN'T SEE.. **HOW**
MUCH EFFORT IT TAKES
BOTH FROM THE CHILD AND
THE PARENTS, WHAT IT IS
YOU **SACRIFICE** TO GET
THERE." FATHER 3

Pediatric Feeding Disorder

Prevalence of Feeding Problems and Parents' Experiences.

Kajsa Lamm



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Licentiate Thesis

by due permission of the Faculty of Medicine, Lund University, Sweden.
To be defended at Health Science Centre, Lund on 26th of August 2022 at 13.00

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Title and subtitle: Pediatric Feeding Disorder Prevalence of Feeding Problems and Parents' Experiences			
<p>Abstract</p> <p>Feeding Problems (FP) are common in children and can be a precursor for Pediatric Feeding Disorder (PFD), which is a complex disorder where four domains interplay: medical, nutritional, feeding skills and psychosocial. Gaining understanding and knowledge of how FP and PFD affect children and parents may facilitate the detection of these conditions earlier, and thus help improve care.</p> <p>The aim of this thesis is to describe the prevalence of Feeding Problems in Sweden and explore how Pediatric Feeding Disorder affect parents and families. The thesis is based on two studies: one cross-sectional study of the prevalence of FP in the western part of Skåne, Sweden, and one qualitative interview study with 20 parents of children with PFD, from different places in Sweden.</p> <p>Study I used the Behavioral Pediatrics Feeding Assessment Scale and found that parents of 8.4 to 9.3% of children aged 10 months to 3 years perceived their child as having FP severe enough to warrant referrals for investigation and possible intervention. Study II showed that parents of children with PFD experienced intense stress in their daily life and expressed a constant struggle to find help for their children, but they also experienced hope and joy when their child's health and feeding improved.</p> <p>Early detection and intervention for children with FP may stop some children's difficulties with feeding from evolving into PFD. Gaining knowledge of prevalence of FP in young children and parents' experiences of living with a child with PFD is an important step in developing interventions to prevent PFD.</p> <p>This thesis builds on and expands previous research and contributes to the knowledge base of a growing research field.</p>			
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Pediatric Feeding Disorder

Prevalence of Feeding Problems and Parents' Experiences.

Kajsa Lamm



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MADE IN SWEDEN 

To Ingrid and Märta,

and all the children with PFD.

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Abstract

Feeding Problems (FP) are common in children and can be a precursor for Pediatric Feeding Disorder (PFD), which is a complex disorder where four domains interplay: medical, nutritional, feeding skills and psychosocial. Gaining understanding and knowledge of how FP and PFD affect children and parents may facilitate the detection of these conditions earlier, and thus help improve care.

The aim of this thesis is to describe the prevalence of Feeding Problems in Sweden and explore how Pediatric Feeding Disorder affect parents and families. The thesis is based on two studies: one cross-sectional study of the prevalence of FP in the western part of Skåne, Sweden, and one qualitative interview study with 20 parents of children with PFD, from different places in Sweden.

Study I used the Behavioral Pediatrics Feeding Assessment Scale and found that parents of 8.4 to 9.3% of children aged 10 months to 3 years perceived their child as having FP severe enough to warrant referrals for investigation and possible intervention.

Study II showed that parents of children with PFD experienced intense stress in their daily life and expressed a constant struggle to find help for their children, but they also experienced hope and joy when their child's health and feeding improved.

Early detection and intervention for children with FP may stop some children's difficulties with feeding from evolving into PFD. Gaining knowledge of prevalence of FP in young children and parents' experiences of living with a child with PFD is an important step in developing interventions to prevent PFD.

This thesis builds on and expands previous research and contributes to the knowledge base of a growing research field.

Abbreviations and definitions

BPFAS	Behavioral Pediatrics Feeding Assessment Scale
CCC	Child-Centred Care
CHCC	Child Health Care Centre / (Barnvårdscentral, BVC)
Children	People under the age of 18
CHS	Child Health Services / (Barnhälsovård, BHV)
CHS nurse	Child Health Services nurse
CHP	Child Health Program
CNI	Care Need Index
DSM-IV/V	Diagnostic and Statistical Manual of Mental Disorders, version IV/V
Eating	Bringing food to the mouth and consuming it
EN	Enteral Nutrition
FD	Feeding Disorder
Feeding	Give food to / being given food
FP	Feeding Problems
G-tube	Gastrostomy tube / gastrostomi, ”knapp”
HCP	Health Care Professionals
ICD-10	International Statistical Classification of Diseases and Related Health Problems, version 10.
ICF	International Classification of Functioning, Disability and Health
ICFQ	Infant and Child Feeding Questionnaire
NG-tube	Naso-gastric feeding tube

Parents	Formal care givers living with the child
PFD	Pediatric Feeding Disorder
SLP	Speech and Language Pathologist
WHO	World Health Organization

Original papers

- I Lamm, K., Landgren, K., Vilhjálmsdóttir, R., Kristensson Hallström, I.,
Feeding problems in young children: a cross sectional study in Sweden.
In manuscript/submitted.
- II Lamm, K., Kristensson Hallström, I., Landgren, K. Parents' experiences of
living with a child with Paediatric Feeding Disorder: An interview study in
Sweden. Scandinavian Journal of Caring Sciences. January 2022.
doi.org/10.1111/scs.13070

Introduction

Eating is one of the most important skills children learn during early childhood, if not the most important. Much of parenting is situated around mealtimes, and parents provide food for their children starting right after birth (Were & Lifschitz, 2018). Feeding is fundamental to parenting (Silverman, 2010), and parents and health care providers assess the health and well-being of the infant by looking at how the child feeds (Delaney & Arvedson, 2008). When feeding their child is easy, parents experience a feeling of taking care of their child. When feeding becomes difficult, both parents and the child can suffer: the child can become malnourished, parents experience stress and attachment can be affected as well (Silverman, 2010).

Many children have mild transient feeding problems in their younger years, but most problems resolve spontaneously, or with minimal intervention from health care providers. However, Feeding Problems (FP) can develop into a more disordered feeding that can profoundly impact the child's development and growth regarding physical, social, emotional and/or cognitive functions (Goday et al., 2019; Were & Lifschitz, 2018).

In 2019, the consensus definition and conceptual framework Pediatric Feeding Disorder (PFD) was published (Goday et al., 2019). PFD is defined as the child not feeding appropriately for their age for more than two weeks and having a dysfunction in one or more of the four domains: medical, nutritional, feeding skill and psychosocial.

A scoping review (Estrem et al., 2022) found that most research on PFD is performed in the UK, USA and Australia, and Hewetson & Singh (2009) noted the same for research on experiences of feeding. The scoping review identified a research gap regarding a lack of studies on children aged between 1 month and 2 years – the period in which children are introduced to and learn to eat solid food. It is important to describe PFD in different health care contexts, as health care systems and cultures differ from nation to nation and results may not always be generalizable.

If identified early, FP may be resolved for many children. To be able to help children with FP or PFD, knowledge about prevalence of these conditions and the experiences of the parents is necessary.

Background

Development of feeding and eating in young children

Eating and feeding are complex tasks that children must learn. Eating is primarily an oral phase, whereas feeding also involves anticipatory reactions, getting the food into the mouth, processing and swallowing it. Feeding is also considered a broader term, including the interactions between children and care givers. Both eating and feeding involves coordinating interactions of many of the body's organs, muscles and nerves, and learning takes place in close interaction with the parents in the parent-child dyad (Aldridge et al., 2010; Chatoor & Ganiban, 2003 ; Delaney & Arvedson, 2008; Goday et al., 2019). The first years of life are important when building competence in eating, regarding both oral motor skills and sensory skills such as being able to tolerate different tastes and textures. Children develop preferences for the taste of different foods early – they learn to like new foods by repeated exposures, and the food must also be presented in a positive context (Birch & Fisher, 1998; Delaney & Arvedson, 2008; Were & Lifschitz, 2018). Feeding development relies on the overall development of the child, and if this is impaired so is feeding (Kleinert, 2017).

When looking at feeding from a parental perspective, from early days in the child's life much of parenting revolves around feeding the child. Parents regard food and feeding as an important subject in relation to their child's health, described in terms of both concern and joy (Almqvist-Tangen et al., 2017; Silverman, 2015a; Were & Lifschitz, 2018). The parent-child relationship is important for the child's feeding development, and vice versa: feeding has an important role to play in the development of the parent-child relationship. Feeding is in itself a form of socialization; positive feeding interactions develop into mealtimes where the child masters feeding skills, develops willingness to try new foods and expresses satiety (Silverman, 2010; Were & Lifschitz, 2018). When parents respect the child's own responsibilities in the parent-child dynamic during feeding and mealtimes, these moments become positive experiences for the child and parent alike (Satter, 2007; Were & Lifschitz, 2018).

Oral motor development from a feeding perspective is typically automated around two to three years of age. However, as early as one year of age, children have gained the

postural control to sit independently, partially feed themselves, and eat most of the foods that the rest of the family eats (Gosa et al., 2020; Livsmedelsverket, 2021; Were & Lifschitz, 2018). Later, children achieve the ability to masticate (bite and chew) tougher textures like whole meat. Feeding and eating is, however, not only a motor activity. The sensory system is deeply involved in eating, and for the child to independently and in a safe and effective way master biting, chewing and swallowing, the motor response must be adequately coordinated with the sensory registration (Were & Lifschitz, 2018). Children need to be presented with and have the opportunity to experience many different tastes and textures, as sensory aspects of feeding involve taste, smell, registration of different textures and temperatures, proprioception, interoception, and sound and vision (Delaney & Arvedson, 2008). Early exposure to vegetables and fruits has been associated with better acceptance of these foods later on (Skinner et al., 2002). Even so, it is not uncommon for children to experience difficulties during feeding development.

Feeding Problems and Feeding Disorders

Feeding Problems

Feeding Problems (FP) are common among children and can be the starting point of a continuum, with mild and often transient difficulties that for some children develop into severe Feeding Disorders (FD) (Estrem et al., 2022; Nygren et al., 2021; Sharpet al., 2010). FP have been acknowledged for a long time, but a definitive classification system or definition has been lacking (Bohlin G, 1995; Bryant-Waugh et al. 2010; Goday et al., 2019; Were & Lifschitz, 2018). FP include the child refusing certain types of food, problems during mealtimes and/or problems with feeding on their own (Crist & Napier-Phillips, 2001). Other symptoms can include selectivity in what foods are accepted, need of distraction during mealtimes and feeding skills that are not age-appropriate.

The time up until two years is critical in feeding development, and FP typically manifest at 6 months to four years of age (Aldridge et al., 2010; Estrem et al., 2022; Silverman, 2015b). FP can show up as problematic or challenging behaviours from the child from the parents' perspective. Young children who are learning to eat seldom have the vocabulary to express why they cannot eat a certain food. They experience the mealtime, and food, as a stressor, and try to avoid it in any way possible. The child's behaviour may be a reaction to a negative sensory experience, for example nausea or

pain, or difficulties in the oral control of the food (Piazza, 2008). Young infants can have painful associations to gastrointestinal issues that can lead to conditioning which can manifest in FP (Goday et al., 2019; Were & Lifschitz, 2018).

Early FP may be an indicator of difficulties in the parent-child relationship (Satter, 1995). If the parent experiences anxiety and stress around their child's mealtimes and growth and perceives their child's feeding as inadequate, they may try to increase the child's intake by different methods such as feeding more frequently, force feeding, or pressuring and coaxing in other ways. This might make the mealtime stressful for the child, resulting in aversion or even more severe consequences as the child tries to avoid being over-fed or force-fed, or tries to avoid mealtimes altogether (Coulthard & Harris, 2003; Goday et al., 2019; Kerzner et al., 2015; van Dijk et al., 2016; Were & Lifschitz, 2018).

The prevalence of FP is difficult to establish due to the lack of consensus regarding definition and classification. In general, younger children have more feeding problems than older (Were & Lifschitz, 2018). In 1986, Swedish researchers found a prevalence of 1.4% of FP for infants aged three to 12 months where FP was defined as colic, vomiting and refusal to eat (Dahl & Sundelin, 1986). Prevalence ranging from 1.4 to 52% has been found in different studies and articles (Arvedson, 2008; Benjasuwantep et al., 2013; Manikam & Perman, 2000; Sdravou et al., 2021; Sharp et al., 2010).

Feeding Disorders

Feeding Disorders can exist on their own but may also be an indicator of developmental delay in early years (Delaney & Arvedson, 2008; Putnick et al., 2022). Historically, a multitude of classifications and definitions regarding FP and FD has made comparing research challenging, including prevalence numbers and outcomes in intervention studies (Bohlin G, 1995; Goday et al., 2019). FD, as well as FP, have traditionally been classified in a dichotomy of non-organic or organic. FD have multiple etiologies, and rarely is there a singular factor that is responsible (Manikam & Perman, 2000; Rybak, 2015; Were & Lifschitz, 2018; Williams et al. 2010). Piazza defined FD as "a heterogeneous set of problems that may include inadequate caloric and nutritional intake, growth failure, skill deficits, oral motor deficits and/or behavioral problems" (2008).

FD differ from Eating Disorders (ED), as children, adolescents and adults with ED have problems with perception of body image, with the exception of Avoidant Restrictive Food Intake Disorder (ARFID) (American Psychiatric Association, 2013).

ARFID is characterized by the child or adolescent having a disturbance in eating or feeding, manifested as lack of interest in food, avoidance based on sensory characteristics of certain food or concerns about aversive consequences of eating, and resulting in weight loss, nutritional deficiency, dependence on enteral feeding or oral nutritional supplements and/or interference with psychosocial functioning. ED are diagnosed and coded by the Diagnostic and Statistical Manual (DSM) (American Psychiatric Association, 2013), whereas FD are to be found in the International Classification of Diseases (ICD) (WHO, 2016).

In the International Classification of Diseases 10th revision (ICD-10), there are mainly two diagnoses for children with FP or FD: *F98.2: Other feeding disorders of infancy and childhood*, which requires the absence of organic disease, or *Feeding Difficulties, R63.3* (Organization, 1990/2016). The Swedish translations for these diagnoses are *matvägran* (F98.2) meaning 'food refusal' or *dåliga matvanor* (R63.3), meaning 'bad food habits'.

Reported prevalence of FD varies, and in the literature it is not always possible to distinguish prevalence of FP from FD. Manikam & Perman (2000), using the terms FP and FD interchangeably, wrote in 2000 that 3-10% of children have more serious FD, referencing Lindberg et al., (1991). They found that 25% of parents had experienced feeding problems for their child in the first six months, and more than 10% experienced ongoing problems. For children with developmental disabilities, FP and FD are more prevalent, as these children face further challenges when it comes to oral feeding development. From one third up to 80-90% of children with developmental disabilities have some level of FD, and for children with Autism Spectrum Disorder numbers as high as 89% have been reported (Sharp et al., 2010; Silverman, 2015). It has also been shown that as the severity of intellectual disability increases, so does the severity of the FD (Kleinert, 2017). Children born pre-term are also known to be at risk of feeding problems (Rommel, De Meyer, Feenstra, & Veereman-Wauters, 2003; van Dijk, Bruinsma, & Hauser, 2016).

Pediatric Feeding Disorder

In 2019, the proposed unifying diagnostic term Pediatric Feeding Disorder (PFD) was published (Goday et al., 2019), which aims for a more holistic approach to FD. It is not only a consensus definition, but also a conceptual framework, useful for both clinical purposes and research. PFD is based on the International Classification of Functioning, Disability and Health (ICF), meaning PFD puts emphasis on functional

limitations (World Health Organization, 2001). In ICF, a biopsychosocial model of health is used to describe functioning as an interaction between bodily structures and functions, activities, and participation in context of environmental and personal factors. In PFD, the four domains shown in Figure 1, can interact and affect one another just as the six domains of ICF.

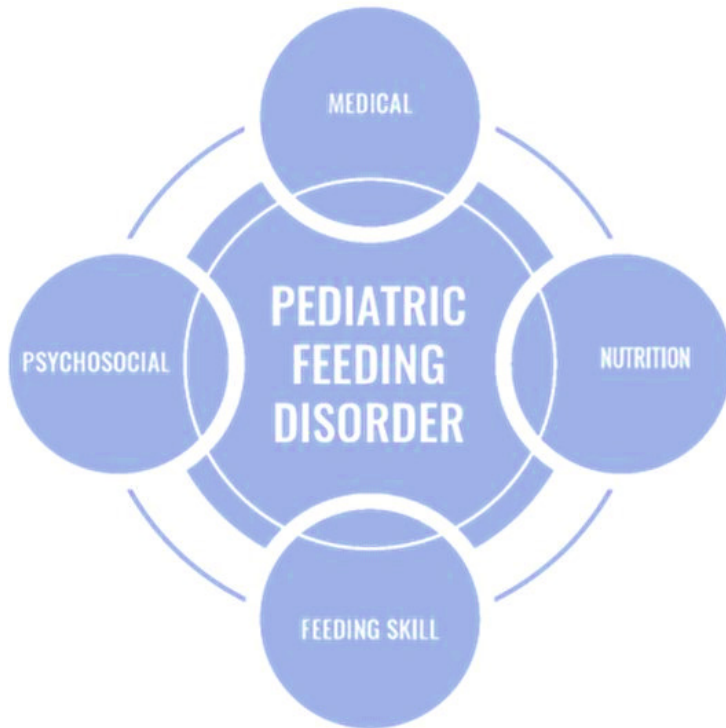


Figure 1. The four domains of PFD. Copyright by Feeding Matters.

PFD is defined as an impaired oral intake, referring to the inability to consume enough liquid and food to meet nutritional requirements, in an age-appropriate way, as shown in the diagnostic criteria cited below. There is often a complex interaction between the domains, and it is important to know that dysfunction in one domain might manifest in another. To separate PFD from ED, PFD should only be diagnosed in the absence of disturbances in body image.

The exact definition of PFD, as published by Goday et al (2019, pg. 125), is:

- A. “A disturbance in oral intake of nutrients, inappropriate for age, lasting at least 2 weeks and associated with 1 or more of the following:
 - 1. Medical dysfunction, as evidenced by any of the following:
 - a. Cardiorespiratory compromise during oral feeding
 - b. Aspiration or recurrent aspiration pneumonitis
 - 2. Nutritional dysfunction, as evidenced by any of the following:
 - a. Malnutrition
 - b. Specific nutrient deficiency or significantly restricted intake of one or more nutrients resulting from decreased dietary diversity
 - c. Reliance on enteral feeds or oral supplements to sustain nutrition and/or hydration
 - 3. Feeding skill dysfunction, as evidenced by any of the following:
 - a. Need for texture modification of liquid or food
 - b. Use of modified feeding position or equipment
 - c. Use of modified feeding strategies
 - 4. Psychosocial dysfunction, as evidenced by any of the following:
 - a. Active or passive avoidance behaviors by child when feeding or being fed
 - b. Inappropriate caregiver management of child’s feeding and/or nutrition needs
 - c. Disruption of social functioning within a feeding context
 - d. Disruption of caregiver-child relationship associated with feeding
- B. Absence of the cognitive process consistent with eating disorders and pattern of oral intake is not due to a lack of food or congruent with cultural norms.”

Terminology in health care changes over time and disorders may be re-classified and re-coded in new versions of ICD or DSM. In 2021, PFD was added to the US version of ICD-10, and the current codes for PFD are R63.31 Pediatric Feeding Disorder, acute, and R63.32 Pediatric Feeding Disorder, chronic. As PFD is a new diagnosis, not many prevalence studies have been published. Kovacic et al (2021) found an annual

prevalence of 2.7–4.6%, going back in medical records and including children whose diagnostic codes could be included in the PFD definition. In children with comorbidities, the prevalence was much higher, for example 35 – 55% in premature or neonate children, and 55–75% for children with gastrointestinal illness (Kovacic et al., 2021).

As research on PFD emerges, its correlation to other definitions and diagnoses regarding feeding and eating evolves. Nygren et al placed ARFID as a subcategory of PFD (2021). A schematic representation of the relationships between FP, PFD and ARFID is shown in Figure 2.

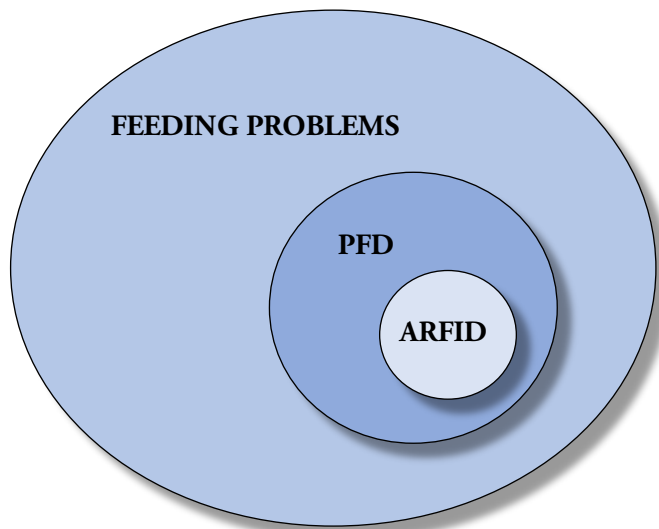


Figure 2. A schematic representation of the relationships between FP, PFD and ARFID

The presence of FD or PFD can lead to parents feeling isolated and anxious, a reduction in the quality of life for the affected child (Simione et al., 2022), and therefore changes and adaptations in how to be a family (Estrem et al., 2018). Parents can be negatively impacted by their child’s PFD, and they report that spending time and energy on searching for health care and the stigma of having a child who eats in a non-typical way can contribute to not getting early help. Laypersons’ and primary health care providers’ lack of awareness about PFD may also contribute (Estrem et al., 2018; Pados et al., 2017; Simione et al., 2022).

Child Health Care in Sweden

In Sweden, almost every child visits the Child Health Services (CHS) – the organization that is in charge of promoting health and development for children aged 0-6 years and when starting school (The Swedish National Board of Health and Welfare, 2014). The CHS is organized in local Child Health Care Centres (CHCCs) and the support and care provided is for the most part delivered by nurses. CHCCs follow the national Child Health Program (CHP) (BHV, 2021a), and the national guidelines regarding food introduction (BHV, 2021b). Children receive regular health visits and health surveillance by child physicians. If need arises, for example if the child is recognized as having FP, children are referred to specialists in primary, secondary and tertiary care such as psychologists, speech and language pathologists (SLP), child physicians and dieticians, as well as occupational therapists and physiotherapists. In some regional hospitals there are multi-profession teams for FD, which is considered to be gold standard in treatment (Lukens & Silverman, 2014). Children who are referred to a SLP may receive feeding therapy, which in some hospitals is provided by a SLP trained in the Sequential Oral Sensory Approach to Feeding (SOS-approach), a method focused on desensitization and building feeding skills (Toomey & Sundseth Ross, 2011).

Children with developmental disorders do have the same right to access to CHS as all other children in Sweden, but also have also access to the Child and Youth Habilitation Services. Children with congenital and acquired severe disorders, such as heart disorders and severe gastro-intestinal illnesses, may not always have contact with the CHS, but instead get their health care from the hospitals and health care at tertiary level.

As shown above, FP and PFD are common in childhood, and affect both child, parents, and family. A recent scoping review found that the majority (63.2%) of the research on PFD was conducted in the USA, Australia and UK. The review identified a research gap regarding prevalence studies with population-based samples, studies with children aged 1 month to 2 years, and studies focusing on the parents' role in caring for children with PFD (Estrem et al., 2022). There is no current data available concerning the prevalence of FP in children in Sweden, nor is there any recent research regarding parents' experiences of living with a child with PFD in Sweden.

In Sweden, the United Nations Convention on the Rights of the Child (UNICEF, 1989) was implemented as law in 2020, and the 24th article states that children have the right to “enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.” To achieve this regarding PFD, it is vital that we gain knowledge of prevalence and parents' experiences of FP and PFD, as a first step. It may contribute to form a base for early detection and intervention for the affected children.

Methodological Framework

This thesis is based on the first stages of the Medical Research Council (MRC) Framework for Complex Interventions (Skivington et al., 2021). The framework builds on six core elements that are to be considered at every stage of the process in developing complex interventions.

The six elements are: 1) Consider context; develop, 2) Refine and (re)test program theory; 3) Engage stakeholders; 4) Identify key uncertainties; 5) Refine intervention; and 6) Economic considerations”. The two articles in this thesis focus on engaging stakeholders (element 3), for example the parents in Study II, and identifying key uncertainties (element 4): the prevalence of FP and experiences of the parents of children with PFD.

Aim

The overall aim of this thesis is to describe and explore Feeding Problems (FP) and Pediatric Feeding Disorder (PFD) in Sweden. The thesis is based on two papers, each with its specific aim:

- To describe the prevalence and degree of FP in typically-developing children under three years of age in Skåne, Sweden. (Paper I)
- To explore Swedish parents' experiences of living with a child with PFD. (Paper II)

Method

Design

This thesis includes two studies, resulting in two articles. Study I was a quantitative survey study to describe the prevalence of FP in children aged 10 months to 3 years. Study II was an inductive qualitative interview study with parents of children with PFD, using content analysis. Table 1 shows an overview of the design of the studies.

Table 1. Overview of the design of the studies

Study	Design	Sample	Data collection	Analysis
1	Cross-sectional descriptive	238 parents of children age 10, 18 and 36 months attending regular CHCC visits	Questionnaires	Descriptive statistics
2	Inductive qualitative	20 parents of children with PFD	Semi-structured individual interviews	Content analysis

Study context

The studies were conducted from November 2019 to December 2021. The first study was performed in close collaboration with the CHS and took place in the west of Skåne. Skåne, Sweden’s southernmost region, is inhabited by 1.4 million people. A mean of 15,600 children were born yearly 2019-2021 (Statistiska CentralByrån, 2022).

The second study was conducted with parents from ten different regions in Sweden, including small and large cities, and parental experiences from different settings of health care for FP and PFD, ranging from CHS to tertiary specialist care in large university hospitals.

Care Need Index

The CHS are free of charge for all children, and are organized in CHCCs, either privately- or publicly-run. Private CHCCs are publicly funded, and the public resources are allocated using the Care Need Index (CNI). The CNI is a socioeconomic index, calculated using indicators for material deprivation (unemployed, unskilled, living in crowded households), demographic factors (elderly people living alone, children under age 5, single-parent families), social instability (moved house in the last 5 years) and cultural needs (ethnicity). Higher rates of these in a catchment area render higher funding for the CHCCs and primary care in the area (Sundquist et al., 2003).

Recruitment process

The sampling for Study I was strategic, as the CHCCs were stratified according to their CNI. There are 101 CHCCs in the western part of Skåne, their CNI ranging from 0.32 to 2.45, mean 1, and median 0.8. The CHCCs were stratified into four groups based on quartiles, with values ranging from <0.619 to >1.196. To ensure a broad demographic sample, the same number of CHCCs were drawn from each group. The managers of the CHCCs were asked about participation in the study via email. If they declined or did not answer after two reminders, another CHCC was drawn from the same CNI group. This process went on until the end of recruitment. In total, 76 CHCCs were invited, 47 did not respond and 9 declined participation. Twenty CHCCs accepted participation, and 19 of these delivered data.

The recruitment of participants for Study I was done by CHS nurses. After the manager of the CHCC had accepted participation in the study, the author of this thesis visited them to deliver study materials and provide information on how to distribute the questionnaires. Nurses were instructed to ask parents about participation consecutively in each age group. Each CHCC was initially provided with 15 envelopes containing the study material, five for each of the three age groups. Parents who gave their consent to participate were given an envelope containing the study material.

Sampling for Study II was purposeful. Posters for recruitment of participants were put up in both small and large cities at Speech and Language Pathology clinics, Child and Youth Habilitation Services and out-patient pediatric clinics, in ten of the 21 counties in Sweden, ranging from north to south. The study poster was also published on social media (Facebook) groups directed at parents of children with feeding difficulties. The poster contained information about the study and asked parents interested in participating to contact the author via email or telephone. Parents who fulfilled the inclusion criteria and contacted the author were asked if their spouse, if applicable, was

interested in being interviewed as well. Time for the interview was planned separately with each parent. Each parent was also asked if they preferred to be interviewed by telephone or online video call.

Study participants

Participants for both studies were parents over 18 years of age, able to understand spoken and written Swedish or English. For Study I, the participants were parents of children coming to their pre-booked well-child visits at the CHCCs, following the national Child Health Program, for children at 10, 18 and 36 months of age. For Study II, the inclusion criterion was having a child aged six months to six years diagnosed with and receiving or having received treatment for FD. The exclusion criterion was having a child investigated by or having received treatment by the author of this thesis.

In Study I, 238 parents answered the questionnaire. Of these 85% were women (n=197). The median age for all parents was 34, range 23-47. Education levels varied from elementary school to university education. Of the children in the study, 62.6% had at least one sibling. Thirteen children had had contact with the health care system regarding illness, 17 regarding FP, and 14 had food-related allergies. For further description of the children and parents, please refer to paper I.

In Study II, 20 parents were interviewed, 14 mothers and six fathers. Their age ranged from 27 to 48 years, and their education level was from elementary school to university degree. Occupation included full and partial parental leave, being on sick leave and working full or part time. The ages of the children with FD ranged from 13 months to 5.6 years. The children had received a variety of diagnoses related to feeding: FD, failure to thrive, ARFID and “unwillingness to eat”. Other diagnoses for the children included genetic syndromes, milk protein allergy, and prematurity, but the majority of the children had no medical diagnosis, besides the feeding-related diagnoses. For further description of the children and parents, please refer to paper II.

Data collection

Questionnaire

In Study I, a Swedish-language version of the Behavioral Pediatrics Feeding Assessment Scale (BPFAS) (Crist & Napier-Phillips, 2001; Johansson, 2022) was used, together

with background data. BPFAS is a parental questionnaire developed to decide whether children have FP serious enough to recommend referral for further investigation of the FP. BPFAS consists of 35 statements answered on a five-point Likert scale. The first 25 statements are headlined “My child” and are phrased as statements regarding frequency of different aspects of the child’s eating behaviours. The following ten statements regard the parent’s reaction to or feelings about the behaviour. Each of the 35 statements has a follow-up question asking if it is a problem for the parent, with yes/no as the alternatives. When scoring BPFAS, a Total Frequency Score (TFS) ranging from 0-175, and a Total Problem Score (TPS), range 0-35, are calculated, and if wanted, frequency and problem scores for child and parent separately. Thresholds for detecting clinically-significant FP are TFS above 84 and a TPS above 9. A questionnaire with background data for the parents and children included: parental age, education, occupation, whether the child had any siblings, allergies, other illnesses, if the parents had sought help for any feeding-related problems for the child and if so, what occupation of Health Care Personnel (HCP) they had met with.

The parents were offered both a paper version and an online option for the survey. The online option was offered via the web-based application Research Electronic Data Capture (REDCap) (Vanderbilt REDCap, version 8.1.7) and could be reached via web link or a QR code. The BPFAS and the demographic questionnaire were put into the same survey in REDCap, and to ensure similarity, the paper version was a printed version of the online survey. The BPFAS, information about the study, and instructions on how to complete the questionnaires were put in envelopes. The envelopes were coded with the age group and CHCC number. Questionnaires could be completed in three ways: 1) in paper form at the CHCC, or 2) in paper form at home and send their response in a prepaid envelope, or 3) online. The paper answers were manually entered into REDCap. Of the included participants in Study I, 141 parents (59.2%) posted the questionnaire, and 97 (40.8%) answered online.

Interviews

The interviews started with practical information about the study, and confirmation that the parent was willing to be interviewed and had understood the study information. Background data was then collected regarding the child’s FD diagnosis, other potential illnesses and their diagnoses, what help the family received from the health care system, and if the child had undergone any medical procedures related to the FD, for example video fluoroscopy (filmed x-ray of swallowing ability). For the interview a semi-structured interview guide based on four areas was used: 1) Your child’s feeding, today and earlier, 2) Your family meals, 3) Family life, considering the FD and 4) Contact with health care providers regarding feeding, now and earlier. A pilot interview was conducted and was included in the analysis since no changes to

the interview guide were considered necessary. The first question was “Can you tell me about your child’s feeding in the beginning?” Probing questions were used, such as “Can you expand on that?” or “How did you feel about that?” The interviews lasted between 29 and 88 minutes. Fourteen interviews were conducted via telephone, and six online. The online interviews were done in the Zoom-client provided by Lund University, meaning that the recording was only temporarily stored on the author’s computer, and all GDPR rules were followed.

Data analysis

Statistical analysis

In Study I, 30 of the 268 questionnaires returned had missing data in the BPFAS frequency section and were therefore excluded. The questionnaires that had missing data in the demographic section were included, thus 238 questionnaires were included in the statistical analysis. Data was exported from REDCap to IBM Statistical Package for Social Sciences, version 28, which was used for statistical analysis. Data was checked for accuracy and missing data, and BPFAS was scored. Scoring above the thresholds indicates a FP serious enough to warrant referrals for further investigation. TFS and TPS, separated according to age group and CNI group, were presented as descriptive statistics (number, percentage, mean and median). To determine significance regarding age groups above threshold, Chi-square was used. As data was not normally distributed, Kruskal-Wallis H-test was used to determine significant correlations with children’s age and CNI groups. The level of significance was set at 0.05.

Content analysis

For the interviews content analysis on a latent level was used (Lindgren et al., 2020). Of the twenty interviews, fifteen were transcribed verbatim by the author and five by a secretary. The latter five were checked for accuracy. De-contextualization and analysis started during the transcription and proofreading of the transcripts. The text was divided into meaning units (MUs) consisting of text and information referring to the same context or content. The MUs were condensed for clarity, and small words, pauses, etc., were removed. A code consisting of a few words was assigned to each condensed MU. At this stage, the level of abstraction and interpretation was still low. Sorting the codes into sub-themes was the beginning of re-contextualization, and a higher level of abstraction. The 12 sub-themes were then grouped into four overarching

themes. The first and last author discussed the analysis of each interview on all levels of the analysis, until consensus was reached. All three authors then discussed the sub-themes and themes and decided on the final themes together.

Preunderstanding

Previous experiences of and knowledge about the research field can be referred to as preunderstanding. The author of this thesis has 18 years of clinical experience working with children with FD, ranging from picky eaters to children with severe dysphagia due to neurological disorders. She has written three books on the subject aimed at parents, and has met many parents of children with PFD in and out of the clinical setting. The preunderstanding pertains to how parents of children with PFD perceive their lives and deal with health care and HCP. During the analysis phase of Study II, the preunderstanding was continuously discussed to avoid biased results.

Ethical considerations

Ethical approval

The studies were conducted according to the Declaration of Helsinki (World Medical Association, 2013). The principles of non-maleficence, beneficence, autonomy, and justice were discussed and adhered to throughout the research period (Beauchamp & Childress, 2019). Ethical approval was obtained from the Swedish Ethical Review Authority (191105/2019-04577).

Non-maleficence and beneficence

Asking parents via interviews or a questionnaire about their child's feeding and their feelings and experiences about it may be considered potentially intrusive into the personal integrity of the parents and their child, and may cause feelings of unease, stress or sadness. This was considered a risk in both studies.

The principles of non-maleficence and beneficence state that the scientific benefits of a study must outweigh the inconveniences and possible risks for the participant. All parents were provided with written instruction saying that if they felt the need to talk about their child's feeding, they should contact their CHS nurse. If they felt uncomfortable about this, contact details for another CHS nurse were provided.

To safeguard the welfare of the participating parents, the researcher had ample time for the interviews, and was well-qualified to direct parents to the correct line of care.

Even though parents were sad and emotional about their child's FD, parents in Study II expressed that it felt good to talk about their child's PFD and how it had affected them and the family. They also expressed a wish to help to prevent other families having to go through the same ordeal.

Autonomy

Participants were ensured confidentiality, and the choice to take part in the studies was autonomous.

In Study I, the participants were asked by the CHS nurse if they wanted to participate. If so, they were given the envelope containing the study questionnaire, information about the study and information on how to answer the questionnaire. Parents answered the questionnaire anonymously, making the choice to answer online or on paper by themselves. The information stated that the care provided by the CHCC would not be affected in any way, should they choose or not choose to participate. The questionnaires that were answered on paper were kept in a secure cabinet, in locked fireproof cupboards dedicated for research, following the directives of the Swedish Data Protection Authority. In REDCap it is not possible to detect who answered a certain questionnaire.

In Study II, participants voluntarily chose to make contact via email or telephone, and made a conscious competent choice to participate. Parents gave their written consent and in the beginning of every interview they were again asked if they were willing to be interviewed. The recorded interviews, transcribed texts, and coded lists with the participants from Study II were kept separate and available only to the researchers responsible for the study.

Justice

In Study I participation was possible if the parent spoke either Swedish or English, but the questionnaire was only available in Swedish.

In Study II, parents with experiences of living with a child with PFD were included, to provide a nuanced and deeper understanding. Both mothers and fathers were interviewed. Care was taken to include as sociodemographically-diverse participants as possible, by stratifying the CHCCs by CNI. In both studies, language could have been a barrier.

Results/Findings

Prevalence of FP

In Study I, 8.4% of the children had a TFS above 84, and 9.3% had a TPS above 9. The results for TFS and TPS according to age group and sex are presented in table 2.

Table 2. Results for TFS and TPS

	TFS above 84, %	TPS above 9, %
All ages	8.4 (n=20)	9.3 (n=22)
10 months (n=75)	4 (n=3)	4 (n=3)
18 months (n=83)	6 (n=5)	7.2 (n=6)
36 months (n=80)	15 (n=12)	16.3 (n=13)
Sex		
Girls (n=115)	9.6 (n=11)	12.2 (n=14)
Boys (n=123)	7.3 (n=9)	6.5 (n=8)

The difference between the age groups was significant for TFS (Chi-square=7.02, df=2, $p=0.03$) and TPS (Chi-square=7.43, df=2, $p=0.024$). The difference between sexes was not significant, nor were the relationships between CNI group or parents' education, in being above or below TFS or TPS thresholds.

Distribution of TFS and TPS scores

For all age groups, the mean TFS was 62.7 (range=41-100, median 60, SD=12.4). The mean TPS was 2.2 (range=0-22, median 0, SD=4.6). There were no statistically-significant associations between TFS/TPS scores and CNI group. Neither was the relationship between parents' education and TFS or TPS statistically-significant.

Regarding age group, results for TFS and TPS differed. Children 36 months of age had a TFS mean score of 66.1 (median 63, SD=14.5) and a TPS score of 3.7 (median=1 SD=6). The TPS (3.7) was significantly higher than corresponding scores for the 10 (1.2) and 18 (1.7) month-old children ($p<0.001$). For TFS, there was no significant difference between the age groups ($p=0.072$).

There were no statistically-significant differences between boys and girls for TFS or TPS. The mean for girls on TFS was 63.8 (range 43-100, median 61, SD=12.6) and for boys 61.6 (range 41-97, median 60, SD=12.2). For TPS it was 2.7 for girls (range 0-21, median 0, SD=5.2) and for boys 1.8 (range 0-22, median 0, SD=4.0). The means, medians and SDs for all children are presented in Table 2 in Article I.

For the 17 children whose parents had sought contact with HCP because of FP, mean TFS was 74.3 (median 74, SD=12.8) and mean TPS was 6.12 (median 4, SD=6.2). Four of these 17 children were above threshold for TFS and five for TPS.

Parents' experiences

Parents' experiences were described in four overarching themes: 1) Living with stress, 2) Advocating for the child, 3) Adapting family life, and 4) Gaining hope. The themes and the sub-themes are presented in Figure 3.

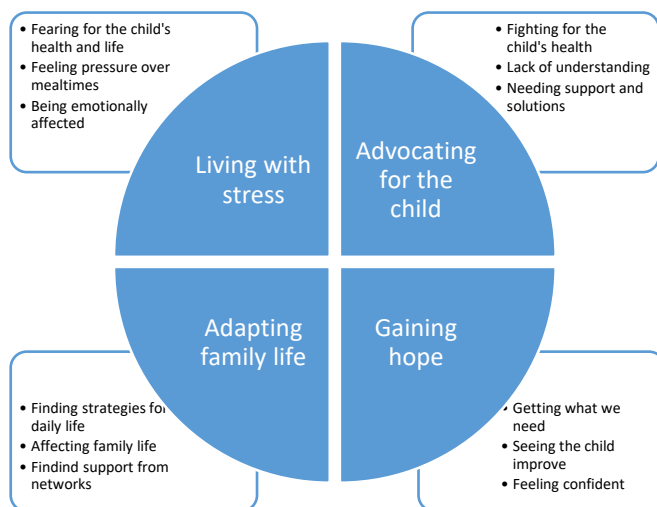


Figure 3. Themes and sub-themes of Study II.

Describing how they early on had realized something was wrong with their child's feeding, parents expressed how they had spent time and effort searching for help. Fearing for their child's life and health made them look for help outside the CHCC, and they described turning to different levels of health care.

The feelings of being misunderstood and not believed were difficult for the parents, and they described having to convince both HCP, relatives, and friends of their child's PFD. One parent said that it was only after she sent a video of her child's disordered feeding that the pediatrician understood and took action accordingly. They described a feeling of powerlessness and not knowing what to do next, but still being the one with the responsibility to take care of the child's feeding and coordinate the health care.

Parents perceived a lack of knowledge among HCP, which made them mistrust the CHCC nurse in some cases, for example when being told the child was fine despite them not feeding in a sustainable way. Parents expressed a need for earlier detection and more effective intervention and told of frustration in the lack of coordination of all the different health care appointments they had to go to. Needing to be persistent and sometimes forceful to access the health care the child needed was hard for parents. To always have to fight for the child's health and rights was described as exhausting.

Feeding their child was described as stressful, and most parents did not enjoy mealtimes or feedings. Panic and stress were common feelings around mealtimes. Parents were worried about meeting nutritional requirements, and also about putting pressure on the child, which they knew could result in the child vomiting, or not wanting to come to the table. Parents felt a deep sorrow about what their child had had to endure. Some situations were described as emotionally difficult for both child and parent, such as inserting a naso-gastric feeding tube on a child that did not want it. Guilt and regret were expressed by parents who had pressured their child into eating before understanding it could be counterproductive. Parents described that not being able to feed their child had created a trauma that had not been resolved. PFD had a profound impact on family life as well; parents described a daily struggle to feed the child, with strict routines that limited outings, restaurant visits and even getting help from grandparents.

Parents described how they had become more of a team, one parent being more involved in the ill child's health care and feeding, and the other having a more supportive role, managing the house, siblings and sometimes being the only one who worked. Hobbies and social activities were put on hold, but even so, the parents had accepted the current situation and that made it more bearable. For some, the child's illness had put too much pressure on the parents' relationship and they had split up.

Support from relatives and, for some, social media groups, was very important. Parents described the latter as having an outlet where they could be themselves and not have to worry about not being understood.

When receiving health care that helped the child to feed better, parents were grateful. They described the feeling of being understood as very important confirmation. When strategies worked out, parents felt confident that they could care for their child. Sometimes receiving adequate health care was perceived as a stroke of luck. The referral to a multi-professional team was very important to those parents who had been to one, and for the families still trying to get to such a team.

Even though they knew it may not last, seeing the child's feeding improve made the parents express feelings of happiness and joy.

Discussion

General discussion

The aim of this thesis is to explore FP and PFD in Sweden, with regards to the core elements of the MRC framework for complex interventions (Skivington et al., 2021).

Study I revealed a 8.4-9.3% prevalence of FP serious enough to justify further investigation and referrals, when using the Canadian thresholds for BPFAS (Crist & Napier-Phillips, 2001). This is in line with other studies using BPFAS (Sdravou et al., 2021), and implies that many children and parents are faced with difficulties at mealtimes and could be in need of help from CHS and other health care facilities. Study II revealed that parents of children with PFD experience stress and anxiety, struggle with feeding their child, and struggle to get help from the CHS and other health care facilities.

The CHS nurse can be one of the very first HCP meeting the parent struggling to feed their child. Almqvist-Tangen et al (2017) wrote that parents pointed out that the results of measuring and weighing the baby at the CHCC assured them that their baby was healthy. As shown in Study II, not all parents received that confirmation, or if they did, they did not always believe what the nurse said if the child was not feeding well. Sometimes the parent was struggling to follow advice regarding how to feed the child, because of the child's PFD. This might cause feelings of inadequacy as a parent, or resentment and mistrust towards the CHCC nurse or other HCP. Estrem et al (2016) found that parents of children with FP were often reassured and not referred to evaluation of the disordered feeding. They also found that parents adapted to the difficulties around feeding, and the FP had a large impact on family life. Estrem (2016) suggests as a clinical implication that HCP should "consider a child to have a feeding problem if parents report problematic feeding behaviors and restrictive or selective intake" (pg 218). Parents in Study II suggested that both nurses and other HCP meeting parents and children need to have more knowledge of FP and PFD to be able to detect it earlier. Children's weight curves do not always show if the child has trouble feeding (Bryant-Waugh et al., 2010; Goday et al., 2019), and therefore it is vital that HCP, family, and perhaps even the wider society, understand the complexity of feeding and eating, and do not dismiss parents with the "wait and see" approach. Some level of anxiety or concern for the child's feeding and overall well-being is inherent in

parenthood. But as caregivers can involuntarily worsen and maintain FD if coaxing their child to eat, force feed or by offering only preferred foods (Field et al., 2003; Were & Lifschitz, 2018), CHCC nurses and other HCP that meet parents of children with budding FP must be able to identify children that are in need of referrals, and separate them from children with typically-developing feeding patterns who have overly anxious parents (Aldridge et al., 2010).

Screening for FP is not routinely done in the CHS in Sweden. Today, the CHCC nurse's first approach and basic tool for detecting FP and PFD is the growth chart and dialogue with the parents, together with referrals to other HCP such as pediatricians, SLPs, psychologists and dietitians. Study I showed that FP is common among children up to the age of three, and the incidence of PFD is also estimated to increase due to improved survival of medically fragile children and advances in medical care (Raatz et al., 2021; Silverman, 2010). Putnick et al argued that by screening young children for FP, early identification of those at risk for developmental delays might be possible. However, these arguments were based on numbers from the USA, where an estimated 37% of pediatricians did not screen for developmental delays at the recommended times (Putnick et al., 2022). In Sweden, where almost all children are seen by the CHS and follow the national Health Care Program (BHV, 2021a), screening for FP to aid in detecting other delays might not be as important. However, parents in Study II told of long delays in detecting the child's PFD and in receiving the support and intervention needed. The detected prevalence of FP is enough to justify the implementation of a screening tool in the CHS, along with increased knowledge of FP and PFD for HCP meeting children.

When assessing children for FP and PFD, a clinical observation, interview and questionnaire are commonly used when assessing children for FP and PFD (Sdravou et al., 2021), and this is also the case in Sweden. Clinical observation refers to actually observing the child feeding and in it is Sweden usually done by SLPs in tertiary care settings, which may not be the best environment in which to observe children feeding in a representative manner.

To give the CHCC nurse and other HCP a chance to understand and objectively describe how the child feeds, a short movie clip taken by the parents in the child's usual feeding setting might prove useful. As Study II shows, parents have reported feelings of mistrust towards HCP they perceive as less knowledgeable in PFD, and so use of a movie clip could create common ground for the parent and HCP. Together with a screening instrument, this could help in early detection and referral. This requires HCP having knowledge of PFD and the four domains. Even if PFD is not implemented in the Swedish version of ICD-10 yet, it is useful as a conceptual framework both in research and in the clinic, since it provides a more holistic approach to understanding feeding related illness.

The BPFAS is translated into Swedish and is widely used in research. This fact, however, is not necessarily an endorsement that it is the most useful questionnaire for Swedish CHCCs. It is quite long, leaves some room for interpretation for the parent answering, and is complicated to score. A shorter screening tool might be easier to implement in the CHS, as the threshold for the nurse to use it during the visit might be lower. For example, a six-question screening tool was derived from the Infant and Child Feeding Questionnaire (Barkmeier-Kraemer et al., 2017) to aid primary care givers in quickly identifying children who struggle to feed, and has been proven valid and reliable in US settings. Also, the proposed framework for patient characterization, published by authors of the PFD definition, could be useful in the clinical setting for pediatricians, SLPs, dieticians, psychologists or other HCP meeting children with PFD (Sharp et al., 9900).

Children and families going through the hardships of PFD need support from the health care system, which brings up the issue of health care costs. Nutritional supplements, referrals, and visits to dieticians and physicians take time and money, both for the families and for the health care professionals (Raatz et al., 2021). Intervening early is an important consideration when assessing health care costs. If left untreated, PFD can lead to the child taking less and less by mouth, which can result in the child receiving enteral nutrition via a naso-gastric tube or a gastrostomy. The cost for enteral nutrition for one child per month in the south of Sweden is approximately 5-6,000 SEK, not including materials, time away from work and other surrounding costs. The most severe cost of PFD, though, is the risk to the child's health and issues in the parent-child relationship.

The clinical feeding assessment and therapy part of treating PFD is mainly done by SLPs in tertiary care settings in Sweden, and SLPs are not commonly employed in primary care units or in CHCCs. Earlier access to mealtime observations and oral motor assessments by a SLP could prove valuable. To achieve this, SLPs need to be employed in CHS in larger numbers than today, as well as being more easily accessible for the CHCC nurse and parents seeking investigation and intervention for a child with suspected FP and/or PFD. Multi-professional teams are not accessible for all families of children with PFD, and might also not be needed in the earlier stages of FP. However, the relative risks associated with untreated feeding problems are pronounced, supporting the need for early intervention (Lukens & Silverman, 2014), and if access to SLPs is facilitated, FP in the early stages might be resolved.

Study II showed that parents spend a lot of time and effort to get HCP to listen and help them find out what is wrong with their child, and this causes anxiety and stress for the parents (Estrem et al., 2018). In Study II, the interviewed parents spoke of fighting for their child's health and life, and how it had affected life for the whole family. This has been described as "deconstruction": living life on the margins and losing the dream of how to be a mother and becoming a nurse and onlooker (Hewetson & Singh, 2009).

In the same study, the theme of “reconstruction” was also found: getting through the brokenness. This was described as finding support, being heard and being offered help and hope (Hewetson & Singh, 2009), which is in line with how parents in Study II described the journey they were on.

Family, particularly parents, plays an integral part in the child’s feeding development, but when investigating FP and PFD, the child’s perspective and rights must be taken into account. In an article describing the “F-words in childhood disability”, Rosenbaum and Gorter highlighted Family factors, Function, and Fun amongst six elements (Rosenbaum & Gorter, 2012) that can serve as a model for feeding intervention. However, the intervention and care need to be delivered with the child in the centre, since oral feeding cannot be sustained over time without the child’s own inner drive to eat. Child-Centred Care (CCC) (Coyne et al., 2016) takes the child’s perspective into account, and moves from family-centred care to a more child-focused care, but with the premise that the child cannot be understood as separate from its family. The child is a key actor of the family, and health care must be delivered with the child’s integrity and privacy in mind. All the same, parents and other caregivers that the child interacts with must also be met as key players in any intervention.

Methodological considerations

The two studies included in this thesis are disparate in methodology but revolve around the same people: children with FP and PFD, and their parents. The different datasets complement each other in a form of scientific triangulation. There are, however, always methodological choices that must be made in research, which may both strengthen and diminish the implication of the results. Scientific rigor concerns the methods chosen to answer the research question; are they the most appropriate, and are they applied with thoroughness and responsibility?

Reliability and validity for the instrument chosen in Study I, BPFAS, is well established (Marshall et al., 2015; Sanchez et al., 2015), and it is the most used parental questionnaire for FP (Estrem et al., 2022). It has been used in different populations (Allen et al., 2015; Brinksma et al., 2020; Jaafar et al., 2019) and countries (Crist & Napier-Phillips, 2001; Dovey et al., 2013; Owen et al., 2012; Sdravou et al., 2021). However, there are no Swedish thresholds established, which is a limitation. On the other hand both the prevalence and the means of TFS and TPS were similar to other studies, implying that the findings can be considered valid. The power calculation assumed a prevalence of children with FP of 25%, and if this had turned out to be the case, the study would have been underpowered since it did not reach the required 289 returned questionnaires. However, as the prevalence was found to be 8.4-9.3%, this is less of a limitation.

The results in Study II must be interpreted through the filter of trustworthiness, which refers to whether the results and data reflects the truth. There are different concepts that together form trustworthiness: credibility, dependability, transferability and confirmability. Credibility concerns the selection of appropriate methods, participants and how well the study procedure is reported. The participants in Study II were parents who were highly motivated to tell their story, which is both a strength and a limitation. Parents who were satisfied with the health care their child had received would maybe not have been as eager to be interviewed and take part in the study as parents who felt a need to share their difficulties, and thus the sampling may be biased. To help the reader decide if the results are transferable to other settings and populations, characteristics of parents and children were described in as much detail as possible without revealing anything that would jeopardise confidentiality. Swedish health care is much different from that in the US where most of the studies on PFD are done, but the results in Study II are comparable to other interview studies with parents of children with FP and PFD, thus strengthening the transferability of the results.

Dependability refers to the stability of data over time, and is demonstrated through describing the research process clearly, with focus on methods and analysis. In Study II, dependability is for example shown through quotations and how the interpretation is based in the data.

Confirmability refers to objectivity of data and its interpretations. In Study II, the three authors had different professions and experiences. During the analysis, the interviews were discussed from different angles and research triangulation was implemented, meaning that the authors read the material independently and then discussed it. Confirmability also depends on the researchers' preunderstanding, and as the author of this thesis has a long experience of children with FP and PFD, her preunderstanding was discussed and scrutinized amongst the authors throughout the work with both studies. Openness to one's own preunderstanding, and new experiences, can be one way of safeguarding against tailoring the results to fit into preconceptions (Nyström & Dahlberg, 2001). The participants' preunderstanding must also be considered; some of the parents in Study II had a prior knowledge of the author of this thesis and were highly motivated to tell their story. They also asked questions regarding the child's feeding and health care. This was met with the author explaining the different roles of researcher and clinician, and any questions regarding the child's health were dealt with after the interview was finished.

The Covid-19 pandemic affected data collection. For Study II, it meant that participants were interviewed by telephone or online video call, meaning that parents from different parts Sweden were able to participate. This allowed for a broader perspective of health care – a strength of this study. When conducting interviews by telephone, body language and facial expressions are not possible to detect, and it can be argued that telephone calls are suited to short impersonal interviews, but not long

more personal interviews (Saarijärvi & Bratt, 2021). The parents were highly motivated to speak about their experiences, and the lack of face-to-face interaction was not considered problematic. For both telephone and Zoom interviews, there can be a risk that the parent is not alone in the room, which might prevent them from speaking freely (Saarijärvi & Bratt, 2021). None of the parents interviewed mentioned not being alone, and this was hence not considered problematic.

For Study I, the author of this thesis was originally intended to be on site at the CHCCs to help nurses with data collection by talking to parents in the waiting room after their visit. As the Covid restrictions prevented her presence on site, data collection was solely dependent on the nurses. Since the nurses knew the families and might know of possible FP, there was a potential risk for selection bias. To avoid this, the nurses were instructed to ask parents consecutively. It is important to differentiate between informed consent and mutual decision-making, where in the latter the health care provider and patient, or in this case, the parent, together make an informed decision. Care was taken to ensure that the parents' decisions were autonomous, and the CHS nurses were instructed not to press parents not willing to participate (Beauchamp & Childress, 2019).

Conclusions and clinical implications

Feeding is vital. When feeding is not going well, the parental role is jeopardized and the child's development can be at risk. Children have a right to access good health care, and because FP are common, HCP meeting parents and children need to have knowledge of FP and PFD to be able to take the correct steps and measures in providing the care needed.

PFD is a complex disorder, where the four domains, i.e. medical, nutritional, feeding skills and psychosocial, often interact. Herein lies the strength of the PFD framework and definition, providing a broad and holistic perspective and a template for clinical assessment of all aspects of feeding. Using both PFD and the Framework for Patient Characterization may facilitate both clinical work and research, even though PFD is not yet implemented as an ICD-code in Sweden.

As nurses and pediatricians meeting children and parents with FP need to be able to determine when a child has FP that warrant further investigation and referral to other levels of care, an educational intervention might prove useful.

In CHS and CHCCs, the implementation of a screening instrument could be of help, and using a short video clip of the child feeding might be useful in creating a mutual base for the dialogue around the child's feeding.

Future research

Aspects of difficulties regarding feeding affect both children and families, but the studies included in this thesis are mainly focused on the parental aspects of FP and PFD. A qualitative interview study of how children perceive living with PFD is relevant, as this is lacking in the literature. The child's perspective must be considered in all health care, and exploring the child's own experiences may be valuable. Children have a right to take part in and decide about their health care and must also be respected in the way they choose to nourish themselves, while also taking their age into account. Following the MRC guidance, further studies may also include perspectives from siblings, extended family and relatives, pre-school and school professionals and HCP.

Furthermore, extended knowledge of the prevalence of PFD in Sweden is needed. Other study designs could be explored, such as a register study.

To be able to design an intervention to help in the prevention of PFD, a health economy study is important. Besides costs for the health care system, a health economy study should consider parents' economic issues such as having to be on extended parental leave or sick leave to be able to care for their child, and health care costs of providing supplemental feeding such as tube feedings and energy supplements.

Populärvetenskaplig sammanfattning

Att lära sig att äta är något av det viktigaste barn gör under sina första år, om inte det allra viktigaste. Mycket av föräldraskapet handlar om att ge barnet mat, och när det fungerar väl med barnets mat så upplever föräldrar en stark känsla av att ta hand om sitt barn. Många barn har milda, övergående ätsvårigheter under sina första år, och ätproblem hos barn, eller Feeding Problems (FP), är vanligt. För en del barn fortsätter svårigheterna och de påverkar både barnen och hela familjen. Det kan resultera i mer komplicerade ätsvårigheter, som på engelska kallas Feeding Disorder (FD). Båda dessa tillstånd kan yttra sig som till exempel selektivitet vad gäller vilken mat barnet kan äta, att inte kunna sitta med vid bordet, beroende av distraktion under måltiden eller att barnet inte har åldersadekvat förmåga att äta.

Det råder inte konsensus gällande prevalens av vare sig FP eller FD, och det har varit svårt att jämföra olika studier på grund av att det inte har funnits någon allmänt accepterad definition av vare sig ätproblem eller ätsvårigheter. En svensk studie från 1986 hittade en prevalens på 1,4 %, medan andra studier nämner siffror på upp till 52 %. Januari 2019 publicerades en artikel som presenterar en konsensusdefinition, vilken författarna hoppas ska underlätta jämförande forskning samt fungera som en diagnos i det kliniska arbetet. Den heter Pediatric Feeding Disorder (PFD) och definieras som att barnet inte kan äta tillräckligt via munnen på ett åldersadekvat sätt, för att klara sin nutrition eller vätskeintag. Svårigheterna ska vara kopplade till minst en av fyra domäner: medicinsk, nutritionell, barnets ätförmåga eller psykosocial. I en ny översikt över forskningsläget fann man att den mesta forskningen på PFD gjorts i USA, Australien och Storbritannien, att det saknades studier på hur många barn som har PFD, och studier gjorda på barn i åldrarna en månad till två år.

Målet med avhandlingen var att undersöka förekomsten av barn med ätproblem i åldrarna 10 månader, 18 månader och 36 månader i Sverige, (studie I) samt undersöka erfarenheter hos föräldrar till barn med PFD (studie II). Studie I är en kvantitativ studie med en enkät med ett skattningsformulär för föräldrar som vid de vanliga hälsobesöken delades ut till föräldrar som kom med sina barn till BVC. Studie II är kvalitativ, och där intervjuades 20 föräldrar till barn med konstaterade ätsvårigheter (PFD) om sina erfarenheter.

I Studie I hittades en prevalens på 8,4–9,3 % av barn som enligt föräldraformuläret skulle kunna ha ätproblem, och som borde remitteras för vidare utredning och eventuell

behandling. Resultaten bedöms vara snarlika de som hittats i andra länder, trots avsaknaden av för Sverige specifika tröskelvärden.

I Studie II berättade föräldrar att de upplevde att de fick kämpa mycket för sitt barn och för att få tillgång till vård. De upplevde att de inte blev trodda när de berättade om barnets ätsvårigheter, och att varken omgivningen eller BVC förstod vidden av svårigheterna. Föräldrarna upplevde mycket stress och oro, men kunde också glädjas när det gick bättre med ätandet för barnet, och lärde sig att lita på sig själva och anpassa livet efter barnets ätsvårigheter.

Att hitta barn med FP tidigt och erbjuda vård och stöd innan problemen hunnit bli befästa, är en nyckel till framgång. Om personal på BVC och andra instanser i vårdkedjan får mer kunskap om PFD och ätsvårigheter, så kan barn och föräldrar få stöd och hjälp tidigare i förloppet. Ett enkelt och kort screeninginstrument att använda när föräldern och barnet är på BVC på de vanliga besöken kan hjälpa till att identifiera barn med FP. Om föräldrar också kan filma sitt barns ätande hemma, så kan BVC-sköterskan och föräldrarna hitta en gemensam förståelse för barnets ätsvårigheter och därifrån arbeta vidare framåt.

Det behövs mer forskning på FP och PFD i Sverige, exempelvis en registerstudie för att studera prevalensen ur ett annat perspektiv, en hälsoekonomisk studie för att förstå kostnader förknippade med ätsvårigheter, samt en intervjustudie med barn som har svårt att äta.

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