

School of Allied Health

**A qualitative study of professional support and therapeutic partnerships,
between Speech-Language Pathologists and the primary carers of a child
with paediatric feeding disorder.**

**Julie Tan
0000-0001-6373-443X**

**This thesis is presented for the Degree of
Master of Philosophy
Curtin University**

July 2024

Declaration

To the best of my knowledge and belief, this thesis contains no material previously published by any other person except where due acknowledgement has been made.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

Human Ethics (For projects involving human participants/tissue, etc) The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007) – updated March 2014. The proposed research study received human research ethics approval from the Curtin University Human Research Ethics Committee (EC00262), Approval Number #HRE2018-0399.

I have obtained permission from the copyright owners to use any third-party copyright material reproduced in the thesis, to use any of my own published work (e.g. journal article, chapter 4) in which the copyright is held by another party (e.g. the publisher). See Appendix 2 -Publishing agreement.

Acknowledgement of Country

I am privileged to live and work on Whadjuk Noogar boodja, land that has been cared for by Indigenous Elders and knowledge holders for thousands of years; land that was never ceded. I honour and respect First Nations people across Australia and the world and thank them for their perseverance in preserving and sharing their culture and history. This always was and always will be Aboriginal land.

Acknowledgements

I most gratefully acknowledge the encouragement and supportive input I have received which has ensured the successful completion of my research project.

Firstly, I would like to thank my academic team:

Associate Professor Naomi Cocks, who journeyed with me across the whole of this project, her knowledge and skill have greatly benefitted the outcome. Her support, encouragement and commitment have been invaluable.

Many thanks also to the others in my supervisory team, Professor Deborah Hersh, Dr Mary Claessen and Dr Christina Fernandes, it was a pleasure to work with you all and to benefit from your knowledge and skills.

Thanks to Dr Elena Gil-Rodriguez for her inspirational teaching and knowledge of Interpretative Phenomenological Analysis.

I offer special thanks to my speech-language pathology colleagues, whose dedicated and authentic practice inspires and informs me daily. Your encouragement and interest in my project invigorated and supported me every step of the way, thank you.

I am deeply grateful to the speech-language pathology profession for the many wonderful opportunities it has given me to work with and learn from inspiring clients and their families, over my thirty years of practice.

I am also grateful to the Australian government for providing me with financial support through the Research Training Program (RTP) Scholarship which enabled me to seize this wonderful opportunity and complete this research project.

Lastly, I extend my heartfelt gratitude to my family, especially to my husband for his unwavering support during the long hours of study, to my daughter for her encouragement and genuine interest in my topic, and to my three granddaughters, who inspire me daily to prove that it is never too late to pursue meaningful goals. I appreciate and celebrate you all!

Abstract

Introduction: Paediatric Feeding Disorder (PFD) is a widely recognised and established diagnostic label for the broad gamut of childhood feeding disorders. The diagnosis unifies the medical, nutritional, feeding skill, and/or psychosocial concerns associated with feeding disorders. The provision of support is essential for families caring for children with PFD, and speech-language pathologists (SLPs) play a critical role in this regard. However, there is a scarcity of published research investigating the perspectives of families and SLPs on the support available for PFD. The recent consensus statement regarding the definition of the term PFD has provided a universally accepted and precise way to talk about this heterogeneous group, creating an ideal opportunity to consider support for this population.

Aims: This project aimed to gain a deeper understanding of the journey of families of children with PFD. It consisted of two studies. The first study aimed to explore primary carers' perspectives on the support they seek and receive for their child/ren with PFD. The second study aimed to elucidate speech-language pathologists' perspectives on the support they offer primary carers of a child/ren with PFD and to identify the enablers and barriers to optimal therapeutic partnerships between primary carers and speech-language pathologists, when working with children with PFD.

Methods: This thesis describes two studies and aims to explore the experiences of two distinct groups of key informants. Study 1 involved conducting semi-structured interviews with sixteen mothers caring for children with PFD, thematic analysis was employed to examine their experiences. Study 2 focused on eleven SLPs experienced in supporting children with PFD and their families in community practice. A dual-analytical approach, combining thematic and idiographic analysis through Interpretative Phenomenological

Analysis (IPA) was used to investigate the SLPs' perspectives.

Results: The research identified several key themes highlighting significant challenges in accessing and providing support for children with PFD. Both families and SLPs reported barriers rooted in systemic issues, including inadequate funding, insufficient training and supervision, limited research, and a lack of community education on PFD. Changes in funding structures and the privatisation of services further restricted SLPs' access to necessary training and supervision and hindered effective multi-disciplinary responses to PFD. Additionally, participants emphasised the fragmented nature of service integration, with limited coordination between different service providers. The lack of a cohesive approach to addressing the training and supervision needs of SLPs in the evolving allied health landscape negatively impacted the quality of services available for children with PFD.

Overall, the themes reflected the substantial challenges faced by both families and SLPs in navigating and delivering support. The findings underscore the critical need for system-wide solutions, encompassing community service providers, healthcare services, the NDIS, and policymakers, to improve outcomes for children with PFD.

Conclusion: This project has provided a better understanding of the families of children with PFD experiences of support and SLPs' experiences of offering support. Widespread education on PFD at both the community and health professional levels is urgently required to facilitate a holistic understanding of PFD and the ramifications that this complex condition has for these children and their families. This would ensure that best practice competency pathways are available for SLPs working in this practice area with integrated pathways of care between all services.

Keywords: Qualitative: Feeding: dysphagia: families: community: PFD

Table of Contents

DECLARATION	I
ACKNOWLEDGEMENT OF COUNTRY	II
ACKNOWLEDGEMENTS	III
ABSTRACT	V
TABLE OF CONTENTS	VII
LIST OF TABLES	XI
CHAPTER 1.0: INTRODUCTION	1
1.1 Author Biography	1
1.2 Outline of Thesis	2
CHAPTER 2.0: PAEDIATRIC FEEDING DISORDER.	4
2.1 A Complex Condition	4
2.2 Medical Domain	5
2.3 Feeding Skill Domain	6
2.4 Psychosocial Domain	7
2.5 Nutritional Domain	7
2.6 Prevalence of Paediatric Feeding Disorder	8
2.7 Diagnoses linked to PFD	9
2.8 Psychosocial Impact of Paediatric Feeding Disorder on the Family	9
2.9 Multi-disciplinary Approach to Paediatric Feeding Disorder	10
2.10 Empirical Evidence in the Management of Paediatric Feeding Disorder	13
2.11 Family Support for Paediatric Feeding Disorder	15
2.12 Family-Centred Practice	18
2.13 Funding and the NDIS	19
2.14 Summary	20

2.15 The Current Thesis	21
2.16 Research Aims	21
2.17 Significance	22
CHAPTER 3.0: METHOD	24
3.1 Research Project	24
3.2 Research design study 1	24
3.3 Participants	25
3.4 Research Procedures	25
3.5 Research Data Analysis	27
3.6 Research Design Study 2	29
3.7 Research Participants	30
3.8 Research Procedure	31
3.9 Data Analysis.	33
3.10 Trustworthiness and Rigour	37
3.11 Reflexivity	38
CHAPTER 4.0: MOTHERS' PERSPECTIVES OF SUPPORT FOR THEIR CHILD WITH FEEDING/ SWALLOWING DISORDERS- JOURNAL PUBLICATION	40
CHAPTER 5.0: "A BAND-AID SERVICE': SPEECH-LANGUAGE PATHOLOGISTS' PERSPECTIVES ON THE CHALLENGES THEY FACE TO SUPPORT CHILDREN WITH PFD AND THEIR FAMILIES".	53
5.0 TITLE PAGE	54
5.1 ABSTRACT 'A BAND-AID SERVICE': SPEECH-LANGUAGE PATHOLOGISTS' PERSPECTIVES ON THE CHALLENGES THEY FACE TO SUPPORT CHILDREN WITH PFD AND THEIR FAMILIES.	55
5.2 INTRODUCTION	56
5.2.1 Prevalence	56
5.2.2 SLP Role with PFD	57
5.2.3 Access to integrated care in the community	57
5.2.4 Confidence and skills of HPs working with children with PFD	59
5.2.5 Policy and Funding	61

5.2.6 Summary	62
5.3 METHODS	62
5.3.1 Ethics	63
5.3.2 Recruitment	63
5.3.4 Participants	64
5.3.5 Data Collection	64
5.3.6 Data Analysis	66
5.3.7 Reflexivity, Rigour and Trustworthiness.	68
5.3.8 Insider research	69
5.4 RESULTS	69
5.4.1 The Importance of the Team	70
5.4.2 Providing Safe Practice	71
5.4.3 Self-Care	71
5.4.4 Surviving “Rocky Seas”	72
5.4.5 Barriers to Support	74
5.5 DISCUSSION	77
5.5.1 Accessing Community Care	77
5.5.2 Preparedness and support	80
5.5.3 Policy and Funding	82
5.6 RECOMMENDATIONS	83
5.7 LIMITATIONS	84
5.8 CONCLUSION	85
REFERENCES	86
CHAPTER 6.0: DISCUSSION OF STUDY 1 AND STUDY 2	91
6.1 OUTLINE	91
6.1.1 Access to Services	92

6.1.2 The ‘Uberisation’ of Allied Health Services	93
6.1.3 Challenges in Supervision and skill development	95
6.1.4 A lack of understanding of Paediatric Feeding Disorder among NDIS Planners	96
6.1.5 Financial barriers to accessing support	97
6.1.6 Continuity of Care for Children with PFD	97
6.1.7 Speech Language Pathologists’ Competence	99
6.1.8 Outdated Recommendations	100
6.1.9 Speech-Language Pathology Training	101
6.1.10 Empirical Evidence	102
6.2 RECOMMENDATIONS	103
6.3 LIMITATIONS AND FUTURE RESEARCH	104
6.4 SUMMARY	105
APPENDICES	106
1: Funding	106
2: Publishing Agreement	107
3: Authorship Agreement	110
4: Group Experiential Themes and Participants’ Quotes	112
REFERENCE LIST	116

List of tables

Table 1: Study 1 Interview Guide	26
Table 2: Study 2 Participant Demographics.....	31
Table 3: Study 2 Interview Guide.....	32
Table 4: Study 2 Participant Experiential Statements.....	36
Table 5: Speech-Language Pathologists demographics.....	64
Table 6: Study 2 Interview Guide.....	65
Table 7: Group Experiential Themes and Participants quotes.....	67

Chapter 1.0: Introduction

1.1 Author Biography

Since becoming a speech-language pathologist (SLP) in the 1990s, I have found that the families who struggled to feed their children, are the ones who remain etched in my memory. There were many, but two of the mothers are particularly unforgettable. Early in my career, I met a mother, whose baby had a yet-to-be-repaired cleft palate. Although trying her best to manage her daughter's challenging feeding, she was accused by her paediatrician of force-feeding her. More recently, I met a young woman, a single parent, who in seeking support from health professionals for her child's selective eating, found herself being reported to the Child Protection Services for neglect. Other mothers I have worked with have recounted that they had members of their own family insinuating that their child did not have a feeding problem but a discipline problem, saying things like "in my day if you didn't eat it for lunch, you got it for dinner". Since qualifying as an SLP, my clients' parents spoke to me of their struggle to cope with so much disbelief and negation of their concerns. I was bewildered and wanted to understand why this was happening. Why did families feel unsupported by their SLPs and other health professionals? What were we missing, and how could we do better? It was these questions that inspired me to pursue research in this area.

I had trained as an SLP in my thirties, and my desire to deliver truly family-centred services was not informed merely by the excellent lecturers at my university but also by my lived experience of being the mother of three children. In my mothering role, I had experienced health professionals using an 'expert' approach. This often meant they seemed unaware of my desire to be involved, informed, or respected as someone important to my children's well-being.

On qualifying as an SLP in Britain, my first job was in the National Health Service, a general practice role, covering a large rural area servicing adults and children across schools, hospitals and nursing homes. Then in 2001, I moved with my family to New Zealand (NZ) where I again worked in a similar role. I then worked at a special educational school. I in 2007, moved into disability services as an assistive technology-focused SLP across the North Island of NZ. In 2013, I came to Perth, Australia and worked in a large, not-for-profit disability organisation, focused on delivering community-based multi-disciplinary team services for children many of whom had paediatric feeding disorder (PFD).

Now I have grandchildren, and I am learning again about dealing with health professionals who appear unwilling to listen to or understand the concerns of my son and daughter-in-law. My grandchildren from birth had many of the symptoms and issues relating to PFD. I have come full circle and now more than ever I have unanswered questions.

These collective experiences inspired me to try to find out what the experiences have been for other families of children with PFD and SLPs attempting to provide support to these families. This was the motivation for me to undertake this MPhil.

1.2 Outline of Thesis

Chapter 1 of this thesis provides biographical content and an outline of the entire thesis. Chapter 2 will discuss Paediatric Feeding Disorder (PFD), focusing on diagnosis, prevalence, and the current role of speech-language pathologists (SLPs) in supporting children with PFD and their families. Chapter 3 will outline the research methodology, detailing the design of the studies discussed in this thesis. The analytical approaches of Study 1 and Study 2 will be described, including data collection and participant selection criteria. Chapter 4 will present the published Journal article “Mothers’ Perspectives of Support for

their Child, diagnosed with Feeding/Swallowing Disorders” published in the Journal of Speech, Language and Hearing in 2021. Chapter 5 will present the submitted journal article “‘A Band-Aid Service’: Speech-Language Pathologists’ Perspectives on the Challenges They Face to Support Children with PFD and Their Families” presently under review by an international journal.

Chapter 6 will present the discussion and provide the themes in the context of the current clinical practice and existing literature, offering recommendations and the conclusions drawn from Studies 1 and 2. The references section will provide detailed information regarding all references used across this thesis.

This qualitative research project aimed to explore the experiences and perspectives of the primary carers of children with PFD and speech-language pathologists on the support provided to children with PFD. In addition, it aimed to identify whether there was a need for practical recommendations to support clinical practice, and if so, what these would be, to improve the experiences of children with PFD and their families.

Chapter 2.0: Paediatric Feeding Disorder.

2.1 A Complex Condition

Historically, childhood feeding problems are well-documented. Various disciplines have proposed multiple diagnostic hypotheses, usually siloed, and using discipline-specific terminology (Estrem et al., 2016). In the mid-twentieth century, a psychoanalytical approach was suggested (Spitz, 1945). Later, children's feeding problems were attributed to disordered parenting (Fischhoff et al., 1971), were defined by the caregiver-child relationship (Davies et al., 2006) or were focused on by behavioural approaches to specific feeding behaviours (Piazza et al., 2003). Feeding disorder was often described as a symptom rather than a stand-alone disorder (Feeding Matters, 2024). This limited identification of the multiple issues for children with feeding problems meant that the associated functional limitations for children were not always acknowledged. Consequently, these siloed views and narrow diagnoses suggest insufficient training and research currently for many professionals seeking to support these children and their families (Aldridge et al., 2010; Gosa et al., 2020; Sharp et al., 2022).

Feeding problems have more recently been described using a typological approach (Dovey et al., 2010; Goday et al., 2019). The most recent consensus statement which attempted to provide a universal definition of Paediatric Feeding Disorder (PFD), utilised this approach to capture and recognise feeding problems as multifaceted and complex (Goday et al., 2019). PFD was defined as "Impaired oral intake that is not age-appropriate, and is associated with medical, nutritional, feeding skill, and/or psychosocial dysfunction" (Goday et al., 2019, p. 124). PFD therefore describes a heterogeneous group of children facing multiple challenges in meeting their nutritional oral intake (Goday et al., 2019).

The PFD consensus statement is the most recent attempt to establish universally accepted multi-disciplinary diagnostic criteria for feeding issues (Goday et al., 2019). The conceptual framework utilised for PFD also captures the functional limitations of the disorder for the child. This is based on the World Health Organization (WHO) International Classification of Functioning (ICF-CY), Disability and Health (World Health Organization, 2007). A framework designed to assess health and disability in children and youth, focusing on functioning rather than solely on disability. Therefore, although the PFD diagnosis was determined by a group of experts from the United States of America (U.S.), it has much to offer health professionals globally.

Each of these four domains will be discussed separately in the following sections; however, they are interconnected, with significant overlap and interaction between them.

2.2 Medical Domain

PFD can manifest as a primary disorder or co-morbidity associated with premature birth, gastrointestinal, respiratory, cardiovascular, and/or neurological systems issues (e.g. neurologic impairments and/or neurodevelopmental disorders, such as autism spectrum disorder), (Zickgraf & Mayes, 2018). Children may have difficulty eating or swallowing from birth, or their challenges may be iatrogenic related to oral aversion resulting from medical interventions, such as nasogastric tube feeding (Krom et al., 2017). These children may also have upper respiratory disorders such as allergies, chronic tonsil, and/or adenoidal issues, and possibly tethered oral tissues (Baxter et al., 2020).

Additionally, PFD, regardless of the aetiology, may result in serious risks to children (Manikam & Jay, 2000). Malnutrition, dehydration, growth faltering, cognitive impairment, emotional dysfunction, susceptibility to chronic illness, and aspiration pneumonia, potentially

impact a child's mortality and morbidity (Lefton-Greif et al., 2014; Proctor et al., 2024). All these medically related factors may affect a child's ability to eat and drink successfully.

2.3 Feeding Skill Domain

Feeding disorders may become evident in early childhood due to illness, injury, or developmental delays that result in sensory or motor deficits affecting one or more stages of deglutition (Siktberg & Bantz, 1999). These deficits can impact a child's ability to manage food in terms of texture, temperature, and bolus size. For example, the introduction of solid foods often highlights difficulties with oral intake (Benfer et al., 2014).

Children with feeding disorders may present as hypersensitive, reacting strongly to specific textures or temperatures, or as hyposensitive, requiring more stimulation to engage with food. Oral stage motor difficulties, such as inefficient chewing or bolus management, can lead to prolonged mealtimes and messy eating behaviours. Pharyngeal deficits, on the other hand, may result in choking or aspiration, impacting the child's ability to swallow safely and protect their airway (Marshall et al., 2016). These challenges often necessitate instrumental evaluations to assess swallowing function and risks.

Management strategies for children with delayed or inefficient feeding skills typically involve texture modification of food and fluids, the use of specialist feeding equipment, and positioning adjustments to optimize safety and efficiency during mealtimes (Goday et al., 2019). For example, Supplementary Appendix 1 of the seminal paper by Goday and colleagues provides detailed examples of these interventions, illustrating the range of supports that can address specific feeding deficits.

2.4 Psychosocial Domain

Issues of a psychosocial nature may relate to the child, the caregiver, and/or the feeding environment. Mismatched caregiver expectations, mental health challenges, and cultural or social misunderstandings can disrupt feeding. A distracting or inconsistent mealtime environment also worsens feeding behaviours. PFD often manifests as learned feeding aversions, stress, disruptive behaviour, food over-selectivity, failure to transition to age-appropriate diets, grazing, or the caregiver's use of maladaptive strategies, further complicating the child's feeding development. The child's behavioural profile may have a complex causal relationship with PFD, with an increased risk of psychological issues, ranging from fear of trying new foods; hypersensitivity to smell, taste, or texture; and fear of choking (Kedesdy & Budd, 1998, p. 131). Children may present with sensory aversion to food related to textures, colours, and temperature (Martins et al., 2008).

2.5 Nutritional Domain

Children with challenges in the nutritional domain may experience restrictions on the different types of food they will consume, the amounts, or the quality of their nutritional intake with the potential to cause malnutrition: "Pediatric malnutrition...an imbalance between nutrient requirement and intake, resulting in cumulative deficits of energy, protein, or micro-nutrients that may negatively affect growth, development, and other relevant outcomes" (Mehta et al., 2013, p. 478). This may result in a diagnosis of weight faltering or subnormal growth previously known as failure to thrive (Shields et al., 2012). Other related outcomes such as obesity, deficiencies in micronutrients and possible dehydration, may result when whole groups of dietary food for example fruits and vegetables are absent from the diet (Goday et al., 2019). These dietary disturbances may impact the developing child profoundly, across all developmental milestones, education, and family life.

2.6 Prevalence of Paediatric Feeding Disorder

PFD affects a large, heterogeneous population of children (Goday et al., 2019). A recent U.S. study found that PFD rates are similar to those of common disorders like eating disorders and autism, estimating that 1 in 23 to 1 in 37 children under five may be affected, with rates rising to 1 in 3 to 1 in 5 among those with coexisting chronic conditions (Kovacic et al., 2021, p. 131). Currently, there are no available statistics on PFD prevalence in Australia. Notably, the number of children diagnosed with feeding disorders continues to increase rapidly, explained in part by improved survival rates of both complex medical conditions and prematurity (Johnson et al., 2016; Pados et al., 2021; Samara et al., 2010). As LaMantia et al., (2016, p. 1) state “Feeding and swallowing difficulty is one of the most common, least understood complications for children with developmental disorders”. So, while prevalence is difficult to ascertain it is reported anecdotally that it is high, and the numbers are increasing. Galai et al., (2023, p. 1) state “Up to 20% of parents are reportedly concerned about their child’s feeding behavior”. Feeding difficulties are reported in many peer-reviewed studies to be as high as eighty per cent of children with developmental disorders (Aldridge et al., 2010; Kovacic et al., 2021; Manikam & Jay, 2000). “Feeding-related concerns are among the most common issues in preschool children who are brought to primary healthcare professionals by parents” (Arvedson, 2008, p. 119). Currently in Australia, the prevalence of PFD is unknown, partly due to the relatively recent adoption of the consensus statement and the heterogeneity of the affected population.

2.7 Diagnoses linked to PFD

Children with Pediatric Feeding Disorder (PFD) may exhibit a limited dietary intake and be described as "picky" or "selective" eaters. These terms may carry negative connotations and are often associated with assumptions about parenting practices. Such descriptors are regarded as dismissive and highlight the belief that this condition is a transient phase that children will eventually outgrow (Chilman et al., 2021).

Avoidant/Restrictive Food Intake Disorder (ARFID), as classified in the DSM-5, is diagnosed only after excluding other eating disorders. It has a significant overlap with PFD. ARFID is increasingly being considered within the four domains of PFD, to ensure no underlying medical or skill-related dysfunctions could be contributing to feeding difficulties, rather than attributing these challenges solely to behavioural factors (Noel, 2023).

2.8 Psychosocial Impact of Paediatric Feeding Disorder on the Family

Feeding a child is a relational activity that involves the family and the primary caregiver in the ultimate nurturing role (Davies et al., 2006), a complex interplay between biology, family, and the social environment (Berlin et al., 2009). The potential for families to experience significant stress is well documented, and there appears to be a direct correlation between the scale of their child's challenges with PFD and their experience with psychosocial disorders (Kedesdy & Budd, 1998; Nelson et al., 2015; Pedron-Giner et al., 2014). The responsibility of caring for a child with PFD can significantly impact family life often dominating mealtimes and limiting other activities (Crist & Napier-Phillips, 2001). Research indicates that caregivers of children with PFD experience heightened levels of anxiety, social isolation, and adverse psychosocial consequences (Cockerill et al., 2016; Harvey et al., 2015;

Lefton-Greif et al., 2014). A recent study emphasised that caregiver stress in these families surpasses that noted with other conditions such as chronic illness or autism (Silverman, et al., 2021). Therefore, to ensure effective support for these families, health professionals must understand the potential for families with children with PFD to experience a higher incidence of stress.

Stress for these families can also be linked to transitions of care, for example, inter-sectoral transfers between secondary (hospital) and primary (community) care, or therapists changing frequently (Johnston & Bennett, 2019). Care pathways could offer the support outlined by Haggerty et al., (2013) supporting caregivers, during times of increased stress, to engage with their allied health team ‘through information sharing and partnership’, (p. 269). A qualitative study of fourteen families in Sweden found that caregivers reported health professionals at childcare centres often had “a lack of understanding and knowledge about PFD” (Lamm et al., 2023 p 956). Similarly, Estrem et al., (2018, p 347), identified that the 12 American families they interviewed had been “distressed” related to a lack of “care coordination” for their children. Families seeking or receiving support for their children with PFD face a particular and complex challenge which frequently requires the involvement of multiple services. A continuity of care approach is therefore essential for families to feel supported.

2.9 Multi-disciplinary Approach to Paediatric Feeding

Disorder

There is a consensus amongst health professionals that the diagnostic and treatment protocols for PFD must be multi-disciplinary (Bertrand et al., 2024; Galai et al., 2022; Goday et al., 2019). However, it is only very recently that a modified Delphi study involving

Australian health professionals was completed, aimed at providing a standardised dataset for defining and measuring care in feeding disorders. This dataset considers the composition of feeding teams and their key performance indicators, enabling the alignment of services with the diagnostic protocol for PFD. This will be a helpful tool for other teams keen to offer best-practice protocols for PFD (Elliot et al., 2024). Parents are often reported to seek this approach as in the study by Cowpe et al., (2014) when parents sought a multi-disciplinary team that promoted “a trusting relationship between family members and professionals” (p. 7). The complexity of the interplay between the four domains of PFD necessitates that all involved with this disorder seek the involvement of a multidisciplinary team. These professionals may include but are not limited to psychologists, doctors, dieticians, speech-language pathologists (SLPs), and occupational therapists (OTs). They may be co-located but are often in disparate locations with varying degrees of coordinated approaches to the child in their care (Sharp et al., 2017).

A key member of this multi-disciplinary approach is the speech-language pathologist (SLP). They are trained in the anatomy, development, physiology, and behaviour underpinning a child’s ability to eat and drink (Gosa et al., 2020). They offer crucial support for families of children with PFD (Arvedson, 2008; Dovey et al., 2010). However, the nature of the support provided by SLPs and the process of building effective therapeutic relationships are not well-defined.

In Australia, the clinical guidelines for the SLP’s role in dysphagia are outlined in the Dysphagia Guidelines published by Speech Pathology Australia, the main professional body representing SLPs in Australia (Speech Pathology Australia, 2012). This document outlines guidelines related to all types of dysphagia management across all age groups. It offers limited guidance related directly to children. It is important to note that these guidelines were

produced before PFD terminology and diagnostic criteria were identified (Goday et al., 2019). They therefore do not consider the heterogeneous nature of children with PFD, and this could have implications for SLPs who are required to offer services to these children. While the responsibility for PFD management is shared across disciplines, SPA's leadership in shaping SLP practice standards can significantly enhance the overall care provided to children with PFD.

Despite the critical role of SLPs in PFD, there is evidence to suggest that SLPs are not providing effective support to this population. Uncertainty in clinical practice is often associated with complex conditions (Cooke et al., 2017; Han et al., 2011; O'Riordan et al., 2011). SLPs globally have identified an inability to deliver effective services for feeding disorders. In the United States, a national survey of SLPs and OTs including over 400 SLPs, Thompson et al., (2024) identified a lack of preparedness and support for their roles with PFD. Bailey et al., (2008) conducted focus groups with 33 school-based SLPs, who reported difficulties translating their dysphagia theory training into clinical practice. Similarly, O'Donoghue & Dean-Clayton, (2008) surveyed 222 school SLPs and found issues between training and self-reported confidence with dysphagia, noting that a lack of training often co-existed with higher levels of confidence in treating dysphagia. Felicetti et al., (2020) surveyed 200 SLPs who reported academic and clinical preparedness issues, while Hutchins et al., (2011) reported a survey of 52 school-based SLPs, finding low levels of confidence and a request for additional training to manage their dysphagia caseloads. Modi & Ross, (2000) in South Africa conducted a study with 75 hospital-based SLPs, who also reported low levels of confidence, restricted access to supervision, limited availability of colleagues with knowledge of dysphagia and a lack of undergraduate preparedness. In New Zealand, Burgess et al., (2016) found the SLPs reported to be under-skilled and lacked resources. Again, in NZ,

Jackson et al., (2021) surveyed health professionals including SLPs on their understanding of children with Avoidant/Restrictive Food Intake Disorder (ARFID) and found that these children and their families faced “a lack of suitable resources and services” (p. 44). Also, in a further NZ survey of 32 SLPs, Jackson et al., (2022) reported challenges to effective communication channels across the team of school SLPs, health professionals and the family. In an Australian study (Tan et al., 2021), mothers reported issues accessing support for their children with PFD. They reported facing barriers in accessing SLPs with knowledge of and interest in PFD. In the scoping review of over 400 studies on PFD, Estrem et al (2022), found a lack of family-centred variables recorded including, family and parent impact of PFD, or quality of life measures. A recent Australian survey of nearly 200 health professionals assessing their training needs, reported a lack of confidence in working with children with PFD. This lack of confidence was explicitly linked to the recency and frequency of practice (Raatz et al., 2023). However, as this study did not exclusively focus on SLPs, it was impossible to identify SLPs’ confidence levels in this area of practice. To further understand why some families of children with PFD may feel unsupported by SLPs in Australia, it is essential to explore SLPs’ perspectives on the support they offer children with PFD.

2.10 Empirical Evidence in the Management of Paediatric Feeding Disorder

In the context of PFD, SLPs lack empirical evidence for all stages of engagement with children and their families (Marshall et al., 2015; Speyer et al., 2022; Voniati et al., 2021) However there is a particular gap in knowledge understanding families’ views on effective and preferred interventions for the treatment and management of PFD (Estrem et al., 2022).

Sharp et al. (2017) conducted a systematic review and meta-analysis, which underscored the challenges therapists face when using research to guide interventions for PFD. The lack of standardised protocols and the variability in treatment approaches, team composition, and therapeutic methods across studies make it difficult for therapists to draw clear conclusions or apply consistent practices. Despite these inconsistencies, the research suggested that interventions generally lead to positive outcomes in feeding behaviours and nutritional status, though clearer guidelines are needed to better inform clinical practice. Evidence-based practice requires replicability of accuracy, precision, and dependability. It assists the navigation of uncertainty, grounding our decisions in the best available findings (Cayley, 2023). This has partly arisen as applying research findings to clinical practice in the context of PFD presents distinct challenges. Currently, a gold standard for assessment, classification, and intervention for paediatric feeding problems, does not exist (Estrem et al., 2016).

In Australia, SLPs have guidance in the form of Professional Standards (Speech Pathology Australia, 2020), to ensure they adhere to evidence-based practice (EBP) principles and processes (Dollaghan, 2007). Often visualised as a triangle EBP focuses on clinical expertise, the best research evidence, and care-giver/client perspectives. However, due to PFD's multifactorial aetiology, careful consideration and judgment when selecting effective intervention and treatment planning requires a balance of all levels of evidence. A recent scoping review aimed at clarifying the clinical aspects of evidence-based practice (EBP) (Brannick et al., 2022) highlighted that "good clinical decisions integrate multiple sources of evidence." The established components of the EBP framework, incorporating client-informed data, or internal evidence, ensure valuable perspectives are captured (Higginbotham & Satchidanand, 2019).

Recent research by Galai et al., (2022, p 5), seeking predictors for PFD highlighted the “diverse sociodemographic and perinatal factors” for children with PFD. This heterogeneous diversity makes rigorous research challenging. For example, randomised control trials (RCTs), are typically referred to as providing high levels of evidence for a particular treatment approach (Jordan et al., 2019). However, RCTs require large fairly homogeneous groups of participants. RCTs therefore are unable to accommodate the extensive variability of children with PFD. In a recent scoping review of the literature on PFD, Estrem et al., (2022), found that studies often lacked sample characteristics or dosage details, impacting replicability, and limiting decision-making regarding issues such as effective treatment approaches. The limited evidence for PFD regarding assessment and treatment decisions may result in feelings of uncertainty for SLPs. Whilst uncertainty is a common feature of many aspects of medical practice (Carter et al., 2016; Han et al., 2011), it is unclear how to manage this uncertainty, particularly when striving to deliver informed and shared decision-making with families and other professional colleagues.

2.11 Family Support for Paediatric Feeding Disorder

In the twenty-first century, globalisation and advancements in healthcare and education have transformed how health professionals support children and their families (Turner, 2018). These transformations have often originated from outside the healthcare field. For instance, changes to global consumer-focused legislation ensured that families had the right to safety and involvement in decisions concerning their child's well-being (Tower, 1994). The Family System theory, which posits that families are complex and that the behaviour of each family member is interrelated, has been instrumental in shaping family-centred practice (Bowen, 1978; Dempsey et al., 2009). This theory advocates for a whole-of-family approach, recognizing the interconnectedness of family dynamics. These

developments have collectively contributed to a more holistic view of child development. Health professionals now consider the child within the context of their family and environment, acknowledging the crucial role that families play in their child's growth and well-being. This shift in perspective has led to more comprehensive and effective support strategies for children and their families.

Health service provision across the Organisation for Economic Co-operation and Development (OECD) countries continues to focus on illness and disease through the biomedical approach (Wade & Halligan, 2017). This approach emphasises deficits and often simplifies conditions to treatable symptoms rather than considering a holistic, person-first perspective. However, there has been a shift towards a more comprehensive model of care. Increasingly, allied health responses have adopted a bio-psychosocial model (Engel, 1982). This approach not only addresses biological processes but also considers the person, their family, and their physical, emotional, and environmental situations. The focus on an individual's ability rather than their disability is best exemplified by the International Classification of Functioning, Disability, and Health guidelines (World Health Organization, 2007). These guidelines identify participation, activities, and functions as central considerations for outcome planning. Consequently, health professionals delivering support using this model should prioritise engagement and capacity building. This approach aligns with a more holistic view of health and well-being, moving beyond the traditional biomedical focus on treating symptoms in isolation.

This more holistic approach to health care also aligns with the socio-ecological perspective (Bronfenbrenner, 1986), which will be employed in this study to examine the support systems available to families. The bio-psychosocial model's focus on the individual within their broader context resonates with the socio-ecological framework's examination of

multiple levels of influence. This analysis will include the microsystem, encompassing immediate and extended family members; the mesosystem, involving friends, support groups, teachers, and carers; the exosystem, which includes all health professionals involved; and the macrosystem, which considers broader policy and service delivery factors. Additionally, the chronosystem will be used to explore how the passage of time and the changing nature of a child's condition impacts their development and family dynamics.

Although there is general agreement that health professionals offering support should prioritise engagement and capacity-building, the precise definition of "support" remains somewhat ambiguous in current research. Schalock et al., (2021) define support as "a focus on reducing the mismatch between individuals' competencies and the requirements of the environments" (p. 98). Furthermore, various types of support exist. For instance, Kyzar et al., (2012) categorize support into emotional, physical, material or instructional, and informational support. To deliver effective care, all these types must be considered.

The importance of family support for children with disabilities is well-documented in the literature. Studies show that optimal family engagement with health professionals leads to improved well-being, family quality of life, satisfaction with parenting, and family unity (Dunst et al., 2007; Neely-Barnes & Dia, 2008). Haggerty et al., (2013) discuss continuity of care, particularly for clients with complex conditions requiring multidisciplinary or cross-agency collaboration. They identify three core elements of care: informational, managerial, and relational, which are necessary for effective support. The continuity of care model emphasizes consistency in communication, joint planning, and engagement with clients and families.

Health professionals following this model provide holistic services centred on communication with both clients and multidisciplinary teams (Forstner & Arnold, 2023). Cowpe

et al., (2014) highlight that the perception of being supported is only achieved when there is an effective partnership between health professionals and families. While the vital role families play in caring for their children is increasingly recognised, the specific elements needed to build supportive therapeutic partnerships between families and SLPs remain unclear, particularly for children with PFD.

2.12 Family-Centred Practice

Family-centred practice (FCP) considers family, the central core of a child's development and is widely recognised as the primary service delivery model for helping professions (Dunst et al., 2007; Kokorelias et al., 2019). FCP also serves as the guiding framework for SLP interventions and practices (Speech Pathology Australia, 2020). Central to this approach is the close collaboration between healthcare professionals and parents, promoting a bio-psychosocial model that informs goal setting and encourages a team-based perspective (Berlin et al., 2009). By placing the child at the core of all decision-making, FCP practitioners aim to ensure safety and quality in service delivery.

The application of FCP by community healthcare professionals is well-documented (Allen & Petr, 1996; Dunst et al., 2007). However, as Dempsey et al. (2009) caution, it is essential to apply FCP in a way that avoids placing undue pressure on families to take on “hands-on” interventions, as this can cause additional stress. Dempsey et al. further emphasize that the way health professionals choose to deliver services is just as important as the support they offer. Inappropriate service delivery decisions can lead to heightened family stress and psychosocial complications (Cockerill et al., 2016; Cowpe et al., 2014; Harvey et al., 2015; Kedesdy & Budd, 1998; Lefton-Greif et al., 2014; Nelson et al., 2015; Pedron-Giner et al., 2014; Siktberg & Bantz, 1999).

Recent standards for SLPs in Australia (Speech Pathology Australia, 2020) highlight FCP as a critical component of any intervention with families. However, there are no clear guidelines on what constitutes effective FCP when working with children with pediatric feeding disorders (PFD). Uncertainty remains about whether families of children with PFD view their partnerships with professionals as supportive and central to successful outcomes. A qualitative American study of 30 family caregivers noted that "treatment approaches should focus on outcomes that are meaningful to caregivers and incorporate principles of family-centered care" (Simione et al., 2020, p. 273). Yet, in a recent scoping review, Estrem et al. (2022) found that many studies lacked key family-centred variables, such as family impact or quality of life measures. This highlights the need to explore whether families of children with PFD perceive the FCP they receive as effective.

2.13 Funding and the NDIS

Australian families access SLP services for their children with PFD through various funding systems, including private payments, state-funded hospital services, and child development services. However, many rely on publicly funded models. These models include three main insurance types: health insurance (Medicare), third-party or transport accident insurance and social insurance (NDIS). Medicare and Transport Accident Insurance, provide part funding, leaving families responsible for additional costs, while the National Disability Insurance Scheme (NDIS) funds the identified needs of participants with a disability (Nickless et al., 2023).

The NDIS, introduced in Australia a decade ago, under the NDIS Act (2013), has significantly reshaped allied health service provision in Australia. Similar to schemes in the UK and New Zealand, the NDIS represents a shift away from paternalistic government-led services, empowering participants with choice and control over the services they access. As a

client-centred, participant-led funding model, it focuses on consumer needs and gives participants control over the funding and decisions regarding their care (National Disability Insurance Scheme, Corporate Plan, 2019). Funded by the federal government, the NDIS was designed to create a marketplace responsive to the needs of individuals with disabilities and their families. However, PFD is not recognised as a standalone diagnosis under the NDIS, meaning funding is only available if feeding issues impact a child's overall functioning as part of their disability. This restricts access to care, for many children, especially those without a disability or those diagnosed with ASD, who may experience service gaps due to limited care coordination or resource constraints (Gavidia-Payne, 2020). Given that access to allied health services is often a critical component of a participant's plan, the NDIS plays a major role in shaping SLP services for children with PFD in Australia (Green & Mears, 2014).

Despite its impact, there are concerns about how the NDIS affects the availability of a highly skilled workforce to support SLP training (Hines & Lincoln, 2016) and its potential to hinder inter-organisational collaborative practice (McKenzie & Smith-Merry, 2023). Notably, no published studies have explored the experiences of families with children with PFD accessing services through the NDIS funding model.

2.14 Summary

In summary, research is essential due to its PFD's complex and multifaceted nature, impacting children's health, development, and family dynamics. Current knowledge gaps, such as the treatments that families report to be meaningful to them, lack of standardised diagnostic criteria, inconsistencies in treatment approaches such as dosage and frequency, and limited understanding of long-term outcomes, hinder the delivery of effective care. Addressing these gaps is crucial not only for improving clinical outcomes but also for

streamlining service delivery and enhancing the quality of life for children and their families. Furthermore, without a deeper understanding of the underlying causes and mechanisms of PFD, interventions may continue to be fragmented and less effective. The need for research is not merely to fill knowledge gaps but to develop a more cohesive, evidence-based framework that ensures early identification, appropriate interventions, and long-term support for children with PFD. This will empower clinicians, policymakers, and families with the tools needed to deliver optimal care and improve health trajectories. We currently do not know what the families' perspectives are on the support they experience for their children with PFD. Nor do we know of the experience of SLPs in providing support to families and children with PFD.

2.15 The Current Thesis

This thesis describes two qualitative studies. One explored the perspectives of mothers of children with PFD experiences of support and the other explored the experiences of SLPs of providing support to children with PFD.

2.16 Research Aims

There were three main aims for this research:

- 1) To explore primary carers' perspectives on the support they seek and receive for their child/ren with PFD.
- 2) To elucidate speech-language pathologists' perspectives on the support they offer primary carers of a child/ren with PFD.
- 3) To identify the enablers and barriers to optimal therapeutic partnerships between primary carers and speech-language pathologists, when working with children with PFD.

2.17 Significance

This research is distinctive in its dual focus on the perspectives of both primary carers and SLPs regarding support for children with PFD. It aims to identify the enablers and barriers to providing effective support, contributing valuable insights into service delivery for this population. The findings are expected to provide current and accurate information that can inform best practice recommendations for service delivery to children with PFD. The experiences of caregivers and the specific support they seek remain under-researched, representing a notable gap in the literature (Estrem et al., 2022). This study, by capturing the experiences of both mothers and SLPs, aims to generate pertinent information that can guide future interventions.

First, the study seeks to understand the perspectives of primary carers, focusing on their views of what constitutes support, from whom they seek it, and where they find it. Additionally, their insights into the main obstacles and facilitators to obtaining support for their children are gathered. This research offers families, as the primary caregivers, the opportunity to voice their perspectives on the challenges and successes they encounter while caring for a child with PFD.

The second focus of the research is on the perspectives of experienced SLPs. By exploring their role and the support they currently offer, the study examines the therapeutic practices and interventions provided to families. This allows for a deeper understanding of the professional knowledge and services available to children with PFD and their families.

By combining the perspectives of both caregivers and practitioners, the research aims to present a comprehensive view of current support practices for children with PFD. The detailed insights gathered can help identify the specific needs of families and children with PFD and suggest ways to address those needs more effectively. This body of knowledge can refine existing practices and contribute to the development of future policies and training

programs for professionals supporting children with PFD. Ultimately, the study's findings have the potential to guide the creation of care pathways that are better aligned with the needs of families and children, ensuring more supportive and effective service delivery.

Chapter 3.0: Method

3.1 Research Project

This chapter details the role of both phenomenological and hermeneutic paradigms in achieving the research objectives of this qualitative research project. The research objectives were to investigate primary carers' perspectives on the support they sought for their children with Paediatric Feeding Disorder (PFD) and to elucidate speech-language pathologists (SLPs), perspectives on the support they provide children with PFD. Further, the aim was to identify the enablers and barriers to optimal therapeutic partnerships between primary carers and speech-language pathologists, when working with children with PFD.

3.2 Research design study 1

Study 1 utilised, a thematic analysis (TA) following recommendations by Braun and Clarke (2006), to capture the lived experience of mothers. The entire research process, which included the collection, management, analysis, and interpretation of data was guided by the epistemic cognition of the lived experience. Thematic analysis offered the flexibility required to listen to, explore, and organise these experiences shared through this research process.

Braun and Clarke's Thematic Analysis (Braun & Clarke, 2006) was used to interpret and fully understand the mothers' report of their support-seeking behaviours and attempts to access support for their child/children with PFD. This method is particularly well-suited for this purpose. TA is a widely used analysis method when considering the 'lived experience' and the perspectives of groups of people, identifying their meaning-making. Braun and Clarke have provided clear guidelines on the appropriate use and implementation of this research approach, which consists of six recursive reflexive phases.

3.3 Participants

Sixteen participants were recruited from various sources, including parent support groups, disability service providers, and private therapy services, through multiple websites and Facebook pages. Purposive sampling ensured that the recruited participants were the primary caregivers of children aged between 2 and 12 years old, identified as having a feeding and/or swallowing condition, currently in receipt of services or having had received services in the past from a range of providers from across the sector including the private, the public and the not for profit (NFP) sector. All residents within the metropolitan area of one particular Australian city. Before beginning the studies, potential participants were provided information detailing the research purpose and their expected involvement. This ensured access to primary carers who due to their experience with their child's complex feeding and mealtime presentation would process "a unique, different or important perspective" (Robinson, 2014, p. 32). Prior to this study, the families and their children were unknown to the first author.

3.4 Research Procedures

Following email contact and information sharing regarding the research purpose, written consent was provided by all participants. The MPhil candidate completed all sixteen interviews. At the beginning of the interview, demographic data was collected through face-to-face conversations, allowing for a more personal and engaging interaction. This approach not only provided a deeper understanding of the participants but also helped establish rapport, making them feel more comfortable and valued as their backgrounds were discussed more naturally and conversationally. To encourage the mothers to take the lead in the discussion, open-ended questioning, reducing the researcher's verbal input and active listening techniques were employed. This non-verbal and verbal signalling supported the participants

to experience being heard and provided empathetic encouragement (Creswell & Miller, 2000; Liamputtong, 2013). Using these means, the participants were made to feel the focus of attention which helped to ensure their data reflected their concerns and interests. The interview guide utilised, targeted probes enabling the collection of more specific information, for example, open-ended questioning, “Tell me a bit more about that”. (Interview guide available Table 1 below) A funnelling technique (Gray, 2017) encouraged all participants to provide elaborate and extended answers. This ensured rich content in the participants’ reports. The questions asked were iteratively modified across all the interviews and influenced by the previous report.

Table 1 *Study 1 Interview Guide*

#	Questions
1	If you were to think of your experience with your child as a journey. Can you tell me about when your child first had issues with feeding and swallowing?
2	How did you find support? Was the support you received helpful or unhelpful?
3	Can you tell me how you have found things, in terms of feeding and swallowing, since then?
4	Has the support you have received for your child been what you had expected?
5	Travelling ahead into the future what support would you like for yourself and your child?
6	If you were to reflect on the journey you’ve travelled, what support do you wish had been available for you, your child, and your family?

The face-to-face, semi-structured interviews were conducted in participant-suggested locations, often their homes, which allowed for a more comfortable and open dialogue. Their participation in the study was acknowledged with a small monetary token for their time and engagement.

The semi-structured nature of the interviews provided the flexibility to delve into the participants' experiences while adhering to a consistent framework. The discussions were recorded and later transcribed verbatim, capturing not only the words but also non-verbal cues like body language and tone, which often revealed deeper emotional undercurrents (e.g. a softer tone or avoidance of eye contact when recounting difficult experiences). These nuances were essential as they offered another layer of meaning to the data.

3.5 Research Data Analysis

After the interviews, Step 1 of the recursive phases of TA familiarisation with the data involved a process of consistent reading and re-reading of the transcriptions and the notes made immediately following all the interviews, coupled with listening multiple times to the recordings of the interviews by the first researcher. Each transcription was reviewed in depth, noting key patterns or moments that aligned with the research questions. This careful process of coding involved systematically tagging interesting features, ensuring that no detail was overlooked.

In step 2 initial codes were generated by line-by-line coding, looking for interesting, common and recurrent themes in the data, and then employing a constant comparison strategy to generate initial themes. This involved grouping these codes into potential themes. This phase was much more than just sorting data; it was an active engagement with the material, looking for connections and overarching ideas. Reviewing the themes required a thorough refinement process, constantly checking to ensure they accurately represented the coded data and could be applied across the entire dataset. Some themes evolved, either being merged with others or separated into more distinct ideas to better reflect the data's complexity.

Defining and naming the themes was a crucial step. Each theme needed to be described in a way that captured its full scope and significance within the data, ensuring that

the essence of the participants' experiences was preserved. Finally, the writing process brought everything together, constructing a coherent narrative that not only presented the findings but also told the story of the data, using participants' voices to illustrate the themes and make the analysis as authentic and compelling as possible.

This personalised and systematic approach to thematic analysis ensured a deep exploration of the participants' lived experiences, all while staying true to their perspectives.

The data were the source material for all themes analysed and dissected (Heidegger, 1962; Liamputtong, 2013). An iterative process ensured that the data led the foci of interest. A 'thick' description was sought "to show rather than tell" (Tracy, 2010, p. 843), sorted into themes, with theme titles and descriptions being identified from the data (Pringle et al., 2011). NVivo 8 software (Bazeley & Jackson, 2013) was used to assist and support the organisation of the data, using matrices to aid the analysis of each of the mothers' transcripts, allowing the identification of patterns and themes within each transcript and across the whole data set (Gibbs, 2007; Saldaña, 2016). Codes were applied to the data, enabling a transition from simple reading to analytical interpretation of the transcripts. The thematic analysis was then supported by examining patterns or themes across the complete dataset. This meant analysing how the participants talked about and understood what was happening to them, using the transcribed interview sessions and any associated notes with actual quotes linked to and described by the themes. To focus on the participants' accounts of their journey is central to any phenomenological account. Major and minor themes were identified by "finding coherent descriptions and explanations that still included all the gaps, inconsistencies, and contradictions inherent in personal and social life" (Miles et al., 2014, p. 10). These themes were reviewed, and new themes were developed until the team of authors agreed on all themes, defined, and named, ending with the writing phase of the data analysis process. These themes were identified with supporting text, grouped, and linked in clusters e.g. power

relations were identified, the mothers reporting feelings of powerlessness and their experience of not being heard or their descriptions of their beliefs and opinions not being valued or believed. This utilisation of the six recursive reflexive phases described by Braun and Clarke (2006), ensured the integrity of the process. The relatively large amount of data offered by the sixteen mothers meant that a TA focusing on identifying cross-case themes was particularly suitable.

Thematic analysis was employed as the primary method to inductively derive insights from the data, ensuring that the coding and theme development emerged directly from the participants' experiences without being influenced by pre-existing frameworks. Once the themes were identified, the ecological systems framework (Bronfenbrenner, 1979) was applied as a conceptual tool to structure and enhance the interpretation of the findings. It is crucial to emphasise that the ecological framework did not guide the initial stages of analysis; rather, it was used post hoc to contextualise and present the findings in a more holistic and comprehensive manner. This approach allowed for a nuanced understanding of the data while maintaining the integrity of the inductive analysis.

3.6 Research Design Study 2

In Study 2, an Interpretative Phenomenological Analysis (IPA) was conducted to explore the perspectives of SLPs experienced in working with children with PFD and their families (Smith & Nizza, 2022). An IPA stance encourages the researcher to consider each unique account of the lived experience, gaining accounts full of nuanced and personal details stated in the participant's terms. As stated by Larkin et al. (2006), this is a detailed consideration and interpretation of the data, quite different from the quantitative tradition of the search for norms across large groups

3.7 Research Participants

Following ethical approval from the Curtin University Human Research Ethics Committee, the MPhil candidate posted the approved recruitment flyer on a special interest group aligned with Speech Pathology Australia, the main association of SLPs in Australia, inviting those interested to contact the researcher. Once participants volunteered their interest, they then suggested others. This purposive, snowball sampling (Robinson, 2014), aimed to access ten SLPs with at least three years of experience working with children with PFD in community practice, in a metropolitan area of an Australian city. The metropolitan aspect of their role was consistent with a previous study 1 completed by some of this research team (Tan et al., 2021- see chapter 4). This resulted in the recruitment of 11 female SLPs. Two had trained in Britain and the remaining nine were trained in Australia. They averaged 10 years of experience in assessing, treating, mentoring, and supervising PFD in the community. Two were employed in the not-for-profit sector and the remaining nine were employed independently. Four SLPs were mothers of children with PFD. The SLPs were all registered members of Speech Pathology Australia and certified practising members of the organisation. This resulted in an informed group of SLPs participating in this study. in an informed group of SLPs being engaged in this study. (Table 2)

Table 2 *Study 2 Participant Demographics*

Aliases	SLP Country of Training	PFD Years of Experience	Workplace	Family Experience with PFD
Charlotte	UK	14	Private practice	No
Amelia	UK	21	Healthcare Not for Profit Organisation	No
Olivia	Australia	7	Private practice	Yes
Isla	Australia	7	Private practice	Yes
Mia	Australia	4	Disability Not for Profit Organisation	No
Ava	Australia	9	Private practice	No
Grace	Australia	5	Private practice	No
Chloe	Australia	4	Private practice	No
Willow	Australia	8	Private practice	No
Matilda	Australia	14	Private practice	Yes
Ella	Australia	12	Private practice	Yes

3.8 Research Procedure

An initial meeting before the interviews allowed the participants to ask questions and discuss the project before participating. Many participants knew of the author's previous study with mothers of children with PFD and were interested in contributing their professional perspectives. All the participants provided written informed consent before the interviews. Semi-structured interviews were conducted online using a flexible interview guide (See Table 3).

Table 3 *Study 2 Interview Guide*

Open Ended Questions	Targeted probes
<p>What in your experience is the role of a speech Pathologist supporting a family with a child with PFD/feeding and or swallowing disorder?</p>	
<p>How do you support a family with a child with PFD/feeding and or swallowing disorder?</p>	
<p>In your experience are there things that make it hard to support a family with a child with PFD/feeding and or swallowing disorder?</p>	<ul style="list-style-type: none"> • Are there things that could be improved about this? • How do you feel about this?
<p>In your experience are there things that make sit easier to support a family with a child with PFD/feeding and or swallowing disorder?</p>	
<p>Are there any things that you would like to do to support a family with a child with PFD/feeding and or swallowing disorder that is currently not available to you?</p>	<ul style="list-style-type: none"> • Why is it unavailable?

This guide was pilot-tested in an initial interview and the questions were refined with input from the research team, this team included the first author (JT) and her academic supervisors, three in the SLP field and one social worker. It incorporated a set of broad questions however the participants were encouraged both by verbal and non-verbal means including active listening techniques and a stated goal of seeking their perspective. Semi-structured interviews were held online, which was convenient for participants and lasted for approximately 60-90 minutes. Participants were provided with written information about the study, including data handling, confidentiality, and the option to withdraw before any publication of the data. The participants were deidentified and any defining details were altered to ensure anonymity. The participants were renamed, using the twelve most popular female names in Australia at that time according to a Google search.

These strategies encouraged the interviewees to lead with their professional and personal experiences and interests in PFD (Smith & Nizza, 2022). Following the interviews, verbatim transcription was completed, using a third-party transcription service (www.otter.ai; Transcription Software, 2016). Each participant confirmed that they were satisfied for the transcripts to be used, with additional comments gained during this stage of member checking added to the dataset of three participants.

3.9 Data Analysis.

The study of SLPs' perspectives on offering support to children with PFD and their families presented a different research challenge than Study 1. Gathering the perspectives of SLPs practising in the field of PFD was fundamentally different from the 'lived experience' of the mothers in Study 1. The data analysis in this study adhered to the recommendations of Smith and Nizza (2022) and employed Interpretative Phenomenological Analysis (IPA), which focuses on the particular context from an ideographic perspective. The initial analysis involved extensive reading and re-reading of each dataset, during which exploratory notes were made to capture the first author's emotive responses rather than attempting an immediate interpretation. A linguistic analysis examined the language used by participants, including metaphors and repetitions. Notably, many participants employed nautical references, such as "port of call," "navigating," and "signposting," which conveyed the multifaceted nature of their experiences, encompassing themes of guidance, uncertainty, emotional engagement, and professional identity.

Each participant underwent a thorough individual analysis, leading to the identification of experiential statements (EPs), which were grouped into fewer personal experiential themes (PETs). A detailed paper trail of notes was maintained with transcripts displayed on large A2 notepads. A table of PETs for each participant, linking data extracts to

highlight similarities and differences across the dataset, a key aspect of IPA's ideographic focus. Subsequently, cross-case analysis facilitated the emergence of group experiential themes (GETs). In the data analysis process, the wider author group took on the role of auditing to ensure rigour and reliability. Initially, the principal analyst conducted exploratory noting by thoroughly examining the collected data, and identifying significant elements of participants' lived experiences. From this, experiential statements were derived, capturing essential meanings and interpretations.

The next phase involved linking experiential statements to create personal experiential statements for each participant. To ensure the analysis was robust and consistent with Interpretative Phenomenological Analysis (IPA) principles, the wider research team independently reviewed 20% of the data. This provided an additional layer of scrutiny, verifying the accuracy and coherence of the derived themes.

Finally, cross-case analysis was performed, comparing and contrasting patterns across participants. This ensured compliance with IPA's idiographic focus while maintaining the depth of interpretation, supported by the wider author group's audit to validate the findings. Team discussions were integral to the interpretative and writing phases of the analysis, ensuring clarity in the construction of emergent and superordinate themes and reinforcing the connection between the themes and the data. Collaborative dialogue between MPhil students and supervisors led to the identification of four overarching themes and 14 sub-themes, enhancing the understanding of the data throughout the reporting process (Smith & Nizza, 2022).

IPA is grounded in philosophies of phenomenology, hermeneutics, and ideography. Drawing on Husserl's emphasis on individuals as meaning-makers, IPA positions participants as 'experiential experts' (Smith & Nizza, 2022, p. 6). IPA offers two significant elements that

differentiate it from TA, which assisted with this exploration of the accounts of SLPs. This was the ‘dual analytic focus’ (Braun & Clarke, 2021, p. 41), ensuring an ideographic perspective, a deep consideration of each participant’s dataset, focused on the particular and unique. Heidegger’s influence on IPA introduces a hermeneutic approach that emphasizes the interpretative nature of the analysis. Researchers using IPA engage deeply with participants to understand their experiences, employing a “double hermeneutic” (Smith & Nizza, 2022, p. 8), where researchers interpret participants’ interpretations of their experiences. This interplay relies on the researcher’s reflexivity and understanding of positionality throughout the research process. Reflexive practices, including journaling and creating an audit trail, enable researchers to document their evolving understanding and challenge their "fore structures" (Heidegger, 1962, p. 153). By fostering awareness of their own beliefs, researchers can authentically engage with the participants’ accounts. The IPA approach provides a comprehensive exploration of each speech-language pathologist's experiences, capturing the intricate connections between embodied experiences, verbal expressions, and emotional responses. This methodology revealed both convergent and divergent thinking among participants, yielding a nuanced understanding of their personal comprehension horizons (Smith, 2011). 10; Gadamer, 1975/1996).

Once this analysis of each individual participant’s dataset was complete, recognition of across-data themes commenced. The SLPs’ use of shared learned concepts and jargon-laden language offered a distinct challenge. As an “insider researcher” (Auburn et al., 2021 p. 23) shared assumptions were required to be unpacked and analysed if more than superficial accounts of the SLP’s practice were to be gathered attempting to apply “the most sensitive

and responsive analysis possible within our epistemological and methodological limits”
(Larkin et al., 2006, p. 108).

Table 4 *Participant Experiential Statements*

Experiential Statements	Participants
Navigating a path	P1, P2, P3, P4, P7, P9
Engaging with families/ building trust	P1, P2, P3, P5, P6, P7, P8, P9, P10, P11
Building family-centered approach	P1, P2, P3, P5, P6, P11
Supporting families to cope	P1, P2, P3, P5, P9, P10, P11
Delivering holistic services	P1, P2, P3, P4, P5, P7, P8, P9, P10, P11
Creatively delivering personalized services	P2, P3, P5, P6, P7, P8, P9, P10
Encountering a lack of understanding of SLP role with PFD	P6, P7, P8, P11
Creating consensus around PFD terminology	P2, P3, P9
Explaining the complexity of PFD	P1, P2, P6, P8, P10
Assessing using frameworks of consideration	P1, P2, P4, P6, P11
Ensuring safety	P2, P3, P5, P6, P7, P10, P11
Building a spectrum of knowledge	P1, P3, P4, P6, P7, P10
Responding ethically to the need	P3, P4, P7, P8, P11
Conceptualising skill development in line with values and soft skills	P1, P3, P6, P7, P8, P10
Dealing with uncertainty	P1, P2, P3, P4, P5, P6, P7, P8, P9, P10, P11
Feeling under-prepared/imposter syndrome	P1, P4, P7, P8, P10
Mentoring less experienced clinicians	P7, P10, P11
Transformational nature of knowledge and learning	P1, P3, P4, P10

IPA focuses on a particular and contextual ideographic perspective. IPA is rooted in the philosophies of phenomenology, hermeneutics, and ideography. Husserl, the principal philosopher of the phenomenological method, provided a paradigm within which to explore peoples’ experiences and viewed people as the makers of meaning, which is valid and real, reminding us to view our participants as the experiential experts (Smith & Nizza, 2022, p. 6). Heidegger, a student of Husserl, led IPA research in a new direction, one influenced by hermeneutics, the theory of interpretation. Therefore, the Heideggerian IPA emphasises the

interpretative nature of this form of analysis. Researchers using IPA attempt to understand an experience not by using revelatory processes but rather by a deep, meaningful engagement between the researcher and those being researched. The relationship between the researcher and participant is inter-related. The researcher listens intently as the participant relates to their experience. The researcher attempted to interpret and assign meaning to the words and descriptions of participants' reports of their experiences. The experience is understood and interpreted from the language and text collected and involves the researcher using the "double hermeneutic" (Smith & Nizza, 2022, p. 8.). This results in a more nuanced consideration of the participants' personal horizons of understanding (Gadamer, 1975/1996).

3.10 Trustworthiness and Rigour

According to Levitt et al. (2018), ensuring reliability in qualitative research involves providing clear and sufficient information to allow for the replication of data gathering, analysis, and establishing a direct link between the data and the findings. In this study, trustworthiness was addressed through several key measures. A reflective journal was maintained by the MPhil student throughout the research process, which played a crucial role in considering her positionality during both studies. The reflective journal spanned all stages, including data collection, conducting pilot interviews, refining the semi-structured interview guide, and maintaining supervision throughout the entire research process. This process ensured that the MPhil student engaged in reflective practice to bracket her own stance, keeping her views distinct from those of the participants.

The interview guide was structured to encourage the use of open-ended, probing questions, prompting the student to seek explanations or expansions on any emerging concepts or ideas. This approach supported the integrity of the data collection process by allowing

participants to fully express their experiences without the researcher's influence. Moreover, the research was guided by the recommendations of the CORE-Q guideline (Tong et al., 2007) across all stages, including the planning, analysis, and reporting of trustworthiness. These combined strategies ensured that the research adhered to high standards of rigor, maintaining the credibility and authenticity of the findings

To ensure the robustness and consistency of the analysis in alignment with Interpretative Phenomenological Analysis (IPA) principles, a random selection of approximately 20% of the data was independently reviewed by the wider research team. This additional layer of scrutiny helped to verify the accuracy, coherence, and credibility of the derived themes. By engaging external reviewers in this process, the study strengthened its analytical rigour, ensuring that the interpretations were well-supported by the data and consistent with the participants' reported experiences. This collaborative approach further enhanced the trustworthiness of the findings by providing an objective verification of the theme development process.

3.11 Reflexivity

The MPhil student's dual role as both a researcher and an insider, a practising SLP with personal and professional connections to PFD, introduced complexities inherent to insider research. Insider research presents both advantages, such as a deeper understanding of the context and a greater rapport with participants, and challenges, including potential biases and influence on participants' responses (Auburn, 2021; Taylor, 2011). Given the student's professional relationships with most participants, there was a heightened risk of assumptions based on shared experiences and the potential for participants to shape their responses based on what they believed the researcher wanted to hear.

To ameliorate these issues, several strategies were employed to safeguard the rigour and integrity of the research. First, a comprehensive reflexive process was maintained throughout the study (Lazard & McAvoy, 2020), including a reflective journal to critically assess the MPhil student's positionality and mitigate bias. This included noting any preconceptions or emotional responses before and after interviews to ensure they were acknowledged and bracketed. Reflexive discussions with the supervisory team further ensured that emerging themes were data-driven and not unduly influenced by the researcher's insider status.

Additionally, transparency was maintained through a detailed audit trail that documented the decision-making process, from data collection to theme development. This helped create clarity around the influence of the researcher's insider perspective, ensuring that it contributed to a deeper understanding of the data rather than skewing the findings. In instances where the researcher's relationship with participants might have influenced the dynamics of the interviews, careful attention was paid to the use of open-ended questions and neutral prompts, encouraging participants to provide authentic and reflective responses.

Finally, member checking was incorporated into the research process, where participants were given the opportunity to review the transcripts and ensure that their perspectives were accurately represented. This process helped mitigate potential power dynamics and reaffirmed the trustworthiness of the findings. These strategies collectively aimed to manage the complexities of insider research, ensuring that the student's close ties to the field enhanced rather than compromised the quality and credibility of the study.

**Chapter 4.0: Mothers' Perspectives of Support for
their Child with Feeding/ Swallowing Disorders-**

Journal publication

Tan, J., Cocks, N., & Claessen, M. (2021). Mothers' perspectives of support for their child, diagnosed with feeding/swallowing disorders. *Journal of Speech, Language and Hearing, 25*(1), 17–28. <https://doi.org/10.1080/2050571X.2021.1904734>

The published paper associated with Study 1 is presented.

Authorship Statement: This research journal publication was produced as part of Julie Tan's Master of Science (MSc) in Speech Pathology at Curtin University, under the supervision of Assoc. Professor Naomi Cocks and Dr. Mary Claessen. Julie Tan holds primary authorship of the resulting scholarly article, with her supervisors listed as co-authors in accordance with ICMJE guidelines. Intellectual property remains with the student, while her supervisors retain the rights to use the findings for academic purposes with appropriate attribution.



Mothers' perspectives of support for their child with feeding/swallowing disorders

Julie Tan , Naomi Cocks  and Mary Claessen 

School of Allied Health, Curtin University, Perth, Australia

ABSTRACT

Mothers of children with feeding and/or swallowing disorders play a significant and important role in their children's care, yet little is known about their perspectives regarding the support they seek and receive to perform this role. This study investigates how mothers regard the support available to them. This included support they needed, sought, had access to, or received, during their journey with their child/ren. Semi-structured interviews were conducted with 16 mothers of children with feeding and/or swallowing disorders. A unique comprehensive exploration of support was ensured using Bronfenbrenner's ecological framework. This allowed for the identification of the sources of support, at an individual and family level, service provider and policy level for children with feeding and/or swallowing disorders in Australia. Transcripts were analysed thematically to identify common themes and patterns. The mothers expressed their strong desire to receive knowledge of their child's condition from health professionals. Their report was consistent with what is known of the barriers in this field of practice including diagnostic confusion of feeding and/or swallowing disorders and the often-fragmented service level response offered to families. The recommendations they offered included better interprofessional communication, inclusion of the family as key team members and a better understanding of the biopsychosocial nature and impact these conditions have, not only on the child, but on the whole family unit.

ARTICLE HISTORY



Received 7 August 2020
Accepted 12 March 2021

KEYWORDS

Feeding disorder; food refusal; mealtime behaviours; mothers; selective/picky eater; qualitative; families

It is estimated that 25% of all children (Manikam & Jay, 2000) and 80% of children with neurodevelopmental disorders have feeding and swallowing disorders (LaMantia et al., 2016). Significantly, even though this population is so large, there has been no universally adopted definition of feeding and swallowing disorders (Arvedson, Brodsky, & Lefton-Greif, 2019; Estrem et al., 2016). This may have resulted in a poorer understanding of these disorders by both health professionals (HPs) and families alike. Recently, Goday et al. (2019) attempted to address this with a consensus statement recommending adoption of the term, Paediatric Feeding Disorder (PFD). This term encompasses all issues related to impaired oral intake considered within the four domains of medical, nutritional, feeding skills and psychosocial factors (Goday et al., 2019). It is possible that prior to publication of the consensus statement, HPs would not have easily identified a child with feeding and swallowing disorders or have a good understanding of the complexity of these disorders (Estrem et al., 2016; Uher & Rutter, 2012). This may have resulted in families receiving delayed or inadequate support for their children, who were either not being identified early enough or were not receiving appropriate onward referrals.

Feeding is a unique relational interaction between the primary carer and the child where the carer takes on a life sustaining role (Davies et al., 2006). Therefore, the primary carers of children with feeding and/or swallowing disorders are at high risk of experiencing significant stress (Aldridge, Dovey, Martin, & Meyer, 2010; Budd et al., 1992; Pedron-Giner, Calderon, Martinez-Costa, Borraz Gracia, & Gomez-Lopez, 2014). Caring for these children can have a disproportionate impact on family life, when mealtimes may dominate the whole day excluding most other activities (Crist & Napier-Phillips, 2001). Stress for families can also be triggered by intersectoral transfers between the secondary (hospital) and primary (community) care when the change causes stress but can also heighten concerns regarding professional competence (Johnston & Bennett, 2019). Research clearly identifies that these primary carers are at risk for high levels of anxiety, social isolation, and negative psychosocial repercussions (Aldridge et al., 2010; Cockerill, van den Engel-Hoek, & Harding, 2016; Lefton-Greif et al., 2014). Currently, HPs from many disciplines provide families with information, direct intervention, and management strategies. These services are mostly offered by HPs using either an 'expert' model or a family centered practice (FCP) model (Kokorelias,

CONTACT Julie Tan  Julie.Tan@postgrad.curtin.edu.au  School of Allied Health, Curtin University, Kent Street, Perth, WA, Australia
© 2021 Informa UK Limited, trading as Taylor & Francis Group

Gignac, Naglie, & Cameron, 2019). Dempsey, Keen, Pennell, O'Reilly, and Neilands (2009) emphasized that the service delivery model, selected by HPs, was as important as the support they offered. Therefore, for families that care for a child/ren with feeding disorder, with their high risk for stress and psychosocial complications, decisions regarding service delivery models are of particular importance (Budd et al., 1992; Cockerill et al., 2016; Harvey, Bryant-Waugh, Watkins, & Meyer, 2015; Hewetson & Singh, 2009; Lefton-Greif et al., 2014; Nelson et al., 2015; Pedron-Giner et al., 2014). However, what remains unknown is whether such models of service delivery provide families with the support they seek.

The African proverb 'it takes a village to raise a child' reminds us that successful parenting requires well-supported and resourced families. Whilst, a multidisciplinary approach is recommended to provide this support (Silverman, 2010), many studies find that services for children with feeding and/or swallowing disorders continue to be delivered by single discipline practitioners, focused solely on their own professional perspective (Baumann, 2015; Nadler, Slosky, Kapalu, & Sitzmann, 2019; Silverman, 2010).

Accurate identification of family support needs is essential to ensuring best therapeutic practices (Thompson et al., 2009). Families caring for children with severe disabilities have reported that they value and seek emotional support, support for physical needs, support in terms of material or instructional needs and support in gaining access to accurate and relevant information (Kyzar, Turnbull, Summers, & Gómez, 2012). Mothers of children with chronic feeding problems have emphasized the importance of both seeking and receiving knowledge (Garro, 2004). Currently, however, it is unknown whether families caring for a child with feeding and/or swallowing disorders either seek similar types of support or look to similar sources for that support, to that of parents with a child with a disability.

While some families with a child with a disability have developed resilience (McConnell, Savage, & Breikreuz, 2014; Ungar, 2011), the available evidence suggests that having a child with feeding and/or swallowing disorders has a stressful impact on the whole family (Budd et al., 1992; Cockerill et al., 2016; Harvey et al., 2015; Jones & Bryant-Waugh, 2013; Lefton-Greif et al., 2014; Pedron-Giner et al., 2014). There is, therefore, a need to determine just what support is provided and sought by these families and how such support is perceived.

The current study explored mothers' experiences of support across the journey with their child with feeding and/or swallowing disorders. Previous research has provided some useful information regarding isolated aspects of support; however, this study seeks to present a comprehensive view of support. A

socio-ecological perspective (Bronfenbrenner, 1979) will assist in providing a clear account of the mothers' experience and ensure understanding of all the potential sources of support and the identification of the gaps or limitations in support. This analysis of the support will include, the microsystem, of both immediate and extended family members, the meso-system, including the individuals' friends, support groups, teachers, and carers, the exosystem including all HPs, and the macrosystem relating to policy and service delivery. While the families' journey caring for their child including the changing nature of these conditions and how the passage of time influences and impacts the child, will be considered at the chronosystem level.

Aim

This article aims to describe the following:

- what mothers' report is supportive, what is unsupportive or may even hinder them in achieving successful feeding and swallowing for their child.
- where they seek support from

Methods

Ethical approval

Ethics Approval was granted by the ethics committee with which all authors are affiliated. All participants were informed about the study and the confidential nature of how their information would be treated and their right to withdraw at any point in the study. Signed consent was provided by all participants.

Study design

This study adopted an Interpretative Phenomenological research methodology utilizing thematic analysis (Braun & Clarke, 2006) to investigate the experiences of mothers of children with feeding and/or swallowing disorders in seeking or receiving support. Thematic analysis has a proven track-record in considering the 'lived experience' and the perspectives of an identified group of people identifying their 'meaning making' (Smith, 2004). This approach provided a thick description of the mother's experiences, full of detail and authentic reflections allowing for the identification of patterns and themes in the data (Braun & Clarke, 2006). As a proven framework in qualitative research, the journey metaphor can be a useful way of thinking about a difficult and challenging pathway for a family (Aita, McIlvain, Susman, & Crabtree, 2003) and it is often used in research when the focus is on a chronic condition e.g., feeding difficulties (Brett, 2004; Green et al., 2016; Scorgie & Wilgosh, 2009; Wu

1. If you were to think of your experience with your child as a journey. Can you tell me about when your child first had issues with feeding and swallowing?
2. How did you find support? Was the support you received helpful or unhelpful?
3. Can you tell me how you have found things, in terms of feeding and swallowing, since then?
4. Has the support you have received for your child been what you had expected?
5. Travelling ahead into the future what support would you like for yourself and your child?
6. If you were to reflect on the journey you've travelled, what support do you wish had been available for you, your child, and your family?

These questions were used as prompts for the researcher during the interviews. The participants' viewpoints were sought, using non-specific and open-ended questioning whilst using techniques including reframing and reflecting on their replies, throughout all the interviews, E.g. ("You mentioned that....Can you tell me a bit more about that?")

Figure 1. Guide for semi-structured interviews.

& Estrem, 2016) This metaphor was employed to frame the parental perspectives linked to episodes of care received on the journey with their child (Aita et al., 2003).

Materials

Purposive sampling was used to recruit participants to ensure that the selected 'individuals had a unique, different or important perspective' (Robinson, 2014, p. 32). Information on the study was posted on the Facebook pages of disability service providers and private therapy service providers resulting in over 20 mothers self-identifying and contacting the main researcher. This phase allowed information on the study to be shared, informed consent to be sought and the criteria for inclusion to be provided to potential participants. Inclusion criteria were as follows:

- The study participant must be the primary carer for a child diagnosed with feeding and or swallowing disorders
- The child they cared for was aged between 2 and 12 years old
- The family resided in the metropolitan area of Perth, Western Australia

Semi-structured interviews with the use of an interview guide created a flexible approach, which elicited in-depth and personal data. The interview guide (See Figure 1) utilized targeted probes to enable the collection of more specific information within the topics raised by the open-ended questioning, 'Tell me a bit more about that.' A funnelling technique encouraged all participants to provide elaborate and extended answers. These techniques signalled empathetic encouragement and resulted in rich content being collected (Creswell & Miller, 2000; Liamputtong, 2013). Demographic information was

also collected using a questionnaire at the beginning of the interview session.

Participants and procedure

The study aimed to recruit the primary carers of children; however, only mothers contacted the researcher. Although this is disappointing, it is not entirely surprising given that it aligns with current Australian statistics which finds that only 4–5% of fathers are the primary carers for their child (Baxter et al., 2018). At the time of the interviews, six mothers were single parents and ten were in married relationships. Six mothers worked full time, two worked part-time and eight were stay-at-home mothers. All the mothers had completed secondary/high school education to at least year 11. Over half had certificates II-IV training college qualifications and six were university graduates.

All the participant's children were either currently in receipt of services or had received services in the past for feeding and/or swallowing disorders from a range of providers from across the sector including private, public and the not for profit (NFP) sectors. The children discussed included 10 boys (62.5%) and 6 girls (37.5%). The children were all aged between 2 and 12 years with a mean age of 5.6 years. The children had a wide range of diagnoses including autism spectrum disorders (ASD) ($n = 4$), sensory processing disorder ($n = 3$), general developmental delay (GDD) ($n = 4$) and growth faltering (Failure to thrive, FTT) ($n = 2$). (See Table 1).

Analysis

The first researcher conducted all 16 interviews across 2018 to September 2019. Thematic analysis of each of the mothers' transcripts, the source material for all themes, ensured identification of themes within each transcript and across the whole data set (Braun & Clarke, 2006; Gibbs, 2007; Heidegger & Krell, 2011;

Table 1. Range of services provided, and co-morbid diagnoses of the children discussed in the study.

Participant	Service providers	Individual Professions	Co-morbid conditions
P1	Public NFP	Speech Pathologist Occupational therapist Social Worker Hospital Chaplain Respiratory team GA team Physio team	Autism Global Developmental Delay Tracheoesophageal fistula
P2	Public NFP Private	ENT Consultant Child Health Nurse Occupational Therapist	Cerebral Palsy Growth faltering (FTT) Sensory processing disorder ADHD Asthma Blood disorder
P3	Public NFP	Speech Pathologist Social worker Palliative team	Capillary Malformation syndrome Microcephaly
P4	Public NFP	General Practitioner Speech Pathologist Occupational Therapist	Severe receptive and expressive communication delay Moderate bilateral hearing loss Autism
P5	Public NFP	Dietetics Feeding team Speech Pathologist Occupational Therapist Physiotherapist Chiropractor Paediatrician Neurologist	Unknown (SWAN) genetic condition Global Developmental Delay
P6	Public NFP	Feeding team Dietitian Paediatrician	Mosaic Trisomy 15 Prader-Willi syndrome Global Developmental Delay
P7	Public Private	Speech Pathologist	Verbal Apraxia Sensory Processing disorder
P8	Public NFP Private	Cleft palate team Speech Pathologist Early intervention team	Velo-cardio facial syndrome Autism
P9	Public NFP	Neurologist Speech pathologist Physiotherapist	5q14.3 microdeletion syndrome
P10	Public Private NFP	Early intervention team Speech pathologist	General developmental Delay ASD
P11	Public Private	Child Health Nurse Dietitian Child development service	Dyslexia
P12	Private Public	Psychologist General Practitioner	None identified
P13	Private Public	Chiropractor Lactation consultant Osteopath Paediatric dentist Paediatrician	Colic/reflux Sensory Processing disorder

(Continued)

Table 1. Continued.

Participant	Service providers	Individual Professions	Co-morbid conditions
P14	Public	General Practitioner Child Health Nurse Homoeopathy Occupational therapist	None identified
P15	Public	Paediatrician Dietitian CPFS	Growth Faltering (FTT)
P16	Public Private	Speech Pathologist Occupational therapist Psychologist	ARFID Sensory Processing Disorder Autism

Liamputtong, 2013; Saldaña, 2016). Data saturation was identified when no new themes were recognized (Klopper, 2008). Bronfenbrenner's ecological framework supported the categorization and analysis of support sources and types (Bronfenbrenner, 1979). Trustworthiness was addressed by continuous consideration of the researcher's positionality throughout the data collection stage, conducting a pilot interview which helped refine the semi-structured interview guide, keeping written information on the decision and rules regarding code and theme production, providing the participants with the transcripts to report on accuracy and using verbatim quotes to ensure clarity around the researchers' findings (Mays & Pope, 2000). Participant numbers were used to ensure the anonymity of the participants. Measures were taken to ensure the researcher's voice was distinct from the mother's voices. A neutral stance is unobtainable; therefore, the researchers attempted to maintain a balanced view (Spinelli, 2014).

Results

All the children discussed in this study had issues of restricted and selective food intake, many had gastroenterological issues, and all had behavioural issues linked to mealtimes. Their mothers provided abundant and nuanced perspectives on the theme of support for their child with feeding and/or swallowing disorders. These themes were explored using a socio-ecological model (Bronfenbrenner, 1979).

Microsystem

All the mothers reported that obtaining knowledge of their child's disorders from HPs was important and that this knowledge would enable them to deal with the multiple and complex issues their children were experiencing.

... she was the best she just took time to explain things to me ... (P9)

... I'm still trying to get information for myself you know. It'd be wonderful to have someone who said, I know all about this I can help you ... (P10)

More than half of this group of mothers spoke of their struggle with their own understanding of ability or disability. This had also been evident at the recruitment stage of the study, when the removal of the word 'disability' from the study title resulted in a large increase in interested participants which perhaps highlights, a perceived stigma related to their own and the wider community's interpretation of that descriptor (Scambler, 1998).

... I've just realized my son has a disability as a first-time parent we just thought that's normal ... (P4)

... I knew she wasn't doing the normal thing ... (P11)

... really difficult to envisage your child will not feed how you expected ... (P3)

Despite the children all having complex co-morbid conditions, all but one of the mothers identified feeding as their highest concern. They reported with the other conditions, they knew who would provide them with support. However, this was not the case with a child with feeding disorder.

... 'But there's no sign, or there's no obvious, 'Does your child not eat properly? Come and see us. Does your child not hear, well that's obvious: go to an audiologist. But with meals it's like, where do I even start? Where do I even say to someone, 'My child won't eat?' There's a real lack of I guess knowledge and a fear of where do I even start? And then you go to your GP, 'cause the Australian health system's set up in such way everything has to be through your GP. Nine times out of 10, he doesn't know either. So, then you're kind of in this weird cycle until you eventually find a specialist, or find someone in that area, who then goes, 'Oh no, there's a whole world here. You just needed to know the door to knock on ... (P4)

Two mothers reported that they found it challenging to access support even when a multi-disciplinary team (MDT) was involved, as the MDT were usually focused on the other issues of their child's particular syndrome, viewing any reported feeding disorder as a minor issue.

They reported negative outcomes for the whole family that they attributed to their child's feeding and/or swallowing disorders, from marital break-ups to conflict between them and their partners or their own parents or in-laws.

... he was down to five foods; it ended my husband and my relationship ... (P2)

... all our family arguments are about food ... (P12)

However, the parents' relationships were not the only ones negatively impacted and also the child and their

siblings. They reported an inability to do things they felt most families take for granted.

... siblings cop it no variety ... (P11)

... sitting together having a family meal is not our reality ... (P4)

... the hardest bit is when you do go out ... (P10)

Five of the mothers reported conflicting parental approaches with their partners, who often struggled to believe that HPs were ignoring or could not offer support for their child's disorders and blamed the mothers for this inability to access support.

... husband saying 'you're always changing' & I'm like I'm not changing, I'm trying ... (P6)

... I didn't want food to become a negative thing that's what he had with his dad ... (P2)

While in intergenerational relationships, the mothers' approaches to child-rearing were viewed as causal to the child's condition. Six mothers reported this felt like overt critique of their mothering skills and was a source of conflict in the relationships with their child's grandparents.

... old-school attitude of 'if he's hungry he'll eat it' isn't helping ... (P4)

... if you don't eat it you get it for lunch the next day ... (P14)

Five mothers also reported a high level of concern from their own immediate family who would join the mothers in trying to seek support or gain answers from the HPs involved.

... Just me and my Mum trying to fight for answers ... (P8)

... I think we went crazy. If it wasn't for my sister and my bestie ... (P7)

However, this type of support could add to the mother's feeling of being responsible for the whole families' discomfort and disappointment with the child's challenges. Three mothers even reflected that accessing family support brought into question their ability to mother their own child.

... My parents, it was a massive thing for them ... (P3)

... friends and family are funny because it's support but also stressful ... (P11)

Mesosystem

Three mothers reported that they found support in social networks, either in the community or on social media. One mother referred to helpful approaches for their child's disorder she had found via online sources. However, she reported that these approaches

were often discussed on American or other international sites. She felt these approaches were not well understood by the local HPs using them in Australia e.g., the Sequential Oral Sensory (SOS) Approach to feeding (Toomey & Ross, 2011).

... you hear horror stories of SOS done the wrong way. It isn't a quick fix ... SOS scary & expensive, the way it is interpreted is different ... (P2)

The Division of Responsibility by Satter (1990) was mentioned as being helpful by two mothers.

... in Canada they did have that help, it wasn't recognized here ... (P2)

... the biggest difference for us was following the division of responsibility model. It was life changing ... (P11)

Two mothers reported that local church groups or individual friends were empathic and helpful in validating the mothers' concerns. However, most of the mothers reflected that the ability to talk with others experiencing the same kind of difficulty would have been highly valued but that this was not readily available to them.

... I haven't come across anyone that's why I feel so alone someone who knows what it does to you to have a child who won't eat your food ... (P10)

... No, I don't think there is anything past the mealtime management course, that I know & I'm on quite a few Facebook forums ... (P13)

Seven mothers reported that being away from home was not easy, due to the lack of availability of suitable foods or embarrassment with their child's inability to eat 'what everyone else was having.' Four mothers had experienced judgmental responses from others in the community because of their child's disorders with eating and drinking.

... I know some people snicker and just think she's being a naughty child ... (P11)

Only two mothers considered their child's school or daycare as supportive of their child's issues. While three of them spoke of these issues not being understood or even accepted by daycare or school.

... This is literally all he will eat and the teacher would just not take no for an answer ... (P4)

Exosystem

A recurring theme throughout all the interviews was that mothers were actively seeking support. In accessing support, they encountered many negative experiences, including disbelief and judgemental attitudes from HPs. This evidenced a complex undermining of their role and competence as mothers. A finding also discussed in Gunnarsson, Hemmingsson, and Hyden

(2013) which reported that mothers sought HPs who would consider and value their experiences.

... a misconception that you have enabled it. There was nothing we did caused that ... (P4)

... too judgmental so we don't share our journey a lot ... (P7)

They viewed the rejection of their concerns and their sense of blame as a reflection of the professionals' view on their own competence as a mother. This attribution of blame is evident in other conditions, often when there is limited knowledge of a particular condition. In the beginning of the understanding of autistic spectrum disorder, 'refrigerator mums' were suggested as causal of their child's condition (Deslauriers, 1967). In the interviews, when the mothers talked of these attitudes, they attempted to re-establish themselves as rational and knowledgeable about their own child, emphasizing that they were doing the best they knew for their child.

... This isn't a lack of parenting ... (P11)

... countless times I was told I was a neurotic mother. I'm not being this crazy mum ... (P8)

Over half of the mothers commented that HPs made causal links and held assumptions of psychosocial or mental health issues that appeared insensitive or without warrant.

... feeding disorder was essentially a consequence of an attachment disorder. Show me a parent who can't get dysregulated attachment when you're trying to feed your child and they won't eat your food. Show me a perfect attachment, throw in a feeding disorder. You know what? it stirs things up. I found that really insensitive ... (P11)

... It was all in my head ... (P2)

This feeling of being judged can be particularly intense for mothers of children diagnosed with failure to thrive or growth-faltering both terms with pejorative undertones (Shields, Wacogne, & Wright, 2012).

... he (the child's Paediatrician) said I had a month to turn things around or he was reporting me to Child Protection ... (P15)

Three mothers also recognized that they often played a passive role in the parent HP relationship perhaps not to be viewed as demanding.

... I'm sick of going into battle. Just to fight for something that's a basic human right ... (P9)

... ..it must just be me ... (P4)

General practitioners attracted criticism from eight mothers who spoke of their perceived role as gatekeeper to other services. The offer of glib and unreasonable suggestions and the unhelpful manner, with which the mothers' concerns were met, meant the

mothers felt that the GPs and Paediatricians were not listening or were not believing their account.

... 'try to end each meal on a happy note'. Feed your child 6-8 times a day', are you kidding me, this is so traumatic ... (P11)

... Well stop breastfeeding and she'll eat ... (P11)

... Have you tried putting vegetables on his plate every day? ... (P4)

... GP seeing him over one and a half years just saying reflux reflux ... (P8)

... Nobody knows how to co-ordinate a complex feeding case ... (P5)

... They were getting us to force feed her but as soon as she was able to fight us off, she wouldn't let us feed her that way. ... (P15)

... He'll grow out of it ... (P2)

Speech pathologists also received criticism from six mothers for showing to have no interest in feeding issues or little understanding of feeding disorders. The mothers reported having to keep trying new speech pathologists until they could find one, who had some interest in this area of practice. The speech pathologists would frequently share their own lack of expertise and confidence with feeding and/or swallowing disorder and five mothers reported changes to their community therapy team were frequent.

... we just do communication ... (P2)

... speechie described symptoms but no intervention ... (P11)

... They were just very uneducated. She had no idea what we were dealing with ... (P8)

... Early intervention speech pathologist won't have anything to do with feeding ... (P7)

... We had a Speechie they did communication. If the speechies had told me. She might not be on a tube ... (P9)

... when I speak to the public speech pathologist she doesn't want to know or even acknowledge that's an issue ... (P7)

Three mothers recalled nurses or child health nurses, who were able to offer valuable support. They mentioned teams particularly in the specialist baby unit as being helpful and knowledgeable about the feeding disorders their child was experiencing.

... Even the nurses that were general nurses, they would help me. And, they had obviously quite extensive knowledge in babies with medical issues and with feeding issues. So, it was very, very hands on ... (P1)

However, this was not the case for two mothers, who reported that nursing staff had an agenda focused

on breast-feeding. This shaped their dealings with the mothers despite the babies not successfully feeding.

... All the nurses hound you for breastfeeding if you want to switch to formula you kind of cop it ... (P9)

Five mothers discussed the transfer of care, from primary healthcare to community care, as being a difficult time for them. This interface between hospital and community services can be challenging related to perceptions of skilled practice within the acute care settings often felt to be the expert model. This highlights a paradigm shift between the primary and secondary care as an issue in the management of feeding and/or swallowing disorders (Johnston & Bennett, 2019).

... I went from having a professional at the hospital to having this rookie ... (P8)

... shown the door with absolutely no support ... (P5)

Comments from five mothers reflected a lack of awareness of the implications for their child, caused by the shift from the acute medical setting to a community-based service delivering. Unbeknown to them, at home, they were now receiving a FCP approach with a focus on the International Classification of Functioning utilizing a functional and participatory approach (WHO, 2007).

... what do you think is important? no offer of what works and sharing of her professional experience ... (P1)

... I didn't know that I had to ask for certain things ... (P9)

Generally, all the mothers reported a lack of communication between the HPs they encountered, and a few noted that the therapists were often changing.

... You have to explain your story each time, it's usually someone different ... (P8)

... Change of therapist, 3 or 4 different ones ... (P1)

... need holistic approach, nobody joining the dots ... (P11)

Macrosystem

Recognition of the importance of professionals working inter-professionally is generally understood (Dew, De Bortoli, Brentnall, & Bundy, 2014; Dunst, Trivette, & Hamby, 2007). However, the means to do this effectively is often a service-level restriction and can be beyond any single HP's control. The long waiting times and restrictions to access feeding teams e.g., often available only for hospital in-patients, exemplifies this.

... I didn't get seen by the feeding team until XX was 12 months, so she sat on a wait list for four months ... (P11)

... the feeding team. I think the referral is 18 months old and I've heard nothing ... (P5)

... the feeding team, I don't know why we sort of fell through, but we do see the cleft team at the hospital every six months, and they got us through our last swallow study, which was unsuccessful again ... (P8)

Chronosystem

Five mothers reflected that the most significant impact of the passage of time on their child was the impact of many transitions of care related to the child's age and stage of development. As previously stated, transitions from the tertiary to secondary care were difficult due to a perceived level of expertise and the limited ongoing consultation between HPs. Furthermore, schools and daycares were identified by two mothers for their lack of supportive and inclusive practice in working with the family to manage the child's feeding and swallowing disorder.

... sort of got discharged, bumped into disability ... (P1)

... school would make Thai green curry we thought he was eating it and then it sort of came to light in the last six months that actually they were giving him completely separate food ... (P4)

Discussion

The mothers in this study discussed 'types of support' that came from all levels of Bronfenbrenner's (1979) socio-ecological framework. Mothers met challenges to being supported at each level. The cumulative impact of this continued failure to have their needs met, caused them to feel conflicted, marginalized, and feeling that neither people nor services understood or cared. Theirs was a lonely journey, as they struggle to make sense of their situation. Even those people, who were supposed to know how to help them, were not always helpful. There was a lack of clarity around who or where they could receive support from. They were often denied access to the few services dealing with their children's condition/s. The reasons they provided for this breakdown in support were related to a lack of understanding, a lack of funding or simply, that their own experiences were not taken seriously.

At the micro/mesosystem level, the mothers involved, all reported feeling that their mental health and capability to nurture their child was implicitly questioned and judged, findings similarly reported in a study of the relationships between mothers and HPs by Gunnarsson et al. (2013). Their insecurity

regarding their competence to care for their child was further reinforced by the negative attitudes of their families and the wider community. They reported feeling that they had to defend themselves against being misjudged and not being believed. This added greatly to the stress of having a child with a serious disorder and meant that their search for support was often a search for a HP who would believe and validate their concerns (Budd et al., 1992).

The exosystem level of professional support had further huge implications for the quality of service that health providers could offer. The mothers in this study were knowledgeable of their child's condition. They all recognized that feeding was a systemic process. In line with previous studies of parents of children with feeding and swallowing disorders, these parents were all able to reliably identify that their child had a difficulty with eating and drinking and were able to see connections among many of the symptoms their child was experiencing (Coulthard, Blissett, & Harris, 2004; Harvey et al., 2015; Wright, Parkinson, Shipton, & Drewett, 2007). For example, a mother of a child with a high risk of choking could appreciate the importance of carefully managing their child's positioning when the child was offered a drink. So, when HPs offered simplistic solutions, the mothers instinctively felt that such advice would not effectively address the problem and that in some instances might even increase the difficulties that they and their child were experiencing.

Dealing with feeding and/or swallowing disorders from a systemic viewpoint is, of course, best practice and is only truly possible by enlisting an interdisciplinary approach (Sharp, Volkert, Scahill, McCracken, & McElhanon, 2017). However, mothers in this study reported only a limited availability of interdisciplinary approaches. They supplied much anecdotal evidence of HPs working in isolation with limited collaboration or communication with other professionals. While feeding teams were available to a few of the mothers, these were usually reported to be difficult to access or provided little follow-up to the families. These mothers were seeking HPs who were able and willing to work collaboratively, clearly communicate their own specialism and help them to seek and include the professions as identified by their child's needs. They sought identification of and access to the appropriate expertise required by their child's particular needs with services being delivered by practitioners who were not constrained by the boundaries of a single-discipline (Baumann, 2015; Keith-Thomas & Baressi, 2007; Nadler et al., 2019; Sharp et al., 2017; Silverman, 2010).

At this macrosystem level, Service delivery models themselves could be problematic. Mothers suggested that HPs utilizing FCP appeared to lack operational definitions and came across as having no clear

direction to guide treatment or even much knowledge about their child's disorder (Epley, Summers, & Turnbull, 2010; Shields et al., 2012). Alternatively, mothers described the 'expert' service model as overly directive and non-inclusive. Thus, no service model appeared to be ideal. Furthermore, in the chronosystem, with the passage of time, when transitions between providers occurred, particularly shifts from the tertiary to secondary care, challenges, due to the lack of cross-sectoral communication between hospitals and community HPs, were evident. These miscommunications were further complicated by community therapy teams undergoing frequent personnel changes.

What the mothers in this study were looking for, had many similarities to Kyzar et al. (2012) which reported that mothers of children with disability sought 'emotional support, support for physical needs, support in terms of material or instructional needs and support in gaining access to accurate and relevant information.' Informational support was identified by all the mothers interviewed. They wanted HPs to provide them with information on, the nature and impact of feeding disorders and the interventions and strategies that might assist them. Like the parents in the Kyzar study, they were also seeking emotional support and recognition of the huge impact these disorders were having on their family life. The mothers clearly recognized that support was an essential prerequisite to good clinical outcomes for their child (Cowpe, Hanson, & Smith, 2014; Garro, 2004; Parrish, 1997). Furthermore, they easily identified barriers to accessing support for their child, including diagnostic confusion around feeding and/or swallowing disorders, as identified in Goday et al., 2019 and a lack of inter-disciplinary approaches to their child's condition resulting in a siloed and fragmented service-level response. The mothers reported that these barriers led to under-diagnosis or misdiagnosis and a lack of onward referral, which often resulted in late identification and diagnosis of their child/ren (Estrem et al., 2016; Goday et al., 2019; Uher & Rutter, 2012).

Such flaws in HPs conceptualization, communication, and delivery of support services to mothers create a great deal of stress for families; this stress is well documented in the research (Budd et al., 1992; Cockerill et al., 2016; Harvey et al., 2015; Jones & Bryant-Waugh, 2013; Lefton-Greif et al., 2014; Pedron-Giner et al., 2014). It was of note in this study that there was no clear uptake of external supports or use of social media. This was perhaps due to time limitations whilst managing a demanding child (Garro, 2004), due to these supports not being readily available or that such services were applicable only to other parts of the world e.g., Canada or the U.S.A. It was of note that the mothers involved in this study mentioned only two approaches suggested for the

management of their child's condition: SOS Approach to feeding (Toomey & Ross, 2011) and the Division of Responsibility (Satter, 1990). Families' feeling supported is a clear goal for HPs because they understand that the feeling of being supported is crucial for good clinical outcomes for their clients. It is, therefore, of concern that many of the mothers in this study felt unsupported by HPs. Furthermore, it is of great concern that this lack of support was associated with each level of the socio-ecological framework.

Practical implications and future research

This study uniquely considers mothers' perspectives on support for their child with feeding and/or swallowing disorders across all the levels of a socio-ecological framework. This study was a first step towards understanding mothers' perspectives. Their suggestions offer clarity for HPs regarding what support it is that they seek. These suggestions, along with the recently published consensus statement (Goday et al., 2019), present HPs with an exciting opportunity to use shared descriptors and improved understandings in working together to support families with such children.

The support HPs offer families should be guided by evidence-based practice (EBP) (Lefton-Greif & Arvedson, 2007). While different diagnoses require the involvement of different HPs, in a recent systematic review it was recommended that an interdisciplinary approach be used with this population and that at a minimum, the following disciplines should be included: psychology, medicine, dietetics, speech pathology and occupational therapy (Sharp et al., 2017). Since the incidence of children with mixed-cause feeding disorders is thought to be as high as 85% (Silverman, 2010), a behavioural component and input from psychological services is an essential element of any treatment plan. The establishment of interdisciplinary teams that place the child and their family in a central role and that communicate regularly with each other using shared concepts and a shared clarity of purpose would better support families by offering them consistent holistic care. Ensuring that HPs engage with the whole family and that they involve them all in decision-making would better support mothers by making them feel less isolated and marginalized. Primary and secondary care services must ensure better communication, understanding and support for families, who are interacting with a complex team of HPs dealing with this broad range of disorders.

The use of FCP is well established in the field of paediatric disability and is understood to be key to building positive relationships with families. However, while a supportive relationship with the family is important, it is not enough on its own to maximise results from

that support' (Dempsey et al., 2009, p. 559). HPs providing support need clear operational definitions of the support they offer families, thus providing families with clarity in terms of what it is they offer. For example, HPs need to be clear whether they offer supportive relationships, information, interventions, management, or some combination of all these types of support. A therapeutic alliance with families effective enough for families to feel supported is necessary in order to build trust. This clarity of what they offer will further support the management of realistic expectations. Here in Australia in the new working environment provided by the NDIS, it is particularly important to be clear as to what the critical elements of FCP are. The well-documented risk of psychosocial issues for these mothers and families makes supporting the families' as a unit, the essential tenet of FCP that must always be considered (Epley et al., 2010).

There is clearly uncertainty on the part of HPs working within this field of practice and this uncertainty needs to be better managed. This study has highlighted a need for HP training to better enable them to deal with children with these disorders as well as with their families. It would be most helpful to align the new consensus statement, with clear operational definitions of practice and interdisciplinary models of service delivery. This would result in a better understanding of the tenets of FCP, with training focused on complex therapeutic relationship building within an area of practice that continues to have high levels of uncertainty (Han, Klein, & Arora, 2011). It is imperative that more research focused on interdisciplinary and intersectoral collaborative work is undertaken to build and establish clearer guidelines for HPs working within this field of practice.

Limitations

This study has several limitations that may require consideration and may help to direct any future research. Recruitment for this study identified 16 mothers. No fathers, grandparents, or other carers were involved and therefore their thoughts and opinions remain unknown. The fathers' views of support are central to any consideration of a family response to caring for a child, but the methods used to identify the primary carers may have worked against inclusion of fathers, given that Facebook pages do tend to favour female participants. Cultural diversity was also not addressed with this group of mothers and it could be of future interest to note any cultural differences in feeding practices between identified cultural groupings. Families, targeted in this study, lived in the metropolitan area, and thus any equity of and accessibility of services for those living in what are considered rural and remote areas were also not considered. However, it is

likely that the additional travel costs for both families and service providers would negatively impact any provision of services for families in a rural or remote setting (Verdon, Wilson, Smith-Tamaray, & McAllister, 2011).

Conclusion

This article uniquely reports on 16 mothers' perspectives on the support they needed, sought, had access to, or were given for their child with feeding and swallowing disorders. It identified that there were gaps in support for them at every level of the eco-system surrounding them and their child. It identifies their calls for more shared understandings and collaborative team working amongst all HPs, improved early identification and timely on-going referrals to ensure the full range of issues confronting children with feeding and/or swallowing issues are addressed. Their experiences highlight systemic issues that intersectoral services and educational institutions need to address regarding training, on-going supervision, and inter-professional approaches. Clear operational guidelines for service delivery and the availability of interdisciplinary team approaches would better ensure a supported workforce that can offer valuable support to families caring for all children with feeding and swallowing disorders.

Acknowledgements

This study was completed as part of a Doctoral of Research degree by the first author. The author would like to acknowledge and thank all participants.

Disclosure statement

No potential conflict of interest was reported by the author(s).

ORCID

Julie Tan  <http://orcid.org/0000-0001-6373-443X>
Naomi Cocks  <http://orcid.org/0000-0002-1744-6979>
Mary Claessen  <http://orcid.org/0000-0002-1087-5041>

References

- Aita, V., Mclvain, H., Susman, J., & Crabtree, B. (2003). Using metaphor as a qualitative analytic approach to understand complexity in primary care research. *Qualitative Health Research, 13*(10), 1419–1431.
- Aldridge, V. K., Dovey, T. M., Martin, C. I., & Meyer, C. (2010). Identifying clinically relevant feeding problems and disorders. *Journal of Child Health Care, 14*(3), 261–270. doi:10.1177/1367493510370456
- Arvedson, J. C., Brodsky, L., & Lefton-Greif, M. A. (2019). *Pediatric swallowing and feeding: Assessment and management*. San Diego, CA: Plural Publishing.
- Baumann, S. L. (2015). The financial case for patient-centered interdisciplinary teams in the United Kingdom. *Nursing*

- Science Quarterly*, 28(3), 234–235. doi:10.1177/0894318415585623
- Baxter, J., Van Hooff, M., Forbes, D., Lawrence-Wood, E., Hodson, S., Sadler, N., ... McFarlane, A. (2018). *Stay-at-home fathers in Australia*. Melbourne: Australian Institute of Family Studies. ISBN: 978-1-76016-167-5.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.
- Brett, J. (2004). The journey to accepting support: How parents of profoundly disabled children experience support in their lives. *Paediatric Nursing*, 16(8), 14.
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge, MA: Harvard University Press.
- Budd, K. S., McGraw, T. E., Farbisz, R., Murphy, T. B., Hawkins, D., Heilman, N., & Werle, M. (1992). Psychosocial concomitants of children's feeding disorders. *Journal of Pediatric Psychology*, 17(1), 81–94. doi:10.1093/jpepsy/17.1.81
- Cockerill, H., van den Engel-Hoek, L., & Harding, C. (2016). Assessing children's swallowing: Parent and professional perceptions. *Tizard Learning Disability Review*, 21(3), 117–125. doi:10.1108/TLDR-08-2015-0033
- Coulthard, H., Blissett, J., & Harris, G. (2004). The relationship between parental eating problems and children's feeding behavior: A selective review of the literature. *Eating Behaviors*, 5(2), 103–115.
- Cowpe, E., Hanson, B., & Smith, C. H. (2014). What do parents of children with dysphagia think about their MDT? A qualitative study. *BMJ Open*, 4(10), 1–8. doi:10.1136/bmjopen-2014-005934
- Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory Into Practice*, 39(3), 124–130. doi:10.1207/s15430421tip3903_2
- Crist, W., & Napier-Phillips, A. (2001). Mealtime behaviors of young children: A comparison of normative and clinical data. *Journal of Developmental and Behavioral Pediatrics*, 22(5), 279–286. doi:10.1097/00004703-200110000-00001
- Davies, W. H., Satter, E., Berlin, K. S., Sato, A. F., Silverman, A. H., Fischer, E. A., ... Rudolph, C. D. (2006). Reconceptualizing feeding and feeding disorders in interpersonal context: The case for a relational disorder. *Journal of Family Psychology*, 20(3), 409–417. doi:10.1037/0893-3200.20.3.409
- Dempsey, I., Keen, D., Pennell, D., O'Reilly, J., & Neilands, J. (2009). Parent stress, parenting competence and family-centered support to young children with an intellectual or developmental disability. *Research in Developmental Disabilities*, 30(3), 558–566.
- Deslauriers, N. (1967). The empty fortress: Infantile autism and the birth of the self. *Archives of General Psychiatry*, 17(4), 510–512.
- Dew, A., De Bertoli, T., Brentnall, J., & Bundy, A. (2014). *Strengthening supports for children 0-8 years and their families: A literature review*. Report, University of Sydney, Australia, May.
- Dunst, C. J., Trivette, C. M., & Hamby, D. W. (2007). Meta-analysis of family-centered helping practices research. *Mental Retardation and Developmental Disabilities Research Reviews*, 13(4), 370–378. doi:10.1002/mrdd.20176
- Epley, P., Summers, J. A., & Turnbull, A. (2010). Characteristics and trends in family-centered conceptualizations. *Journal of Family Social Work*, 13(3), 269–285. doi:1080/10522150903514017
- Estrem, H. H., Pados, B. F., Thoyre, S., Knaf, K., McComish, C., & Park, J. (2016). Concept of pediatric feeding problems from the parent perspective. *MCN: The American Journal of Maternal/Child Nursing*, 41(4), 212–220. doi:10.1097/NMC.000000000000249. ISSN: 0361929X15390683.
- Garro, A. (2004). Coping patterns in mothers/caregivers of children with chronic feeding problems. *Journal of Pediatric Health Care*, 18(3), 138–144. doi:10.1016/j.pedhc.2003.08.001
- Gibbs, L. (2007). What have sampling and data collection got to do with qualitative research? *Australian and New Zealand Journal of Public Health*, 31(6), 540–544.
- Goday, P. S., Huh, S. Y., Silverman, A., Lukens, C. T., Dodrill, P., Cohen, S. S., ... Phalen, J. A. (2019). Pediatric feeding disorder: Consensus definition and conceptual framework. *Journal of Pediatric Gastroenterology and Nutrition*, 68(1), 124–129. doi:10.1097/MPG.0000000000002188
- Green, A., Abbott, P., Delaney, P., Patradoon-Ho, P., Delaney, J., Davidson, P. M., ... DiGiacomo, M. (2016). Navigating the journey of aboriginal childhood disability: A qualitative study of carers' interface with services. *BMC Health Services Research*, 16(1), 1–11.
- Gunnarsson, N. V., Hemmingsson, H., & Hyden, L. C. (2013). Mothers' accounts of healthcare encounters: Negotiating culpability and fulfilling the active mother role. *Journal of Discourse & Society*, 24(4), 446–460. doi:10.1177/0957926513482069
- Han, P. K., Klein, W. J., & Arora, N. K. (2011). Varieties of uncertainty in health care: A conceptual taxonomy. *Journal of Medical Decision Making*, 31(6), 828–838. doi:10.1177/0272989X10393976
- Harvey, L., Bryant-Waugh, R., Watkins, B., & Meyer, C. (2015). Parental perceptions of childhood feeding problems. *Journal of Child Health Care*, 19(3), 392–401. doi:10.1177/1367493513509422
- Heidegger, M., & Krell, D. F. (2011). *Basic writings: From being and time (1927) to The task of thinking (1964)*. London: Routledge Classics.
- Hewetson, R., & Singh, S. (2009). The lived experience of mothers of children with chronic feeding and/or swallowing difficulties. *Dysphagia*, 24(3), 322–332.
- Johnston, J. L., & Bennett, D. (2019). Lost in translation? Paradigm conflict at the primary-secondary care interface. *Medical Education*, 53(1), 56–63. doi:10.1111/medu.13758
- Jones, C. J., & Bryant-Waugh, R. (2013). The relationship between child-feeding problems and maternal mental health: A selective review. *Advances in Eating Disorders*, 1(2), 119–133. doi:10.1080/21662630.2013.742972
- Keith-Thomas, A., & Barresi, I. (2007). Feeding disorders in children: Taking an interdisciplinary approach. *Pediatric Annals*, 36(8), 478–483. Retrieved from <https://link.library.curtin.edu.au/gw?url=https://www.proquest.com/scholarly-journals/feeding-disorders-children-taking/docview/217557327/se-27accountid=10382>
- Klopper, H. (2008). The qualitative research proposal. *Curationis*, 31(4), 62–72.
- Kokorelias, K. M., Gignac, M. A., Naglie, G., & Cameron, J. I. (2019). Towards a universal model of family centered care: A scoping review. *BMC Health Services Research*, 19(1), 564. doi:10.1186/s12913-019-4394-5
- Kyza, K. B., Turnbull, A. P., Summers, J. A., & Gómez, V. A. (2012). The relationship of family support to family outcomes: A synthesis of key findings from research on severe disability. *Research and Practice for Persons with Severe Disabilities*, 37(1), 31–44. doi:10.2511/027494812800903247
- LaMantia, A. S., Moody, S. A., Maynard, T. M., Karpinski, B. A., Zohn, I. E., Mendelowitz, D., ... Popratiloff, A. (2016). Hard to swallow: Developmental biological insights into pediatric dysphagia. *Journal of Developmental Biology*, 409(2), 329–342. doi:10.1016/j.ydbio.2015.09.024

- Lefton-Greif, M. A., & Arvedson, J. C. (2007, August). Pediatric feeding and swallowing disorders: State of health, population trends, and application of the international classification of functioning, disability, and health. In *Seminars in speech and language* (Vol. 28, pp. 161–165). New York, NY: Thieme Medical Publishers.
- Lefton-Greif, M. A., Okelo, S. O., Wright, J. M., Collaco, J. M., McGrath-Morrow, S. A., & Eakin, M. N. (2014). Impact of children's feeding/swallowing problems: Validation of a new caregiver instrument. *Dysphagia*, 29(6), 671–677. doi:10.1007/s00455-014-9560-7
- Liamputtong, P. (2013). *Research methods in health: Foundations for evidence-based practice* (2nd ed.). South Melbourne, VIC: Oxford University Press.
- Manikam, R. P., & Jay, A. (2000). Pediatric feeding disorders. *Journal of Clinical Gastroenterology*, 30(1), 34–46. ISSN: 0192-0790.
- Mays, N., & Pope, C. (2000). Qualitative research in health care. Assessing quality in qualitative research. *British Medical Journal*, 320(1), 50–52. doi:10.1136/bmj.320.7226.50
- McConnell, D., Savage, A., & Breikreuz, R. (2014). Resilience in families raising children with disabilities and behavior problems. *Research in Developmental Disabilities*, 35(4), 833–848. doi:10.1016/j.ridd.2014.01.015. ISSN 0891-4222.
- Nadler, C., Slosky, L., Low Kapalu, C., & Sitzmann, B. (2019). Interdisciplinary treatment for pediatric feeding disorders. In R. Rieske (Ed.), *Handbook of interdisciplinary treatments for autism spectrum disorder* (pp. 131–150). Cham: Springer.
- Nelson, K. E., Lacombe-Duncan, A., Cohen, E., Nicholas, D. B., Rosella, L. C., Guttman, A., & Mahant, S. (2015). Family experiences with feeding tubes in neurologic impairment: A systematic review. *Pediatrics*, 136(1), e140–e151.
- Parrish, M. (1997). Family adaptation to a child's feeding and swallowing disorder: A social work perspective. *Seminars in Speech and Language*, 18(1), 71–78. doi:10.1055/s-2008-1064063
- Pedron-Giner, C., Calderon, C., Martinez-Costa, C., Borraz Gracia, S., & Gomez-Lopez, L. (2014). Factors predicting distress among parents/caregivers of children with neurological disease and home enteral nutrition. *Child: Care, Health and Development*, 40(3), 389–397. doi:10.1111/cch.12038
- Robinson, O. C. (2014). Sampling in interview-based qualitative research: A theoretical and practical guide. *Qualitative Research in Psychology*, 11(1), 25–41. doi:10.1080/14780887.2013.801543
- Saldaña, J. (2016). *The coding manual for qualitative researchers*. London: SAGE.
- Satter, E. (1990). The feeding relationship: Problems and interventions. *Journal of Pediatrics*, 99, 249–257. doi:10.1016/S0022-3476(05)80017-4
- Scambler, G. (1998). Stigma and disease: Changing paradigms. *The Lancet*, 352(9133), 1054–1055. doi:10.1016/S0141-6736(98)08068-4
- Scorgie, K., & Wilgosh, L. (2009). Including as a care-full journey: A parent's perspective. *Developmental Disabilities Bulletin*, 37, 203–220.
- Sharp, W. G., Volkert, V. M., Scahill, L., McCracken, C. E., & McElhanon, B. (2017). A systematic review and meta-analysis of intensive multidisciplinary intervention for pediatric feeding disorders: How standard is the standard of care? *The Journal of Pediatrics*, 181, 116–124.
- Shields, B., Wacogne, I., & Wright, C. M. (2012). Weight faltering and failure to thrive in infancy and early childhood. *British Medical Journal*, 345, 1–7. doi:10.1136/bmj.e5931
- Silverman, A. H. (2010). Interdisciplinary care for feeding problems in children. *Nutrition in Clinical Practice*, 25(2), 160–165. doi:10.1177/0884533610361609
- Smith, J. (2004). Qualitative research in psychology. *Qualitative Research in Psychology*, 1(1), 39. doi:10.1191/1478088704qp0040a
- Spinelli, E. (2014). Descriptive challenging in existential therapy. *Dasein*, 3, 11–27.
- Thompson, J. R., Bradley, V. J., Buntinx, W. H. E., Schalock, R. L., Shogren, K. A., Snell, M. E., ... Yeager, M. H. (2009). Conceptualizing supports and the support needs of people With Intellectual disability. *Intellectual Developmental Disability*, 47(2), 135–146. doi:10.1352/1934-9556-47.2.135
- Toomey, K. A., & Ross, E. (2011). SOS approach to feeding. Perspectives on swallowing & swallowing disorders. *Dysphagia*, 20(3), 82–87. doi:10.1007/s00435-010-0360-0
- Uher, R., & Rutter, M. (2012). Classification of feeding and eating disorders: Review of evidence and proposals for ICD-11. *Journal of World Psychiatry*, 11(2), 80–92. doi:10.1016/j.wpsyc.2012.05.005
- Ungar, M. (2011). The social ecology of resilience: Addressing contextual and cultural ambiguity of a nascent construct. *American Journal of Orthopsychiatry*, 81(1), 1–17. doi:10.1111/j.1939-0025.2010.01067.x
- Verdon, S., Wilson, L., Smith-Tamaray, M., & McAllister, L. (2011). An investigation of equity of rural speech-language pathology services for children: A geographic perspective. *International Journal of Speech-Language Pathology*, 13, 239–250. doi:10.3109/17549507.2011.573865
- World Health Organization (WHO). (2007). *International classification of functioning, disability and health: Children & youth version: ICF-CY*. Geneva: World Health Organization. Retrieved from <https://apps.who.int/iris/handle/10665/43737>
- Wright, C. M., Parkinson, K. N., Shipton, D., & Drewett, R. F. (2007). How Do toddler eating problems relate to their eating behavior, food preferences and growth? *Pediatrics*, 120(4), 1069–1075. doi:10.1542/peds.2006-2961
- Wu, Y. K., & Estrem, H. (2016). *An unexpected journey: Managing care for young children with feeding problems*. Paper presented at the XX biennial International conference on infant studies, New Orleans, LA.

Chapter 5.0: “‘A Band-Aid Service’: Speech-Language Pathologists’ Perspectives on the challenges they face to support Children with PFD and Their Families”.

This chapter includes a copy of the paper reporting on Study 2 which has been submitted to a journal and is currently under review.

Authorship Statement: This research journal publication was produced as part of Julie Tan’s Master of Science (MSc) in Speech Pathology at Curtin University, under the supervision of Assoc. Professor Naomi Cocks, Professor Deborah Hersh, Dr Mary Claessen. and Dr Christina Fernandes. Julie Tan holds primary authorship of the resulting scholarly article, with her supervisors listed as co-authors in accordance with ICMJE guidelines. Intellectual property remains with the student, while her supervisors retain the right to use the findings for academic purposes with appropriate attribution.

5.0 Title Page

“A Band-Aid Service’: Speech-Language Pathologists’ Perspectives on the challenges they face to support Children with PFD and Their Families”.

Julie Tan¹, Deborah Hersh^{2,3}, Mary Claessen^{2,4}, Christina Fernandes², Naomi Cocks²

1. Post-graduate student, School of Allied Health, Curtin University, Perth, Western

Australia

2. Speech Pathology, School of Allied Health, Curtin University, Perth, Western Aus-

tralia

3. School of Allied Health Science and Practice, Adelaide University, Adelaide, Aus-

tralia

4. Speech pathology Australia, Melbourne, Victoria

This study was approved by the Human Research Ethics Committee of the authors' institution.

Correspondence regarding this article should be directed to Julie Tan, School of Allied Health, Curtin University, Kent Street, Perth.

Email: julie.tan@postgrad.curtin.edu.au

Acknowledgements

This study was completed as part of an MSc Research Degree. The author would like to acknowledge and thank all participants.

5.1 Abstract ‘A Band-Aid Service’: Speech-Language Pathologists’ Perspectives on the Challenges they Face to Support Children with PFD and Their Families.

Speech-language pathologists (SLPs) support children with Paediatric Feeding Disorder (PFD) and their families. However, international research has found that SLPs face significant challenges when working with children with PFD, including inadequacies related to their training. Whilst recent research found parents in Australia felt SLPs, had limited knowledge and interest in PFD, no previous research has explored the experiences of SLPs working with children with PFD in Australia.

This study sought the perspectives of 11 experienced SLPs working in a community context, in an Australian city via semi-structured interviews. An Interpretative Phenomenological Analysis approach was used to ensure a thorough consideration of SLPs’ perspectives, enablers and/or barriers to support were explored.

Participants in this study emphasised that working collaboratively with families, in a multidisciplinary team, ensures safe, holistic care. They highlighted limited awareness of PFD amongst referring agents and reported feeling underprepared to offer support related to limited training and lack of competency guidelines. Systemic barriers included policies and funding which impacted families’ access to support and potentially contributed to their perceptions that SLPs lack understanding of PFD. These findings align with international research on SLPs working with PFD. Future research should address the systemic barriers to best practice service delivery.

Keywords: Dysphagia: Feeding: Qualitative: Community; Health Professionals

5.2 Introduction

Paediatric feeding disorder (PFD) is a universal naming convention and diagnostic criterion for childhood feeding disorders. The term was coined based on the following expert consensus statement: “PFD is defined as impaired oral intake that is not age-appropriate and associated with one or more of the four domains of medical, nutritional, feeding skills, and psychosocial factors” (Godoy et al., 2019, p. 125). Before this stand-alone diagnosis, feeding disorders could be viewed as symptoms of other conditions or as having multiple diagnostic and naming conventions (Estrem et al., 2022).

PFD is a heterogeneous diagnosis and therefore identifies a broad-spectrum population of children. It can have significant consequences. Aspiration-induced lung disease, malnutrition, developmental deficits, prolonged feeding times, dependency on enteral feeding, dehydration, impaired growth, poor quality of life, and caregivers' stressful interactions are all possible outcomes of PFD (Lefton-Greif & Arvedson, 2016; Norman et al., 2024; Sharp et al., 2022). Appropriately identifying and effectively managing PFD is therefore essential for the health and well-being, of the child and the family.

5.2.1 Prevalence

There is some debate regarding the prevalence of PFD. In the United States of America (U.S.), Kovacic et al. (2021) found the prevalence of PFD was comparable to that of “commonly diagnosed disorders such as eating disorders and autism” (p. 131). They stated for children under five, between 1 in 23 to 1 in 37 children and as high as 1 in 3 to 1 in 5 children who had coexisting chronic conditions, had PFD. However, Rosen (2021), highlighted that challenges such as inconsistencies in definitions, diagnostic criteria, and

limited awareness among healthcare providers make it difficult to determine the accurate prevalence of PFD. Currently, no prevalence statistics of PFD in Australia are available.

5.2.2 SLP Role with PFD

In most English-speaking countries, Speech-Language Pathologists (SLPs) offer crucial support to families of children with PFD (Arvedson, 2008). They are trained in the anatomy, physiology, development, and behaviour underpinning a child's ability to eat and drink (Gosa et al., 2020). When reviewing the literature on SLPs supporting children with PFD and their families, three key topics consistently emerge. These are access to services, health professionals' (HPs) competence with PFD, and the impact of policy and funding on services. Each of these topics plays a critical role in shaping the delivery of care for children with PFD. Given that service delivery, HPs competence, and funding differ between countries (Jones et al., 2020; Nickless et al., 2023; Raatz et al., 2023), it is important to consider how the context in which any research that is carried out on HPs' experience of working with children with PFD could impact results.

5.2.3 Access to integrated care in the community

The complexity of the interplay between the four domains of PFD, (medical, nutritional, feeding skills, and psychosocial factors), necessitates the involvement of multiple disciplines (Goday et al., 2019). It is widely agreed that best-practice diagnostic and treatment protocols for PFD require a multidisciplinary approach (Bertrand et al., 2024; Galai et al., 2022; Goday et al., 2019; Gosa et al., 2020). Integrated, collaborative, multidisciplinary teams (MDTs) offer holistic, person-centred care, and provide families with consistent advice that reduces confusion and stress (Brenner et al., 2018). Parents of children with feeding disorders are often reported to seek this team approach (Cowpe et al., 2014; Dadich et al.,

2023). These teams may include but are not limited to psychologists, doctors, dieticians, occupational therapists and SLPs (Gosa et al., 2020). SLPs are considered to have a key role in such teams (Gosa et al., 2020). Effective MDT care in PFD relies on robust communication and information-sharing practices between the team members. This is especially important when the HPs are not based together but are in disparate locations, as is often the case in community practice (Brenner et al., 2018). This collaborative practice enhances the quality of care by aligning the HPs' approach thus ensuring consistency for families.

MDT service delivery is currently endorsed across much of Australia, in many practice areas, for example, aged care and paediatric autism (Patient Experience Agency, 2023). Despite the recognised benefits, families of children with complex conditions face significant barriers to accessing MDT services (Brenner et al., 2018). This issue is recognised internationally and is linked to limited health service integration

In addition to limited access to integrated MDT services. SLPs working with children with PFD may face restricted availability to relevant assessment tools that guide treatment options. Australian research suggests issues with accessing diagnostic equipment for SLPs in community practice. An example is the challenge community-based SLPs face in accessing videofluoroscopic studies (Howells et al., 2019), the 'gold standard' diagnostic tool for swallowing difficulties in clients with PFD (Arvedson, 2008). These assessments assist SLPs in defining physiological swallowing status and can be essential for considering client safety (Re et al., 2019). The tools are available only in hospitals and have been reported to be difficult to access for Australian community-based SLPs working with adults with dysphagia (Howells et al., 2019; Rumbach et al., 2018). It is currently unknown if, community-based SLPs working with paediatric clients in Australia report similar access issues.

The financial burden of accessing community care appears to be increasing for families. In Australia, Nickless et al. (2023) identified the financial burden of accessing general SLP services, not specific to PFD, as a "major issue" for families (p. 462). The overwhelming demand for public services has led to extended wait times for SLPs, ENT specialists, and paediatricians, compelling families to seek private alternatives (Teoh & Darvell, 2021). This is especially important for families of children with PFD, as the financial costs associated with the condition are internationally recognised as substantial (Feeding Matters, 2019; Okada et al., 2022). However, SLPs' perceptions of these funding-related challenges to access services in Australia and their impact on SLPs supporting children with PFD and their families remain unexplored.

5.2.4 Confidence and skills of HPs working with children with PFD

Effective care of children with PFD requires MDT with the necessary skills and confidence to work effectively with these children with PFD and with their families (Goday et al., 2019). However, there is evidence internationally that confidence and skills within the MDT are problematic. In the study by Jones et al. (2020), SLPs in NZ perceived that many HPs lacked the confidence to care for children with PFD. Similarly, a survey of HPs in the U.K. (Aldridge et al., 2010) found no central guidance for making onward referral decisions for these children. This resulted in them waiting until children displayed “biological consequences” of their feeding issues (p. 265). In N.Z., Burgess et al. (2016) and Jackson et al. (2021) identified communication barriers that hindered multidisciplinary collaboration. Until the recent study by Elliot et al. (2024), a modified Delphi study with Australian HPs, there were no standardised datasets for defining and measuring team care in feeding disorders in Australia. This study specified team composition, and key performance indicators and

aligned services with the diagnostic protocols for PFD. While this study is useful in terms of providing some guidelines regarding how a team should support a child with PFD, it did not explore the lived experiences of SLPs working with a child with PFD.

In addition to other HPs feeling confident and skilled, it is important that the SLPs also feel confident and skilled when working with children with PFD. International studies which included SLPs who deliver services for children with PFD have consistently highlighted the significant challenges they face. Studies in the U.S. suggested that SLPs felt unprepared and unsupported in their roles and lacked confidence in applying dysphagia training (Bailey et al., 2008; Hutchins et al., 2011; Thompson et al., 2024). Similarly, a European study, by Felicetti et al. (2020) found that SLPs felt they received inadequate academic and clinical preparedness to work with children with PFD. Similarly, in South Africa, Modi and Ross (2000), found hospital-based SLPs struggled with large caseloads and insufficient training. In Australia, a survey of over 100 HPs including SLPs by Raatz et al. (2023) identified low confidence in PFD, related to the frequency and recency of PFD practice. Whilst this study gives some insight regarding SLPs lacking confidence in Australia, it did not explore why they felt they lacked confidence.

What little is known about the experiences of SLPs working with children with PFD in Australia suggests it is challenging. In a study by Tan et al. (2021), 16 mothers of children with PFD, reported SLPs giving no clear direction regarding their child's treatment needs and having limited knowledge or interest in PFD. As this study did not explore the perspectives of the SLPs themselves, the reasons for the perceived lack of clear direction and limited knowledge or interest in PFD among the SLPs were not clear. It is therefore essential that the perspectives of the SLPs working in Australia with this population are explored. To fully

understand the SLPs' practice, it is important to consider the Australian context including the influence that policy and funding have on the delivery of services.

5.2.5 Policy and Funding

In Australia, SLP services in the community are commonly accessed through several publicly funded models, through public services, or privately funded options. The primary funding options in Australia are Medicare, which offers partial subsidies and the National Disability Insurance Scheme (NDIS), which provides support for people with disabilities. The NDIS Act (Commonwealth Government of Australia, 2013), aligns with similar schemes in other Organisation for Economic Co-operation and Development (OECD) countries, reflecting a global shift away from paternalistic government-led services (Needham, 2013). However, the NDIS does not always recognise PFD as an eligible need. In Australia, a recent study by Nickless et al. (2024) found that NDIS services appear to be limiting the dosage and intensity of SLP therapy sessions. This has the potential to result in suboptimal treatment outcomes. However, it is unknown if SLPs specifically dealing with children with PFD have identified this as an issue.

The changes in the allied health environment in Australia, have also been identified as causing SLPs to face barriers to skill attainment. This is due to a reduction in clinical placement opportunities for students. Before, the NDIS, SLPs experienced in PFD working for large organisations mentored undergraduate SLPs. This has been reported to have become increasingly problematic, in the new marketised environment (Attrill et al., 2023; Hines & Lincoln, 2016). This is particularly concerning given that new graduates comprise much of the NDIS workforce. Currently there is no understanding if this shortage of practical training in PFD has undermined the confidence and competence of newly graduated SLPs. If it is,

then this maybe, contributing to the families' perceptions of inadequate support described in Tan et al. (2021).

5.2.6 Summary

Taken together these findings highlight the importance of gaining a deeper understanding of SLPs' perspectives on supporting children with PFD in the Australian context. Investigating the SLPs' perspectives is crucial to understanding potential enablers or barriers that Australian families may face, in seeking support for their child with PFD from SLPs. This study explores the experiences and perspectives of 11 SLPs in community practice, in one city in Australia. This builds on previous research focused on parental views (Tan et al., 2021) contributing to a more comprehensive understanding of effective support for children with PFD and their families.

5.3 Methods

Interpretative Phenomenological Analysis (IPA), (Smith & Nizza, 2022) was selected for this study to ensure a detailed exploration of the participants' experience and sense-making regarding their role in PFD. IPA's roots are in the philosophies of phenomenology (the philosophy of experience), hermeneutics (the philosophy of interpretation) and ideography (a focus on the individual). IPA views participants as the "experiential experts" (Smith & Nizza, 2022, p. 6). First, IPA applies an idiographic approach, where individual datasets are analysed in detail before interpreting group-level themes, a "dual analytic focus" (Braun & Clarke, 2021, p. 41). Second, the analysis is characterised by the "double hermeneutic" (Smith & Osborn, 2007), whereby the participant and the researcher play active roles with the "researcher interpreting the participants interpreting their experience" (p. 52).

Thus, IPA ensures a deep, meaningful engagement between the researcher and those being researched.

5.3.1 Ethics

This study was approved by the Human Research Ethics Committee of the researchers' institution. Participants were provided with written information about the study, including data handling, confidentiality, and the option to withdraw before any data publication. The participants were deidentified and defining details were altered to ensure their anonymity. The study's participants were given pseudonyms from popular female names in Australia. To prevent potential jigsaw identification of participants, detailed contextual biographical information has been omitted from this paper.

5.3.2 Recruitment

Following ethics approval, the primary researcher posted a recruitment flyer in a special interest group affiliated with Speech Pathology Australia, the primary professional association for SLPs in Australia. This flyer invited interested SLPs to contact the researcher directly. Volunteers were then encouraged to recommend other potential participants, utilising a purposive snowball sampling method (Robinson, 2013). This ensured the identification of SLPs with at least three years of experience, working with children with PFD, in metropolitan community settings. This recruitment approach was consistent with a prior study by Tan et al. (2021), conducted by some members of the current research team, which had targeted metropolitan-based families.

5.3.4 Participants

The study included 11 female SLPs. Two were trained in Britain, while the remaining nine were trained in Australia. These participants had an average of 9 years of experience assessing, treating, mentoring, and supervising others related to PFD within community practice. Nine SLPs were independent practitioners, and two were employed in the not-for-profit sector. Four participants had personal experiences with PFD in their families. All participants were certified practising members of Speech Pathology Australia. See Table 5.

Table 5 *SLP demographics*

Aliases	SLP Country of Training	PFD Years of Experience	Workplace	Family Experience with PFD
Charlotte	UK	14	Private practice	No
Amelia	UK	21	Healthcare Not for Profit Organisation	No
Olivia	Australia	7	Private practice	Yes
Isla	Australia	7	Private practice	Yes
Mia	Australia	4	Disability Not for Profit Organisation	No
Ava	Australia	9	Private practice	No
Grace	Australia	5	Private practice	No
Chloe	Australia	4	Private practice	No
Willow	Australia	8	Private practice	No
Matilda	Australia	14	Private practice	Yes
Ella	Australia	12	Private practice	Yes

5.3.5 Data Collection

An initial meeting before the interviews allowed the participants to ask questions and discuss the project. Many participants knew of the researcher's previous study with mothers

of children with PFD and were interested in contributing their professional perspectives. All participants provided written informed consent before the interviews commenced. Semi-structured interviews were conducted online, convenient for the participants, lasting approximately 60-90 minutes. A flexible interview guide was used. See Table 6.

Table 6 *Study 2 Interview Guide*

Open-ended Questions	Targeted Probes
<p>What in your experience is the role of an SLP in supporting a family with a child with PFD?</p>	
<p>How do you support a family with a child with PFD?</p>	
<p>In your experience, are there things that make it easier to support a family with a child with PFD?</p>	
<p>In your experience, are there things that make it harder to support a family with a child with PFD?</p>	<p>Are there are things that could be improved about this?</p>
<p>Are there are things you would like to do to support a family with a child with PFD that is currently not available to you?</p>	<p>Why is it unavailable?</p>

This guide was pilot tested in an initial interview and the questions both open-ended and probing were refined with input from the research team (who at this stage included, two SLPs and a social worker). The guide, utilised verbal and non-verbal means, to encourage

participants to express their experiences freely. These included active listening and a stated goal of seeking the participants' professional, and personal experiences and interests in PFD (Smith & Nizza, 2022). On completing each interview, verbatim transcription was obtained, using a third-party transcription service (www.otter.ai; Transcription Software, 2016). Each participant confirmed satisfaction, with the transcripts to be used. Additional comments gained during this stage of member checking were added to the dataset of three participants.

5.3.6 Data Analysis

The data analysis in this study adhered to the recommendations of Smith and Nizza (2022) and employed IPA, an inductive approach characterised by an idiographic focus. The initial analysis involved extensive listening to, reading and re-reading of each dataset, during which exploratory notes were captured in the margins. These initial notations focused on the primary researcher's responses, while resisting any immediate attempt at interpretation. Next, a linguistic analysis examined the language used by participants, including metaphors and repetitions. Then, conceptual elements were interpreted from the data. While IPA suggests that this preliminary phase is primarily for mapping out the data, it is also a critical time for researchers to reflect on and interrogate any preconceptions or personal interests they may bring to the analysis (Motta & Larkin, 2022).

Each dataset underwent this thorough individual analysis, leading to the formulation of experiential statements (EPs), these were then, clustered into fewer personal experiential themes (PETs). A detailed paper trail of notes was maintained with transcripts displayed on large A2 notepads for each dataset individually and a table of PETs was compiled for each participant. These linked data extracts allowed consideration of any convergence and

divergence contained within individual dataset, a key aspect of IPA’s idiographic focus. Subsequently, cross-case analysis facilitated the emergence of group experiential themes.

This epistemological approach, as outlined by O'Connor and Joffe (2020), involved “a phase of informal intercoder comparison and discussion” (p. 4). This approach ensured that participant quotes were analysed for thematic coherence, verifying the primary researcher’s interpretations were in alignment with the participants’ intended meanings, thus maintaining a direct link between the data and identified themes (Levitt et al., 2018). The research team reviewed around 20% of the data to confirm the coherence and credibility of themes interpreted by the primary researcher. These discussions were essential to both the interpretative and writing phases of analysis. See Table 7.

Table 7 *Group Experiential Themes and Participants’ Quotes*

Group Experiential Themes	Participants' Quotes by Theme
The Importance of the Team	Ava, Charlotte, Ella, Isla, Matilda, Olivia, Willow.
Providing safe practice	Charlotte, Ella, Matilda.
Self-care	Amelia, Ava, Charlotte, Ella, Isla, Olivia.
Surviving “rocky seas”	Amelia, Charlotte, Chloe, Ella, Grace, Isla, Matilda, Olivia, Willow.
Barriers to support	Ava, Amelia, Chloe, Ella, Grace, Isla, Matilda, Mia, Olivia, Willow.

5.3.7 Reflexivity, Rigour and Trustworthiness.

The study adhered to the Consolidated Criteria for Reporting Qualitative Research (CORE-Q) guidelines (Tong et al., 2007), ensuring rigour in planning, analysis, and reporting. As Yardley (2000) notes, establishing validity and rigour in qualitative research is challenging, but alternative criteria like transparency, reflexivity, and coherence can effectively evaluate such studies. The primary researcher reflected on “contradictions and differences in understanding” arising throughout the collaborative team discussions (Braun and Clarke, 2022, p. 4). IPA was selected for this project as it is an “inherently interpretative practice and meaning is not fixed within data” (Braun and Clarke, 2022, p.2). This process demands reflexivity and the researcher’s awareness of their positionality (Nizza et al., 2021). The primary researcher maintained a reflective journal, documenting preconceptions, and emotional responses, assisting her understanding of her positionality and remaining mindful of her pre-existing thinking, or “fore structures” (Heidegger, 1962, p. 153), ensuring that the participants’ voices remained central to the analysis and findings. IPA ensures meaningful engagement with participants, closely interpreting the meanings conveyed by their language and descriptions rather than seeking revelatory insights.

Reliability and trustworthiness were assured throughout the data collection and analysis phases, by the primary researcher’s participation in reflexive in-depth discussions with the research team and attendance at a series of IPA training workshops (Lazard & McAvoy, 2020). The research team included an SLP with extensive experience in the assessment and treatment of adults with dysphagia who is also an experienced qualitative researcher, an SLP who lectures on paediatric feeding disorders, an SLP experienced in paediatric communication disorders and a social worker with a child with a disability. Their

contribution from design to analysis, included discussion and feedback on the themes and contributing to the writing up of the journal publication.

5.3.8 Insider research

The primary researcher's dual role as researcher and practising SLP introduced complexities associated with insider research (Auburn et al., 2021). Insider research offers advantages, such as a deeper contextual understanding and easier rapport with participants, but it also brings challenges, including potential biases and the risk of influencing participants' responses (Auburn et al., 2021; Taylor, 2011). It was therefore essential to practice rigorous self-reflection to gain clarity of positionality and to manage bias balanced by the phenomenological attitude of open curiosity (Greenberg, n.d.). Given the shared profession and interest in PFD, there was a potential that participants might have tailored their responses to align with the researcher's expectations. However, there were no hierarchical or employment ties between the participants and the researcher, minimising power dynamics concerns (Yardley, 2000).

5.4 Results

The collaborative dialogue between the primary researcher and the research team contributed to the interpretation of five group experiential themes, deepening the overall understanding of the data throughout the reporting process (Smith & Nizza, 2022). The first theme "importance of the team" relates to the service delivery model espoused by the SLPs. The second theme, "providing safe practice," relates to ethical service considerations. The third theme, "self-care", included the SLPs' thoughts on role security and shared responsibilities. The fourth theme "surviving rocky seas" focused on the challenges of managing PFD including being under-prepared, having limited supervisory support and

limited treatment protocols. Finally, the fifth theme, "barriers to support" outlined the obstacles SLPs face, related to service delivery challenges, while highlighting the perceived lack of awareness of PFD in the community.

5.4.1 The Importance of the Team

This theme focuses on the SLPs' belief in the importance of the MDT approach in PFD management. The team approach was felt to be beneficial to the holistic care of their client, while also offering them collegial support.

While Charlotte stated: *"SLPs are often the first port of call"*, Ella emphasised the SLPs' important role in team creation, *"link them in with other care professionals within the community because we simply cannot work alone, we do need an OT, we do need a dietitian, we do need medical expertise"*. Matilda defined the importance of this comprehensive team approach: *"not just the allied health teams, it's the medical, it's the family, it's the child, it's the school, it's talking to the NDIS planners"*. Ava's focus was on how SLPs favour a family-centred approach incorporating authentic engagement with families: *"understanding how to coach, how to be part of the team rather than coming in as an expert. I don't think I've ever seen an expert model work"*. Olivia spoke of this authentic, personalised approach pivotal to establishing trusting relationships: *"I'll be honest with families, that I need to talk to someone or need to find something out"*. Willow further emphasised the importance of this personalised approach: *"think about the child and the family as individuals, and that there is no cookie-cutter approach"*. Isla felt this approach encouraged trust: *"a family that is supported, talks with you about what's happening, how things are going, and whether things are working or not"*. She also reported that when families had not received this approach, the SLPs would be required to repair the flawed prior engagement.: *"The biggest thing, I find*

really difficult, is families not trusting the professionals. They've been let down for so many years".

5.4.2 Providing Safe Practice

SLPs reported facing complex ethical challenges in supporting families of children with PFD, with issues extending beyond feeding to include broader family needs and psychosocial factors. Matilda illustrated this with a metaphor: *"an iceberg image where feeding is at the very top, but it's so complex underneath"*. The SLPs described offering ongoing support to help families build emotional resilience, manage setbacks, and maintain a positive outlook. They provided families with information to keep them informed about treatment options, care strategies, and available support resources. They spoke of balancing respect for family autonomy with child safety. Charlotte shared her experience working with a family struggling to accept their child's PFD diagnosis: *"they wanted to get their child to eat and get their life back to normal"*. Ethical tensions may also arise when SLPs must consider the potential risks associated with their proposed interventions. Ella expressed this concern when coaching families on dietary changes, asking: *"When the mother goes home, am I putting the child at risk?"*.

5.4.3 Self-Care

The SLPs emphasised the importance of life-long learning and support from their professional network as essential coping strategies when working with children with PFD and their families. Being part of a supportive network helped them maintain mental well-being, providing a sense of security and shared responsibility.

Amelia emphasised that collaborative practice and the resulting sense of collective responsibility fostered a supportive team environment: *“having those other professionals involved, helps us, just making sure we’re on the right track”*. Ella referred to her team as her *“professional tribe”* expressing a profound sense of connection and belonging that offered her security and camaraderie: *“having a tribe...it’s having a complete tribe”*.

The SLPs shared various strategies for self-support. For example, Charlotte relied on her knowledge of child development to guide her practice: *“are they chewing as you would expect at that developmental age?”*. Ava drew on her understanding of the anatomy and physiology of the head and neck, to enhance her management of PFD, stating: *“we use the same muscles to talk”*. Their pragmatic approach included reading widely and being receptive to knowledge from various professions globally, utilising resources like podcasts, online training, and the latest journal articles. Isla noted: *“all the channels for evidence now, are not so clear cut, we’ve got lots of other ways that we might find out information”*.

Olivia and others identified their commitment to life-long learning as an essential coping strategy in navigating the uncertainties of PFD. Charlotte summarised this sentiment: *“I did another course...it just builds on what you’re seeing...you can’t unsee what you’ve seen in those courses”*.

5.4.4 Surviving “Rocky Seas”

The participants unanimously reported feeling under-prepared to handle PFD. This led not only to reduced confidence but also to uncertainty about their clinical practice. This uncertainty was created by multiple factors including limited preparation at the undergraduate level, the absence of competency pathways for post-graduate clinical development, a shortage of supervisors, and insufficient treatment protocols. Their descriptions of these issues

contained linguistic choices that underscored their concerns as when Ella describes navigating through: *"rocky seas"* and Charlotte reflecting on the complexity of PFD stated: *"The challenge is navigating where to go next and not giving up too easily"*.

Many participants described limited opportunities to gain PFD competencies at the undergraduate level. Willow remarked, *"I don't think it prepared me at all"*, Isla added, *"it would have been nice to come in with some kind of knowledge initially... but ...you went in blind, essentially"*. Ella expressed concern that even newly graduated SLPs were managing clients with PFD: *"new grads... haven't been exposed...taught this stuff"*. Isla speculated that this lack of preparation might lead some SLPs to avoid identifying PFD in children: *"special needs kids, there are mealtime issues... all the time...a lot of clinicians ignore it"*.

Several participants attributed their uncertainty to the lack of clinical guidelines or competency pathways from their professional body, Speech Pathology Australia, Grace observed, *"there's no quality control"*, while Ella remarked, *"we all have the best intentions, but we don't have a competency framework"*. Ella further expressed that Speech Pathology Australia could support SLPs more when working with PFD, *"in early intervention, we've done so well in gaining awareness and funding... but this area has been overlooked"*.

Participants also emphasised the need for supportive networks at every stage of working with PFD, Olivia noted, *"having the support above me really helped me with my decision-making"*. However, Grace found accessing supervision challenging: *"I found many clinicians with experience...are very protective of their knowledge"*. Some SLPs noted a lack of consensus on treatment approaches among colleagues, in online and face-to-face meetings, noting that the discussion could become adversarial. Chloe remarked: *"I really do like reading different people's opinions. I think sometimes it can be quite aggressively said...on"*

some posts. But I think it's good that the debate and the conversation is happening". Ella added: *"I think clinically, we become quite frightened as clinicians, we don't want to be vocal, we don't want to rock the boat"*. Grace expressed a desire for more open collaboration: *"I wish we could comfortably go and learn from each other and be okay to ask questions"*.

Many SLPs reported delivering therapies with limited evidence, openly sharing these limitations with families while continuing their search for effective solutions. As Matilda expressed, she wanted to understand, inform, and provide guidance: *"I want to know, I understand that they would want to know, so I give them signposts"*, Amelia also spoke of *"signposting"*. While Chloe admitted: *"I think I still do things that don't have as much evidence"*. Olivia communicated this to families: *"I'm doing the best I can now and tomorrow, things might change. I'll know more tomorrow"*. There was broad agreement that the complexity of PFD requires an eclectic approach, blending various methods rather than using any single approach in isolation. As Ella noted: *"I use all of them together, not one on its own, I bring it all together and use a little bit of everything"* with Isla adding: *"Our role is to help guide the family"*.

5.4.5 Barriers to Support

Many SLPs reported facing systemic obstacles in providing services to families. They felt this affected their ability to offer equitable and comprehensive care. They reported challenges with funding, collaborative practice, and continuity of care pathways, compounded by a lack of understanding of PFD in the broader community.

The participants reported constraints in funding which challenged their ability to offer services, at the appropriate time and at a dosage level that was therapeutically appropriate to the need. As Ella stated: *"we are under-resourced and underfunded; I get GPs referring for*

two sessions. *It takes me two sessions just to figure out what's going on*". Amelia and Grace reported that these funding issues meant equitable service provision could present a challenge beyond their control. For example, Amelia described access to services as *"a bit of a postcode lottery"*, and Grace highlighted the challenges of her workplace in a low socioeconomic area with limited resources, describing what she could offer as *"a band-aid service"*.

Some of the challenges reported are related to service delivery within the NDIS. Grace relayed that NDIS funding reduced team approaches and impacted dosage decisions as insufficient hours were available: *"the NDIS has damaged the quality of the service that we can give because it's essentially...looking at sustainability, not quality"*. Isla reported that the rollout of the NDIS had resulted in an emphasis on profit margins: *"organisations won't often cover costs of Professional Development. They want you doing billable hours"*. Chloe and others reported children whose PFD-related needs went unrecognised by NDIS planners resulting in no funding being available to meet their needs: *"their first plan is not as likely to have funding for PFD, unless they are tube fed, and not even when they are tube-fed"*. Willow expressed concern that newly qualified professionals deliver on NDIS plans independently or with minimal supervision. noting, *"Over and over again, positions are expecting new grads to deal with really complex feeding"*. However, Ava and Mia expressed some positive aspects of NDIS-funded services, that were favourable for service delivery including Support Coordination (a service available to some recipients of NDIS funding) which they felt assisted with team coordination.

Seven SLPs shared their experiences of challenges to intersectoral multi-disciplinary teamwork. Some had first-hand experience of supporting clients, when the HPs funded by various funders, in disparate locations and using different service-delivery models were not delivering integrated MDT care, as Mia stated: *"you'll have four different clinicians all*

recommending different things". Ava, Matilda, and Isla highlighted the challenges of finding a team of skilled clinicians: *"finding people who understand that this is part of their role"* (Ava). While Isla mentioned a scarcity of allied health clinicians: *"we can call upon OTs or physios or dieticians but...in this climate, they're not always readily available"*. Isla amongst others also raised the issue of continuity of care pathways, for families transitioning from hospital-based to community services: *"I think there's a real disconnect between the hospital systems and NDIS, we can't just have the family in the middle with nothing. And saying catch you later"*. She also reported that team approaches could be challenging: *"I've had appointments where the medical teams were quite standoffish with me for even being in the room, asking, 'why are you here with the family?'"* (Isla). Ella felt these intersectoral challenges were often related to funding issues: *"tertiary sites do not support community clinicians. They're under-resourced"*.

Many SLPs highlighted challenges related to a general lack of understanding about PFD, especially among employers, other healthcare professionals, and the general public. This knowledge gap resulted in families not accessing SLP support or created barriers to SLP services and multidisciplinary team support, as Chloe observed: *"the majority wouldn't realise that that's something that we can support with"*. Ella, Willow, and Isla noted that families often struggled to secure referrals to SLPs. Willow added that a lack of knowledge about PFD and the SLP's role can create obstacles: *"the families need to be able to then communicate with the GP to get that referral because I find that's a roadblock"*.

The SLPs reported how this lack of understanding about PFD impacted them in the workplace. Most participants described feeling undue pressure from employers who did not grasp the complexities of PFD, as Grace shared: *"they couldn't support me...I had to see the clients. I didn't feel comfortable. But it was my role, and I was the most experienced on the*

team...I was only three years out”. Olivia reflected: “I was expected to know a lot about feeding...the bosses would come to me saying, well you should know about this, I'd say, well, I'm not sure, it's really complex”. These demands were often related to caseload numbers and productivity targets with Amelia noting: “everything nowadays is just KPIs; there is no breather to just think”.

5.5 Discussion

This qualitative study of 11 Australian SLPs working with children with PFD identified several enablers and barriers to their work. A key enabler highlighted was the importance of delivering services as part of an integrated MDT. This collaborative approach between families and the HPs ensured that the complex needs of the children with PFD and their families were met, aligning the HPs strategies to provide a consistent approach. Additionally, the SLPs emphasised that improving community awareness of PFD is essential to achieving equitable access to comprehensive and timely services. The participants recognised the importance of ongoing support and professional development to better prepare themselves for working with this population, noting that many felt underprepared and lacked adequate resources. This study also sheds light on the systemic barriers that the SLPs reported families face when accessing care from SLPs for their children with PFD. These barriers were related to current policies and funding limitations. They may contribute to the perception that SLPs may lack interest or understanding of PFD, a concern raised in the study by Tan et al. (2021).

5.5.1 Accessing Community Care

The SLPs reported numerous challenges in providing adequate support for children with PFD. They reported constraints in families gaining timely diagnoses, appropriate

referrals, and access to skilled HPs and MDT care in community settings. Intersectoral collaboration between community and hospital-based teams was also problematic, which they suggested led to fragmented care.

A key concern highlighted in this study was that parents reported encountering frontline practitioners, such as doctors, health nurses, and NDIS planners, being unable to recognise their child's issues as related to PFD. Onward referrals or funding would then be delayed or denied. This is a similar issue raised in a UK study by Aldridge et al. (2010) who reported that HPs, tended to wait until physical consequences from the children's feeding issues became apparent before making onward referrals (p. 265). While the Australian stakeholder report "Mind the Gap" (Smith-Merry et al., 2018) found under-identification was an issue for individuals with psychosocial disabilities, when up to 50% of them were unable to access adequate NDIS services and support. It is therefore reasonable to extrapolate that a limited understanding of PFD among frontline HPs and NDIS planners may significantly impact timely access to appropriate care for children with PFD. Addressing this situation necessitates improved education and training for frontline HPs and NDIS planners, alongside the development of standardised guidelines for PFD diagnosis and referral pathways.

All the participants, in this study, wanted to provide a holistic MDT response to children with PFD and their families, which is considered best practice (Bertrand et al., 2024; Galai et al., 2022; Goday et al., 2019; Gosa et al., 2020). However, they reported this could be challenging due to multiple factors including, HPs in disparate locations, time constraints and an inability to access HPs skilled in PFD. Brenner et al. (2018), in their systematic review of MDT services, identified similar constraints in access to MDT services for children with complex conditions internationally. This was reportedly due to limited health service integration. This suggests that without systemic improvements to healthcare integration and

support, achieving best-practice MDT care for children with PFD will remain challenging and may limit the effectiveness of the care families receive.

Participants reported issues in the primary and secondary healthcare interface. They felt this was due to ineffective communication pathways, restricted information transfer and, structural barriers between the services. These challenges were attributed by some, to insufficient time and funding. However, others noted, that established care pathways were absent, and communication often depended on the goodwill of those involved, rather than any coordinated approach. This challenge to integrated care between hospital and community care was also noted in a survey of SLPs caring for feeding tube-dependent children in NZ by Jones et al. (2020). This suggests that, without integrated care pathways, continuity and quality of care between healthcare sectors will remain fragmented, potentially adversely affecting outcomes for children with PFD.

The participants further reported, that in their role as community-based SLPs, they were often restricted in their access to essential diagnostic assessments of children with PFD, such as videofluoroscopic swallowing studies (Arvedson, 2008). This is similar to reports in Australia, of SLPs supporting adults with dysphagia in the community (Howells et al., 2019; Rumbach et al., 2018). This suggests that barriers to diagnostic resources in community contexts may be widespread across age groups, potentially hindering effective assessment and management of children with PFD and emphasising the need for improved access to specialised diagnostic tools for community-based practice.

Another major concern raised by participants was the financial burden on families seeking PFD services in the community, which many felt was a barrier to equitable and sustainable access to allied health support. Studies in the U.S. by Feeding Matters, (2019) and

Okada et al. (2022) have recognised the significant associated costs for families having a child with PFD. A recent study in Australia by Nickless et al. (2023) found that accessing general SLP services, not specific to PFD, was a "major issue" financially for families. Many SLPs in this study noted that the high cost of accessing services could hinder families' ability to obtain the necessary care for their children with PFD. The SLPs further reported that funding constraints, influenced by policy and service delivery models, often restricted their control over the frequency and duration of interventions. This limitation potentially impacts the efficacy of PFD management, as optimal treatment requires personalised, intervention schedules

These themes highlight the need for improved integration of services, established care pathways, better access to diagnostic tools for community-based SLPs and consideration of the funding for SLP services. Addressing these issues is crucial for enhancing the quality of care provided to children with PFD and their families and for aligning practice with evidence-based recommendations for MDT approaches in PFD management.

5.5.2 Preparedness and support

The SLPs in this study felt underprepared for their role in supporting children with PFD and their families. There were many reports of inadequate training and preparation for their role with PFD. These reports align with the body of international research which considers SLPs and their role in children with PFD (Bailey et al., 2008; Burgess et al., 2016; Felicetti et al., 2020; Hutchins et al., 2011; Jackson et al., 2021; Modi & Ross, 2000; Thompson et al., 2024). Many participants reported limited access to supervision and mentoring, as a significant concern. Additionally, SLPs reported a lack of clear competency

and credentialing guidelines, causing them to be unsure of the required expertise for managing PFD effectively. These issues will be addressed individually.

In Australia, undergraduate SLP education is regulated by Speech Pathology Australia, which encompasses training for all client populations affected by dysphagia, including PFD. The Dysphagia Position Paper (Speech Pathology Australia, 2012) is the foundational guideline for university training programs. However, since the paper was published before PFD was formally recognised with a clear definition, it does not specifically address PFD. The guidelines offer little detail on competency requirements for managing paediatric clients with dysphagia, only stating that newly qualified SLPs should be competent with "a healthy... infant with an isolated feeding difficulty" (p. 12). This leaves all children with PFD classified as complex cases, requiring management by SLPs with postgraduate training, though no specific postgraduate qualifications for PFD are defined. In Australia, the pathway to clinical specialisation in PFD is informal and uncertified by Speech Pathology Australia, contrasting with countries like the U.S., where advanced certification in swallowing and swallowing disorders is recognised and regulated by the American Speech-Language-Hearing Association (ASHA).

Most participants in this study expressed the need for competency and credentialing guidelines from Speech Pathology Australia, viewing them as essential for best practice and to assist in guiding employers of SLPs. They emphasised the importance of standardised qualifications and training for SLPs working with PFD. While recognising that PFD management is a multidisciplinary responsibility, participants felt Speech Pathology Australia could do more to support SLPs. They believed clearly defined practice standards would significantly improve the care provided to children with PFD. A further major concern was the lack of standardised protocols in existing research, which underscored the necessity of

these guidelines. As noted by Reilly et al. (2004), professional bodies in speech pathology have a responsibility to “provide advice where evidence is limited” (p. 340).

The participants unanimously raised the challenge of providing and accessing supervision. They highlighted issues regarding the availability of experienced colleagues and financial constraints in the post-NDIS era. Previously, SLPs with expertise in PFD working in large organisations mentored undergraduate SLPs and their less experienced peers. However, with the introduction of the NDIS, universities now face challenges in ensuring adequate clinical placements and comprehensive training in PFD for undergraduate students (Attrill et al., 2023; Hines & Lincoln, 2016). Although innovative training approaches, such as Human Patient Simulation as reported by Ward et al. (2015), are available for clinical preparation, these methods remain limited and accessible to only a small number of students across Australia.

5.5.3 Policy and Funding

Many SLPs in the study acknowledged insufficient attention to workforce training and supervision for PFD. The reasons for this gap were complex, with many linking it to policy and funding challenges. Participants reported that supervision and professional development opportunities specific to PFD had diminished over the past decade, since the introduction of the NDIS. This has been reported to have resulted in a fragmentation in service delivery, insufficient attention to workforce training and supervision, and a reduction in collaborative practice due in part, to the increasing numbers of SLPs in private practice in the post-NDIS era (Attrill et al., 2023; Hines & Lincoln, 2016; McKenzie & Smith-Merry, 2023; Nickless et al., 2023).

5.6 Recommendations

This study presents themes derived from individual semi-structured interviews with 11 Australian SLPs working in community practice, highlighting key enablers and barriers to supporting children with PFD and their families. The themes reveal that the experiences of these SLPs align with international perspectives on PFD. Enablers included the importance of integrated MDTs, which fostered collaboration among HPs and families to meet complex needs consistently. Additionally, improving community awareness of PFD was deemed essential for equitable access to timely services, alongside ongoing professional development and better preparation for SLPs. Barriers included systemic challenges related to current policies and funding restrictions that hinder families' access to care, issues of continuity in care and inadequate intersectoral collaboration among professionals. Further research is needed to determine whether the themes identified in this study apply in other regions. Based on these themes, several recommendations are made to address these issues:

- Speech Pathology Australia in collaboration with policymakers, frontline clinicians, universities, and user groups could develop clinical guidelines for SLPs working with PFD, in addition to those currently addressing dysphagia only, at both undergraduate and postgraduate levels.
- There could be active steps taken by all relevant stakeholders to increase multidisciplinary consultations including healthcare providers, patients, and caregivers, to develop shared care plans, address gaps, set communication protocols, and periodically review care pathways for seamless continuity across hospital and community services.

- Policymakers, allied health professional bodies, and all stakeholders could collaboratively address changes in the allied health sector, particularly concerning funding for children with PFD and the training and supervision of SLPs dealing with PFD.
- There could be increased community awareness campaigns about PFD by HPs to address the need for timely referrals to relevant professionals.
- A research agenda could be developed by Speech Pathology Australia in collaboration with frontline clinicians, universities, and user groups collaboration with prioritising, identification and evaluation of treatment options for PFD that families consider most meaningful. This agenda should also address the generalisability of findings to ensure that treatment approaches are broadly applicable and effective across various family and community contexts.

5.7 Limitations

This study provides an initial exploration of SLP services for PFD in Australia. It however has certain limitations. There were some participants, SLPs who were also, parents of children with PFD. This may have introduced bias, as their personal experiences could influence their professional perspectives. Additionally, the study focused solely on SLPs' perspectives, limiting a full understanding of PFD's heterogeneous nature. Future research should engage a diverse group of SLPs and related HPs from various regions and specialities to enhance generalisability and inform evidence-based practice and policy for PFD services.

5.8 Conclusion

The themes elicited from individual interviews with 11 SLPs in Australia highlighted being part of a multidisciplinary team as a key enabler in supporting children with PFD. They further highlighted the SLPs' perceptions of significant barriers to SLP practice with PFD, including systemic issues such as insufficient training, a lack of competency and credentialing pathways, and limited intersectoral care coordination. These challenges were reported to be further complicated by funding issues and low community awareness of PFD.

This aligns with international research which reports similar issues of inadequate training, insufficient multidisciplinary collaboration, and a lack of standardised guidelines. The study emphasises that further research is needed to determine whether the themes elicited in this study apply to other areas.

Declaration of interest: The authors declare no conflicts of interest. The authors alone are responsible for the content and writing of this paper. The authors declare no competing financial interests.

Additional information: Funding: Julie Tan was funded by the Australian Government Research Training Program Scholarship

References

- Aldridge, V. K., Dovey, T. M., Martin, C. I., & Meyer, C. (2010). Identifying clinically relevant feeding problems and disorders. *Journal of Child Health Care*, 14(3), 261-270. <https://doi.org/10.1177/1367493510370456>
- Arvedson, J. C. (2008). Assessment of pediatric dysphagia and feeding disorders: Clinical and instrumental approaches. *Developmental Disabilities Research Reviews*, 14(2), 118-127. <https://doi.org/10.1002/ddrr.170>
- Attrill, S., Foley, K., Gesesew, H. A., & Brebner, C. (2023). Allied health workforce development for participant-led services: Structures for student placements in the National Disability Insurance Scheme. *BMC Medicine*, 23(1), 95. <https://doi.org/10.1186/s12916-023-02778-4>
- Auburn, E., Gott, M., & Hoare, K. (2021). Experiences of an insider researcher - interviewing your own colleagues. *Nurse Researcher*, 29(3), 22-28. <https://doi.org/10.7748/nr.2021.e1794>
- Bailey, R. L., Stoner, J. B., Angell, M. E., & Fetzer, A. (2008). School-based speech-language pathologists' perspectives on dysphagia management in the schools. *Language, Speech, and Hearing Services in Schools*, 39(4), 441-450. [https://doi.org/10.1044/0161-1461\(2008/07-0041](https://doi.org/10.1044/0161-1461(2008/07-0041)
- Berlin, K. S., Hobart Davies, W., Lobato, D. J., & Silverman, A. H. (2009). A biopsychosocial model of normative and problematic pediatric feeding. *Children's Health Care*, 38(4), 263-282. <https://doi.org/10.1080/02739610903235984>
- Bertrand, V., Tavolacci, M. P., Bargiacchi, A., Leblanc, V., Déchelotte, P., Stordeur, C., & Bellaïche, M. (2024). Analysis of feeding and eating disorders in 191 children according to psychiatric or gastroenterological recruitment: *The PEDIAFED cohort study. European Eating Disorders Review*, 32(3), 589-605. <https://doi.org/10.1002/erv.3063>
- Braun, V., & Clarke, V. (2021). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and Psychotherapy Research*, 21(1), 37-47. <https://doi.org/10.1002/capr.12360>
- Braun, V., & Clarke, V. (2022). Toward good practice in thematic analysis: Avoiding common problems and becoming a *knowing* researcher. *International Journal of Transgender Health*, 24(1), 1-6. <https://doi.org/10.1080/26895269.2022.2129597>
- Brenner, M., Kidston, C., Hilliard, C., Coyne, I., Eustace-Cook, J., Doyle, C., Begley, T., Barrett, M., J. (2018). Children's complex care needs: a systematic concept analysis of multidisciplinary language. *European Journal of Pediatrics* 177, 1641-1652 (2018). <https://doi.org/10.1007/s00431-018-3216-9>
- Burgess, A., Purdy, S., & Jackson, B. (2016). Allied HPs' perspectives of working with dysphagia in a rural paediatric team. *The New Zealand Medical Journal*, 129(1435), 87-89. Retrieved from <https://www.proquest.com/scholarly-journals/allied-health-professionals-perspectives-working/docview/1793543542/se-2?accountid=10382>
- Commonwealth Government of Australia. (2013). National Disability Insurance Scheme Act 2013. Canberra: Australian Government. <https://www.legislation.gov.au/Details/C2012B00230>
- Cowpe, E., Hanson, B., & Smith, C. H. (2014). What do parents of children with dysphagia think about their multidisciplinary teams? A qualitative study. *British Medical Journal Open*, 4(10). <https://doi.org/10.1136/bmjopen-2014-005934>.
- Dadich A, Kaplun S, Kaplun C, Hopwood N, Elliot C. (2023). 'it was that ... specialist ... that finally listened to us ... that's probably a weird answer to what you were

- expecting’: clinician and carer perspectives on brilliant feeding care. *Health Expect.* 26: 488-497. <https://doi.org/10.1111/hex.13683>
- Elliot, C., Hopwood, N., Moraby, K., Crockett, N., Wright, S., Vanos, K., Furey, K., Hammond, A., Handley, S., Dalby-Payne, J., Dadich, A., Gottschalk, B., Ooi, C. Y., & Woolfenden, S. (2024). New consensus definition on defining and measuring care for children with paediatric feeding disorder. *Journal of Paediatrics and Child Health*, 60(2–3), 58–66. <https://doi.org/10.1111/jpc.16534>
- Estrem, H. H., Park, J., Thoyre, S., McComish, C., & McGlothen-Bell, K. (2022). Mapping the gaps: A scoping review of research on pediatric feeding disorder. *Clinical Nutrition ESPEN*, 48, 45-55. <https://doi.org/10.1016/j.clnesp.2021.12.028>
- Feeding Matters. (2019). Economic impact study. *Feeding Matters*. <https://www.feedingmatters.org/economic-impact-study>
- Felicetti, C., Richardson, K., & Mansolillo, A. (2020). Dysphagia management in schools: A survey of speech-language pathologists. *Perspectives of the ASHA Special Interest Groups*, 5(3), 582-591. https://doi.org/10.1044/2020_PERSP-19-00091
- Fisher, M., Freeman, T., Mackean, T., Friel, S., & Baum, F. (2020). Universal health coverage for non-communicable diseases and health equity: Lessons from Australian primary healthcare. *International Journal of Health Policy and Management*, 11(5), 690-700. <https://doi.org/10.34172/ijhpm.2020.232>
- Gadamer, H. G. (1996). *Truth and method* (2nd rev. ed.). Sheed and Ward. (Original work published 1975)
- Galai, T., Friedman, G., & Moses, M. (2022). Demographic and clinical parameters are comparable across different types of pediatric feeding disorder. *Scientific Reports*, 12, 8596. <https://doi.org/10.1038/s41598-022-12562-1>
- Goday, P. S., Huh, S. Y., Silverman, A., Lukens, C. T., Dodrill, P., Cohen, S. S., Delaney, A. L., Feuling, M. B., Noel, R. J., Gisel, E., Kenzer, A., Kessler, D. B., Kraus de Camargo, O., Browne, J., & Phalen, J. A. (2019). Pediatric feeding disorder: Consensus definition and conceptual framework. *Journal of Pediatric Gastroenterology and Nutrition*, 68(1), 124-129. <https://doi.org/10.1097/MPG.0000000000002199>
- Gosa, M. M., Dodrill, P., Lefton-Greif, M., & Silverman, A. (2020). A multidisciplinary approach to pediatric feeding disorders: Roles of the speech-language pathologist and behavioral psychologist. *American Journal of Speech-Language Pathology*, 29(2), 956-966. https://doi.org/10.1044/2020_AJSLP-19-00069
- Greenberg, N. (n.d.). Phenomenological attitude. *Art & Science of Animal Behavior*. <https://neilgreenberg.com/ao-phenomenological-attitude/>
- Heidegger, M. (1962). *Being and time*. Harper and Row.
- Hines, M., & Lincoln, M. (2016). Boosting the recruitment and retention of new graduate speech-language pathologists for the disability workforce. *Journal of Clinical Practice in Speech-Language Pathology*, 18(2), 50-54.
- Howells, S. R., Cornwell, P. L., Ward, E. C., & Kuipers, P. (2019). Understanding dysphagia care in the community setting. *Dysphagia*, 34(5), 681-691. <https://doi.org/10.1007/s00455-018-09971-8>
- Hutchins, T. L., Gerety, K. W., & Mulligan, M. (2011). Dysphagia management: A survey of school-based speech-language pathologists in Vermont. *Language, Speech, and Hearing Services in Schools*, 42(2), 194-206. [https://doi.org/10.1044/0161-1461\(2011/10-0057\)](https://doi.org/10.1044/0161-1461(2011/10-0057))
- Jackson, B. N., Turner, L. A. T., Kevany, G. L., & Purdy, S. C. (2021). Five years of avoidant/restrictive food intake disorder: No consensus of understanding among HPs in New Zealand. *Speech, Language and Hearing*, 1-9. <https://doi.org/10.1080/2050571X.2021.1926620>

- Jones, E., Southwood, H., Cook, C., & Nicholson, T. (2020). Insights into paediatric tube feeding dependence: A speech-language pathology perspective. *International Journal of Speech-Language Pathology*, 22(3), 327–337. <https://doi.org/10.1080/17549507.2020.1754910>
- Kovacic, K., Rein, L. E., Szabo, A., Kommareddy, S., Bhagavatula, P., & Goday, P. S. (2021). Pediatric feeding disorder: A nationwide prevalence study. *Journal of Pediatrics*, 228, 126-131.e3. <https://doi.org/10.1016/j.jpeds.2020.07.047>
- Lazard, L., & McAvoy, J. (2020). Doing reflexivity in psychological research: What's the point? What's the practice? *Qualitative Research in Psychology*, 17(2), 159-177. <https://doi.org/10.1080/14780887.2017.1400144>
- Lefton-Greif, M. A., & Arvedson, J. C. (2016). Pediatric feeding/swallowing: Yesterday, today, and tomorrow. *In Seminars in Speech and Language*, 37(4), 298-309. Thieme Medical Publishers. <https://doi.org/10.1055/s-0036-1587702>
- Levitt, H. M., Bamberg, M., Creswell, J. W., Frost, D. M., Josselson, R., & Suárez-Orozco, C. (2018). Journal article reporting standards for qualitative primary, qualitative meta-analytic, and mixed methods research in psychology. *American Psychologist*, 73(1), 26-46. <https://doi.org/10.1037/amp0000151>
- McKenzie, K., & Smith-Merry, J. (2023). Responding to complexity in the context of the National Disability Insurance Scheme. *Social Policy and Society*, 22(1), 139-154. <https://doi.org/10.1017/S1474746422000562>
- Modi, N., & Ross, E. (2000). The current practices, training and concerns of a group of hospital-based speech therapists working in the area of dysphagia. *South African Journal of Communication Disorders*, 47(1), 3-14. <https://doi.org/10.4102/sajcd.v47i1.217>
- Motta, V., Larkin, M. (2022). Absence of other and disruption of self: an interpretative phenomenological analysis of the meaning of loneliness in the context of life in a religious community. *Phenomenology and the Cognitive Sciences*. 55–80 (2023). <https://doi.org/10.1007/s11097-022-09832-8>
- Needham, C. (2013). The boundaries of budgets: Why should individuals make spending choices about their health and social care? In J. Butcher & D. Gilchrist (Eds.), *The Three Sector Solution: Delivering Public Policy in Collaboration with Not-for-profits and Business* (pp. 319-336). ANU Press. <https://doi.org/10.22459/TSS.07.2016.15>
- Nickless, T., Davidson, B., Finch, S., Gold, L., & Dowell, R. (2024). Aligned or misaligned: Are public funding models for speech-language pathology reflecting recommended evidence? An exploratory survey of Australian speech-language pathologists. *Health Policy OPEN*, 6, 100117. <https://doi.org/10.1016/j.hpopen.2024.100117>
- Nickless, T., Gold, L., Dowell, R., & Davidson, B. (2023). Public purse, private service: The perceptions of public funding models of Australian independent speech-language pathologists. *International Journal of Speech-Language Pathology*, 25(3), 462–478. <https://doi.org/10.1080/17549507.2023.2213864>
- Nizza, I., Farr, J., & Smith, J. A. (2021). Achieving excellence in interpretative phenomenological analysis (IPA): Four markers of high quality. *Qualitative Research in Psychology*, 18(3), 369-386. <https://doi.org/10.1080/14780887.2020.1854404>
- Norman, V., Zühlke, L., & Morrow, B. (2024). Care burden and support needs of caregivers of infants and children with CHDs and dysphagia. *Cardiology in the Young*. Advance online publication. <https://doi.org/10.1017/S1047951124000271>
- O'Connor, C., & Joffe, H. (2020). Intercoder reliability in qualitative research: debates and practical guidelines. *International journal of qualitative methods*, 19, <https://doi.org/10.1177/1609406919899220>

- Okada, J., Wilson, E., Wong, J., Luo, M., Fiechtner, L., & Simione, M. (2022). Financial impacts and community resources utilization of children with feeding difficulties. *BMC Pediatrics*, 22, 1-7. <https://doi.org/10.1186/s12887-022-03566-x>
- Otter.ai. (2016). *Otter.ai*: Transcription software. Retrieved from <https://www.otter.ai>
- Patient Experience Agency. (2023, May 9). *Multidisciplinary teams in healthcare: What does it all mean?* <https://www.patientexperienceagency.com.au/blog/multidisciplinary-teams-in-healthcare>
- Raatz, M., Marshall, J., Ward, E. C., Dickinson, C., Frederiksen, N., Reilly, C., & Fernando, S. (2023). Understanding training needs in pediatric feeding for allied HPs: An Australian perspective. *American Journal of Speech-Language Pathology*, 32(2), 452-468. https://doi.org/10.1044/2022_AJSLP-22-00232
- Re, G.L., Vernuccio, F., Di Vittorio, M.L., Scopelliti, L., Di Piazza, A., Terranova, M.C., Picone, D., Tudisca, C., Salerno, S. (2019). Swallowing evaluation with videofluoroscopy in the paediatric population. *Acta Otorhinolaryngology Italian* ;39(5):279-288. <https://doi.org/10.14639/0392-100X-1942>.
- Reilly, S., Oates, J., & Douglas, J. (2004). *Evidence-based practice in speech pathology*. London: Whurr.
- Robinson, O. C. (2013). Sampling in interview-based qualitative research: A theoretical and practical guide. *Qualitative Research in Psychology*, 11(1), 25–41. <https://doi.org/10.1080/14780887.2013.801543>
- Rosen, R. (2021). Prevalence of feeding disorders: A tough reality to swallow. *The Journal of Pediatrics*, 228, 13-14. <https://doi.org/10.1016/j.jpeds.2020.08.070>
- Rumbach, A., Coombes, C., & Doeltgen, S. (2018). A survey of Australian dysphagia practice patterns. *Dysphagia*, 33(2), 216–226. <https://doi.org/10.1007/s00455-017-9849-4>
- Sharp, W., Silverman, A., Arvedson, J., Bandstra, N., Clawson, E., Berry, R., McElhanon, B., Kozlowski, A., Katz, M., Volkert, V., Goday, P., & Lukens, C. (2022). Toward better understanding of pediatric feeding disorder: A proposed framework for patient characterization. *Journal of Pediatric Gastroenterology and Nutrition*, 75(3), 351-355. <https://doi.org/10.1097/MPG.0000000000003519>
- Smith, J. A., & Nizza, I. E. (2022). *Essentials of interpretative phenomenological analysis*. American Psychological Association. <https://doi.org/10.1037/0000259-000>
- Smith, J. A., & Osborn, M. (2007). Pain as an assault on the self: An interpretative phenomenological analysis of the psychological impact of chronic benign low back pain. *Psychology & Health*, 22(5), 517–534. <https://doi.org/10.1080/14768320600941756>
- Smith-Merry, J. N., Hancock, A., Bresnan, I., Yen, J., Gilroy, G., & Llewellyn, G. (2018). Mind the gap: The National Disability Insurance Scheme and psychosocial disability. Final report: Stakeholder identified gaps and solutions. University of Sydney: Lidcombe.
- Speech Pathology Australia. (2020). *The principles of practice: Family-centred practice*. <https://www.speechpathologyaustralia.org.au>
- Speech Pathology Australia. (2012). *Dysphagia position paper* (Publication No. SPA PP-2012-001). Speech Pathology Australia. Retrieved from [https://www.speechpathologyaustralia.org.au/files/public/Position_Papers/Dysphagia_position_paper_2012_\(revised\).pdf](https://www.speechpathologyaustralia.org.au/files/public/Position_Papers/Dysphagia_position_paper_2012_(revised).pdf)
- Tan, J., Cocks, N., & Claessen, M. (2021). Mothers' perspectives of support for their child with feeding/swallowing disorders. *Speech, Language and Hearing*, 25(1), 17–28. <https://doi.org/10.1080/2050571X.2021.1904734>
- Taylor, J. (2011). The intimate insider: Negotiating the ethics of friendship when doing insider research. *Qualitative research*, 11(1), 3-22. <https://doi.org/10.1177/1468794110384447>

- Teoh, H. J., & Darvell, M. (2021). Reducing Paediatric Outpatient Waitlists-A Proposed Allied Health Multidisciplinary Approach. *Open Journal of Preventive Medicine*, 11, 63-70. <https://doi.org/10.4236/ojpm.2021.112006>
- Thompson, K.L., Romeo, C., Estrem, H.H., Pederson, J., Peterson, M., Delaney, A.L., Raebaey, P., Sharp, W.G. (2024). Preparedness of Speech Language Pathologists and Occupational Therapists to Treat Pediatric Feeding Disorder: A Cross-Sectional Survey. *Dysphagia*, 1-13 <https://doi.org/10.1007/s00455-024-10718-x>
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal of Qualitative Health Care*, 19(6), 349-357. <https://doi.org/10.1093/intqhc/mzm042>
- Ward, E. C., Hill, A. E., Nund, R. L., Rumbach, A. F., Walker-Smith, K., Wright, S. E., Kelly, K., & Dodrill, P. (2015). Developing clinical skills in paediatric dysphagia management using human patient simulation (HPS). *International journal of speech-language pathology*, 17(3), 230–240. <https://doi.org/10.3109/17549507.2015.1025846>
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, 15(2), 215–228. <https://doi.org/10.1080/08870440008400302>

Chapter 6.0: Discussion of Study 1 and Study 2

6.1 Outline

This chapter explores the themes interpreted from the participants' accounts in Studies 1 and 2, highlighting the challenges and enablers in supporting children with PFD. While participants identified significant barriers to accessing support—such as systemic challenges in service provision, funding limitations, and policy constraints—they also emphasised opportunities for improvement. These included effective MDT approaches and family-centered practices, reported to be pivotal in fostering better community engagement and service delivery. Together, these findings provide a balanced perspective on the complexities of navigating support systems for children with PFD. The discussion is organised into key themes that address critical aspects of service delivery and professional practice in the field. These include access to services, which examines availability and affordability challenges, and the ‘uberisation’ of allied health services, which explores the impact of market-driven models on care quality and accessibility.

The chapter also addresses equitable access, continuity of care, focusing on the benefits of consistent and coordinated support; and SLPs’ competence, which considers the skills required to meet the complex needs of children with PFD.

Finally, the discussion advocates for improvements in SLP training, and raises the importance of empirical evidence to inform practice. These themes collectively report on the systemic and professional factors experienced by these families and practitioners when supporting children with PFD.

6.1.1 Access to Services

Both mothers and SLPs expressed significant concerns about the lack of support available for children with PFD. Participants in both studies highlighted the limited availability of holistic services, noting that many HPs, educators, community organisations, and even the media lacked adequate knowledge of PFD.

Mothers reported that essential services for PFD were often denied by general practitioners (GPs), paediatricians, SLPs, and NDIS planners due to a poor understanding of the disorder's complex symptoms. This lack of knowledge frequently made professionals dismiss or overlook the children's needs. Mothers perceived these HPs particularly GPs, paediatricians, and NDIS planners as gatekeepers who failed to act on PFD-related issues. They attributed this lack of empathy and responsiveness, to the professionals' insufficient awareness and understanding of PFD.

This gatekeeping behaviour reflects a misalignment between parental and professional concerns about feeding issues. As Aldridge et al. (2010) noted, medical professionals often lack clear guidance on making referral decisions and may delay action until the "biological consequences" of feeding issues become apparent (p265). Similarly, Goday et al. (2019) identified diagnostic confusion or incomplete diagnoses. More recently Nickless et al. (2024) highlighted how many communication and swallowing disorders remain "misunderstood by funding gatekeepers".

Both mothers and SLPs, emphasised the scarcity of HPs experienced in PFD, with MDTs being particularly difficult to access. Previous research in New Zealand and Australia (Jackson et al., 2021; Jeyendra et al., 2013; Jones et al., 2022; Psaila et al., 2014) identified

low confidence among professionals in managing PFD and a lack of coordinated multidisciplinary responses. In studies 1 and 2, the reports of children accessing an MDT approach were rare. Instead, participants described isolated and fragmented services that lacked collaborative practice. These gaps were often attributed to funding constraints and resource shortages, resulting in inequitable access to care.

Mothers in Study 1, also noted that HPs often adopted an overly directive, expert-driven model of care rather than a truly collaborative FCP. This hierarchical approach positioned professionals as authoritative figures, making decisions with minimal input from families. Such practices conflict with the principles of FCP, which prioritise shared decision-making, partnership, and respect for families' insights into their child's needs. Furthermore, when FCP was implemented, it often lacked operational clarity. While HPs used FCP-related terminology, they rarely provided actionable definitions or demonstrated how these principles should be applied in practice. As a result, care appeared fragmented, leaving families uncertain about their roles in the therapeutic process.

These findings underscore the urgent need for clearer care pathways for children with PFD, and the importance of public awareness campaigns to promote a better understanding of PFD. Greater awareness within both the medical community and the broader public is essential to ensure that PFD is better recognised and managed. Addressing these systemic issues is fundamental to improving access to services for children with PFD. The next section will consider the transformative impact of the NDIS on the delivery of allied health services.

6.1.2 The 'Uberisation' of Allied Health Services

Both mothers and the SLPs shared their perspectives on the NDIS, a participant-led funding model aimed at promoting equality and inclusion for all (National Disability

Insurance Scheme Act, 2013). While the NDIS represents a transformative shift in allied health service provision, these changes have also introduced significant challenges.

The term "uberisation" (Hickie, 2019), has been used to describe the impact of the NDIS on service delivery. This pejorative term highlights concerns about the fragmentation of healthcare services (McKenzie & Smith-Merry, 2023), neglect of workforce training and supervision needs, and the erosion of collaborative practice (Attrill et al., 2023; Hines & Lincoln, 2016). Before the introduction of the NDIS, experienced HPs within larger organisations routinely mentored undergraduate SLPs and less experienced colleagues. However, the shift to a consumer-led funding model has disrupted these mentorship opportunities, leaving significant gaps in the professional development and competency of the workforce.

This issue is compounded by a growing demand for SLPs, driven by an increasing number of children being diagnosed with PFD. Participants expressed concerns that the NDIS's reliance on market forces risks undermining the regulation of service quality and the delivery of consistent excellence across allied health services. The current market-driven system offers limited solutions for addressing the training and supervision needs of healthcare providers (Attrill et al., 2023) while failing to adequately support or incentivise collaborative practice between service providers, particularly in complex areas such as PFD management (Brenner et al., 2018).

Allied health organisations, including Speech Pathology Australia, in partnership with the National Disability Insurance Agency (NDIA), have a critical role in developing and implementing care pathways suited to this new practice environment. Ensuring a sustainable, high-quality allied health workforce requires focused efforts to address training deficits,

foster collaboration, and prioritise professional development within the evolving NDIS framework.

A more detailed consideration of the themes related to the supervision of SLPs will now be considered.

6.1.3 Challenges in Supervision and skill development

In Study 2, SLPs reported significant challenges with employment practices, particularly for early-career SLPs. Many new-to-practice clinicians were expected by employers, to manage clients with PFD, without adequate supervision or guidance. The rapid expansion of private practice services, driven by changes introduced with the NDIS, has further complicated career development and skill acquisition for SLPs working in this area.

These supervision challenges are not unique to Australia. A recent study from New Zealand similarly highlighted a lack of supervisory support for SLPs (Jackson et al., 2021). All SLPs in Study 2 emphasised the difficulties of providing effective supervision, citing issues such as limited availability and financial constraints in the context of the NDIS.

The impact of the NDIS on SLP training and development cannot be overstated. Relying on “goodwill” agreements for supervision is unsustainable, and experienced SLPs must be adequately compensated for their contributions to mentoring and training. Developing a structured competency pathway, as outlined in a Speech Pathology Australia (SPA) position paper, and fostering collaboration between SPA and the NDIS to address the supervision burden, could provide a viable solution to these challenges.

6.1.4 A lack of understanding of Paediatric Feeding

Disorder among NDIS Planners

Both the mothers in Study 1 and the SLPs in Study 2 highlighted concerns about NDIS planners' limited understanding of PFD. Currently, there are no training programs or competency requirements for planners in this area, creating a critical gap in the NDIS framework. As a personalised service, the NDIS relies on participants and their carers to identify and advocate for necessary services. This model places a significant burden on families, particularly when dealing with complex conditions like PFD, which may not be fully understood by planners.

This issue is not unique to PFD. Cortese et al. (2019) noted that individuals with complex needs often experience inadequate support under the NDIS, reporting that such needs “were not addressed by the (NDIS) scheme” (p. 899). Similarly, the *Mind the Gap* report by Smith-Merry et al. (2018) found that fewer than half of individuals with psychosocial disabilities received adequate support through NDIS funding, often due to the complexity of their diagnoses.

The findings from these studies, along with the current research, suggest that NDIS planners may not consistently respond to detailed information and reporting about participants' needs. This underscores the need for families to have access to resources and support that enable them to effectively advocate for their children. Comprehensive education for families and targeted training for planners around complex conditions like PFD would help bridge these gaps and ensure equitable access to appropriate services.

6.1.5 Financial barriers to accessing support

Themes from Study 1 and Study 2 underscored the significant barriers families face in accessing support for their children with PFD, with funding emerging as a critical issue. A study by Teoh and Darvell (2021) in Australia highlighted that families attempting to see a paediatrician were confronted with “waitlists spiralling out of control” (p. 64), a challenge attributed to increasing referrals to the public healthcare system. This situation often extends beyond paediatricians to include allied health services, ENT specialists, and dental care, further complicating access.

Faced with these challenges, families may turn to private services, incurring substantial "out-of-pocket expenses" (Feeding Matters, 2019; Nickless et al., 2023). These expenses, combined with the broader financial burden of caregiving, create significant strain for families of children with PFD. In a U.S. study, Okada et al. (2022) found that the financial impact extends beyond medical costs, as parents often reduce their working hours to meet their caregiving responsibilities.

Addressing these financial barriers is essential for ensuring equitable and sustainable access to allied health services. Without targeted solutions, families will continue to face significant economic hardship, undermining their ability to provide the necessary support for their children with PFD.

6.1.6 Continuity of Care for Children with PFD

Continuity of care for children with PFD remains a significant challenge, as identified by participants in both Study 1 and Study 2. A critical issue lies in the fragmented care

pathway between hospital-based and community HP services. While children with PFD often receive specialised care in hospital settings during acute or neonatal stages, their transition to community-based services after discharge is frequently unstructured. This lack of continuity forces parents to navigate complex healthcare systems independently, often without adequate guidance or support.

These findings align with Psaila et al. (2014), who documented similar challenges in transitioning pre-term infants from hospital to home. They highlighted ineffective communication and limited information transfer between services, which were also reported by participants in our studies. Inadequate handover practices, often due to time constraints and funding limitations, were a recurring theme.

Community-based SLPs expressed significant challenges in accessing essential diagnostic tools like videofluoroscopic studies, which are typically hospital-based. Such assessments are critical for accurately diagnosing and managing PFD (Arvedson, 2008). Without access to these tools, community SLPs face difficulties in delivering comprehensive care. These concerns are not unique to paediatrics; Australian research highlights similar issues in managing adult dysphagia in community settings (Howells et al., 2019; Rumbach et al., 2018).

Addressing these barriers requires a review of collaboration between hospital and community services and the development of clear, structured care pathways. Best-practice models, including consistent access to multidisciplinary team management, are essential for supporting children with PFD and their families (Bertrand et al., 2024; Galai et al., 2022; Goday et al., 2019). Strengthening the continuity of care, between tertiary and community services, will help reduce the burden on families and empower community SLPs to deliver effective and reliable care.

6.1.7 Speech Language Pathologists' Competence

In Study 1, mothers expressed dissatisfaction with SLPs' perceived lack of competence in managing PFD and implementing family-centred practices. They described instances where SLPs appeared dismissive, avoided PFD-related services, or focused on unrelated issues. Similarly, Estrem et al. (2022) in a systematic review of services for PFD, highlighted gaps in family-centred variables, such as measuring parental impact and quality of life. A desire to understand SLPs' perspectives on how they support children with PFD motivated the design of Study 2, to explore SLPs' perspectives on their service delivery.

Study 2 revealed that SLPs' uncertainty in managing PFD stemmed from insufficient training, inadequate support, and a lack of clinical guidelines or competency pathways. Participants identified challenges, including limited community understanding of PFD, restricted access to multidisciplinary teams, and insufficient funding. These barriers contributed to an environment of uncertainty for the SLPs, which extended beyond simply a lack of confidence..

Existing literature supports these findings. For example, Bailey et al. (2008), Burgess et al. (2016), and Felicetti et al. (2020) identified similar issues with SLPs delivering PFD services globally. Recent studies, such as Jackson et al. (2021) in New Zealand and Raatz et al. (2023) in Australia, highlight resource shortages and insufficient training for managing PFD and related disorders. These findings resonate with the experiences of SLPs in the current study.

To address these issues, the study highlights the need for clear competency pathways, updated clinical guidelines, and improved training during undergraduate studies, including more clinical placements. The findings underscore the importance of implementing these

recommendations to enhance SLPs' competence in managing PFD effectively. Further research should explore strategies to overcome barriers and support SLPs in delivering optimal care for children with PFD and their families.

6.1.8 Outdated Recommendations

The SLP participants identified the lack of standardised practice recommendations as a significant concern. In Australia, Speech Pathology Australia oversees undergraduate SLP education, encompassing client populations affected by dysphagia, including PFD. However, the Dysphagia Guidelines (Speech Pathology Australia, 2012), which guide SLP training programs, were published before PFD was recognised as a distinct condition. As a result, they do not specifically address PFD.

These guidelines provide only limited direction, stating that newly qualified SLPs should be competent to manage “a healthy... infant with an isolated feeding difficulty” (p. 12). This categorisation implies that all children with PFD are considered complex cases requiring advanced practice. However, the guidelines fail to specify how to achieve this advanced practice, outline postgraduate training requirements, or delineate detailed competencies for managing PFD. Instead, they defer competency attainment and credentialing to individual SLPs and their employers, an unreliable and inconsistent system, particularly in the post-NDIS era (Nickless et al., 2023).

The lack of updated and specific guidelines has created significant challenges for SLPs. With the introduction of the NDIS, the number of SLPs working in private practice has increased, further complicating efforts to establish consistent competency standards. Without clear national recommendations, SLPs and their employers lack the guidance necessary to provide appropriate training, supervision, and mentoring for managing PFD effectively.

A critical recommendation is for Speech Pathology Australia to collaborate with universities to develop structured competency pathways. These pathways should clarify the minimum training, supervision, and mentoring standards required for SLPs working with PFD. Clear guidelines would also compel employers to support their SLPs in achieving the competencies necessary to provide effective care for children with PFD.

The role of universities is central to addressing these challenges. Updating university curricula to incorporate detailed competency pathways for PFD management is essential. By ensuring that future SLPs receive adequate training and clinical exposure during their studies, universities can lay the foundation for a more reliable and standardised approach to PFD management. Collaboration between Speech Pathology Australia, universities, and clinical settings is vital to ensuring future recommendations meet the needs of both SLPs and the families they serve.

6.1.9 Speech-Language Pathology Training

The challenge for universities that deliver SLP training is how best to meet their undergraduate students' need for more comprehensive training in PFD, particularly how to resolve the need for clinical placements, with the introduction of the NDIS, universities now face challenges in ensuring adequate clinical placements and comprehensive training in PFD for undergraduate students (Attrill et al., 2023; Hines & Lincoln, 2016). Although innovative training approaches, such as Human Patient Simulation as reported by Ward et al. (2015), are available for clinical preparation, these methods remain limited and accessible to only a small number of students across Australia. The rise in the number of children diagnosed with PFD requires that newly graduated SLPs are at least at a novice level and are then fully supported

on their journey to competency by clear guidelines. A graduate pathway of training, supervision, and mentoring standards could support this development. However, to support and develop SLP practices, within the area of PFD, research is central to the development of services. We will now consider some of the challenges PFD presents in research.

6.1.10 Empirical Evidence

The heterogeneous nature of PFD presents challenges to conducting randomised controlled trials (RCTs) or other studies requiring large sample sizes (Arvedson et al., 2010; Marshall et al., 2015; Voniati et al., 2021). Key obstacles include limited sample sizes, participant grouping based on factors like age, diagnosis severity, and feeding issues, as well as complex ethical considerations, such as withholding treatment. These issues complicate all research designs, especially when selecting outcome measures, which must standardise factors like behaviour, nutritional status, and caregiver stress. Long-term interventions further complicate research logistics by requiring effective tracking of treatment outcomes, maintaining participant engagement, and measuring results over time (Estrem et al., 2022).

SLPs are often criticised for the lack of group-designed research like RCTs. However, as Robey and Schultz (1998) noted, this debate is often unproductive. A more effective approach may be for SLPs to consider research designs that reflect a comprehensive understanding of the challenges posed by PFD. Qualitative or mixed methods research can offer a more flexible and nuanced understanding of PFD than traditional quantitative approaches. Additionally, practice-informed evidence, focusing on family-centred outcomes, may provide a more relevant perspective by incorporating diverse sources such as clinical data, client feedback, and parental perspectives (Estrem et al., 2022).

Given PFD's complexity, SLPs could also expand their knowledge by exploring research in related fields such as ENT, dentistry, and nursing, which have seen increased research output (Pereira et al., 2022; Dong et al., 2023; Hill & Pados, 2020). Engaging with this growing body of work could enrich SLPs' understanding of PFD. As Reilly et al. (2004) emphasised, research within discipline-specific silos is no longer sufficient. Encouraging more SLPs to conduct research in the PFD practice area, supported by a prioritised research agenda in the Australian allied health context (Finch et al., 2021), would help address these gaps. PFD services must be informed by robust research, balancing real-world challenges with ethical responsibilities to provide a nuanced perspective.

Based on the research themes identified by the mothers and SLPs involved, several recommendations will now be presented.

6.2 Recommendations

This project sought the perspectives of key informants on PFD. These participants, mothers of children with PFD and SLPs experienced in working with children who have PFD highlight the challenges in accessing and providing support for a child with PFD. To address these challenges, several recommendations are suggested:

- Funding issues including the lack of financial support for children with PFD should be recognised and addressed by all stakeholders, policymakers, and the allied health professionals' bodies.
- Models of care comprised of integrated pathways established between hospital and community services should be developed with collaborative approaches by all stakeholders.

- Speech Pathology Australia (SPA) should establish minimum training, supervision, and mentoring standards for SLPs working with PFD at both undergraduate and postgraduate levels.
- There should be more public awareness campaigns about PFD.
- A prioritised research agenda should be developed in the Australian allied health context focused on PFD.

6.3 Limitations and Future Research

This research explored the perspectives of families of children with PFD and the perspectives of speech-language pathologists who offer them support. Although these studies provide valuable insights into services for PFD, they also have limitations. These studies were conducted with a small sample of mothers and SLPs from a single geographical metropolitan area; therefore, the results may not be generalisable to other contexts. Study 2 focused solely on speech pathologists' perspectives within a complex, multidimensional disorder. A broader study incorporating viewpoints from professionals across all four domains would provide more comprehensive insights. There were some participants, in study 2, SLPs who were also, parents of children with PFD. This may have introduced bias, as their personal experiences could influence their professional perspectives. research should investigate these issues in additional areas, with a larger and more diverse sample to enhance our understanding of this complex area of speech-language pathology service delivery.

6.4 Summary

This qualitative research project explored themes from two small groups of key informants: mothers of children with PFD and experienced SLPs who support these children. The findings revealed systemic concerns across the ecological systems framework, including challenges in accessing community and health services, insufficient funding, and gaps in policy. Both groups expressed particular concerns regarding the impact of the NDIS on service delivery, including its effect on SLP training and the availability of multi-disciplinary teams (MDTs).

However, the findings also highlighted positive enablers in service delivery. Both mothers and SLPs emphasised the importance of MDT and family-centred practice (FCP) approaches, which were viewed as pivotal in fostering effective support and collaboration. Despite challenges, these approaches were identified as strengths that can address systemic barriers and enhance care for children with PFD and their families. Additionally, the research underscored the need for competency pathways and improved integration between services to support children with PFD and their families more effectively.

The detailed insights from both service providers and recipients offer a clear picture of current support practices for children with PFD. They help identify the specific needs of families and children with PFD and suggest potential ways to address those needs. The themes analysed in this study contribute to the growing knowledge in this area and may inform future policies and training for those supporting children with PFD. Further research is required to determine whether the themes elicited in this study apply to other areas.

Appendices

1: Funding

Julie Tan was funded by the Australian Government Research Training Program Scholarship (RTPS).

2: Publishing Agreement

Publisher agreement regarding the published article on study 1 in Chapter 4.



Taylor & Francis Group

PUBLISHING AGREEMENT

This is an agreement under which you, the author, assign copyright in your article to Informa UK Limited registered in England under no. 1072954 trading as Taylor & Francis Group, Registered Office: 5 Howick Place, London, SW1P 1WG (hereinafter 'Taylor & Francis') to allow us to publish your article, including abstract, tables, figures, data, and supplemental material hosted by us, as the Version of Record (VoR) in the Journal for the full period of copyright throughout the world, in all forms and all media, subject to the Terms & Conditions below.

Article (the "Article") entitled:	Mothers' perspectives of support for their child with feeding /swallowing disorders
Article DOI:	10.1080/2050571X.2021.1904734
Author(s):	Julie Tan, Naomi Cocks, Mary Claessen
To publish in the Journal:	Speech, Language and Hearing
Journal ISSN:	2050-5728

STATEMENT OF ORIGINAL COPYRIGHT OWNERSHIP / CONDITIONS

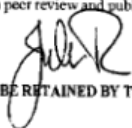
In consideration of the publication of the Article, you hereby grant with full title guarantee all rights of copyright and related rights in the above specified Article as the Version of Scholarly Record which is intended for publication in all forms and all media (whether known at this time or developed at any time in the future) throughout the world, in all languages, for the full term of copyright, to take effect if and when the Article is accepted for publication in the Journal.

ASSIGNMENT OF PUBLISHING RIGHTS

I hereby assign Taylor & Francis with full title guarantee all rights of copyright and related publishing rights in my article, in all forms and all media (whether known at this time or developed at any time in the future) throughout the world, in all languages, where our rights include but are not limited to the right to translate, create adaptations, extracts, or derivative works and to sub-license such rights, for the full term of copyright (including all renewals and extensions of that term), to take effect if and when the article is accepted for publication. If a statement of government or corporate ownership appears above, that statement modifies this assignment as described.

I confirm that I have read and accept the full Terms & Conditions below including my author warranties, and have read and agree to comply with the Journal's policies on peer review and publishing ethics.

Signed and dated:

 15.03.21

THIS FORM WILL BE RETAINED BY THE PUBLISHER.

ASSIGNMENT OF COPYRIGHT: TERMS & CONDITIONS

DEFINITION

1. Your article is defined as comprising (a) your Accepted Manuscript (AM) in its final form; (b) the final, definitive, and citable Version of Record (VoR) including the abstract, text, bibliography, and all accompanying tables, illustrations, data, and media; and (c) any supplemental material hosted by Taylor & Francis. This assignment and these Terms & Conditions constitute the entire agreement and the sole understanding between you and us ('agreement'), no amendment, addendum, or other communication will be taken into account when interpreting your and our rights and obligations under this agreement, unless amended by a written document signed by both of us.

TAYLOR & FRANCIS' RESPONSIBILITIES

2. If deemed acceptable by the Editors of the Journal, we shall prepare and publish your article in the Journal. We may post your accepted manuscript in advance of the formal publication of the VoR. We reserve the right to make such editorial changes as may be necessary to make the article suitable for publication, or as we reasonably consider necessary to avoid infringing third-party rights or breaching any laws; and we reserve the right not to proceed with publication for whatever reason.
3. Taylor & Francis will deposit your Accepted Manuscript (AM) to any designated institutional repository including PubMedCentral (PMC) with which Taylor & Francis has an article deposit agreement; see 4 iv (a) below.

RIGHTS RETAINED BY YOU AS AUTHOR

4. These rights are personal to you, and your co-authors, and cannot be transferred by you to anyone else. Without prejudice to your rights as author set out below, you undertake that the fully reference-linked Version of Record (VOR) will not be published elsewhere without our prior written consent. You assert and retain the following rights as author(s):
 - i. The right to be identified as the author of your article, whenever and wherever the article is published, such rights including moral rights arising under § 77, Copyright, Designs & Patents Act 1988, and, so far as is legally possible, any corresponding rights we may have in any territory of the world.
 - ii. The right to retain patent rights, trademark rights, or rights to any process, product or procedure described in your article.
 - iii. The right to post and maintain at any time the Author's Original Manuscript (AOM; your manuscript in its original and unrefereed form; a 'preprint').
 - iv. The right to post at any time after publication of the VoR your AM (your manuscript in its revised after peer review and accepted for publication form; a 'postprint') as a digital file on your own personal or departmental website, provided that you do not use the VoR published by us, and that you include any amendments or deletions or warnings relating to the article issued or published by us; and with the acknowledgement: 'The Version of Record of this manuscript has been published and is available in <JOURNAL TITLE> <date of publication> <http://www.tandfonline.com/<Article DOI>>'.
 - a. Please note that embargoes apply with respect to posting the AM to an institutional or subject repository. For further information, please see our [list of journals with applicable embargo periods](#). For the avoidance of doubt, you are not permitted to post the final published paper, the VoR published by us, to any site, unless it has been published as Open Access on our website.
 - b. If, following publication, you or your funder pay an Article Publishing Charge for retrospective Open Access publication, you may then opt for one of three licences: CC BY, CC BY-NC, or CC BY-NC-ND; if you do not respond, we shall assign a CC BY licence. All rights in the article will revert to you as author.
 - v. The right to share with colleagues copies of the article in its published form as supplied to you by Taylor & Francis as a digital print or printed reprint on a non-commercial basis.
 - vi. The right to make printed copies of all or part of the article on a non-commercial basis for use by you for lecture or classroom purposes provided that such copies are not offered for sale or distributed in any systematic way, and provided that acknowledgement to prior publication in the Journal is given.
 - vii. The right, if the article has been produced within the scope of your employment, for your employer to use all or part of the article internally within the institution or company on a non-commercial basis provided that acknowledgement to prior publication in the Journal is given.
 - viii. The right to include the article in a thesis or dissertation that is not to be published commercially, provided that acknowledgement to prior publication in the Journal is given.
 - ix. The right to present the article at a meeting or conference and to distribute printed copies of the article to the delegates attending the meeting provided that this is not for commercial purposes and provided that acknowledgement to prior publication in the Journal is given.
 - x. The right to use the article in its published form in whole or in part without revision or modification in personal compilations, or other publications of your own work, provided that acknowledgement to prior publication in the Journal is given.
 - xi. The right to expand your article into book-length form for publication provided that acknowledgement to prior publication in the Journal is made explicit (see below). Where permission is sought to re-use an article in a book chapter or edited collection on a commercial basis a fee will be due, payable by the publisher of the new work. Where you as the author of the article have had the lead role in the new work (i.e., you are the author of the new work or the editor of the edited collection), fees will be waived. Acknowledgement to prior publication in the Journal should be made explicit (see below).

Acknowledgement: This <chapter or book> is derived in part from an article published in <JOURNAL TITLE> <date of publication> <copyright Taylor & Francis>, available online: <http://www.tandfonline.com/<Article DOI>>

If you wish to use your article in a way that is not permitted by this agreement, please contact permissionsrequest@tandf.co.uk

WARRANTIES MADE BY YOU AS AUTHOR

5. You warrant that:
 - i. All persons who have a reasonable claim to authorship are named in the article as co-authors including yourself, and you have not

- fabricated or misappropriated anyone's identity, including your own.
- ii. You have been authorized by all such co-authors to sign this agreement as agent on their behalf, and to agree on their behalf the priority of the assertion of copyright and the order of names in the publication of the article.
- iii. The article is your original work, apart from any permitted third-party copyright material you include, and does not infringe any intellectual property rights of any other person or entity and cannot be construed as plagiarizing any other published work, including your own published work.
- iv. The article is not currently under submission to, nor is under consideration by, nor has been accepted by any other journal or publication, nor has been previously published by any other journal or publication, nor has been assigned or licensed by you to any third party.
- v. The article contains no content that is abusive, defamatory, libelous, obscene, fraudulent, nor in any way infringes the rights of others, nor is in any other way unlawful or in violation of applicable laws.
- vi. Research reported in the article has been conducted in an ethical and responsible manner, in full compliance with all relevant codes of experimentation and legislation. All articles which report in vivo experiments or clinical trials on humans or animals must include a written statement in the Methods section that such work was conducted with the formal approval of the local human subject or animal care committees, and that clinical trials have been registered as applicable legislation requires.
- vii. Any patient, service user, or participant (or that person's parent or legal guardian) in any research or clinical experiment or study who is described in the article has given written consent to the inclusion of material, text or image, pertaining to themselves, and that they acknowledge that they cannot be identified via the article and that you have anonymized them and that you do not identify them in any way. Where such a person is deceased, you warrant you have obtained the written consent of the deceased person's family or estate.
- viii. You have complied with all mandatory laboratory health and safety procedures in the course of conducting any experimental work reported in your article; your article contains all appropriate warnings concerning any specific and particular hazards that may be involved in carrying out experiments or procedures described in the article or involved in instructions, materials, or formulae in the article; your article includes explicitly relevant safety precautions, and cites, if an accepted Standard or Code of Practice is relevant, a reference to the relevant Standard or Code.
- ix. You have acknowledged all sources of research funding, as required by your research funder, and disclosed any financial interest or benefit you have arising from the direct applications of your research.
- x. You have obtained the ~~necessary written permission~~ necessary written permission to include material in your article that is owned and held in copyright by a third party, which shall include but is not limited to any proprietary text, illustration, table, or other material, including data, audio, video, film stills, screenshots, musical notation and any supplemental material.
- xi. You have read and complied with our policy on publishing ethics.
- xii. You have read and complied with the Journal's Instructions for Authors.
- xiii. You have read and complied with our guide on peer review.
- xiv. You will keep us and our affiliates indemnified in full against all loss, damages, injury, costs and expenses (including legal and other professional fees and expenses) awarded against or incurred or paid by us as a result of your breach of the warranties given in this agreement.
- xv. You consent to allowing us to use your article for marketing and promotional purposes.

GOVERNING LAW

- 6. This agreement (and any dispute, proceeding, claim or controversy in relation to it) is subject to English law and the parties hereby submit to the exclusive jurisdiction of the Courts of England and Wales.

3: Authorship Agreement

This Authorship Agreement ("Agreement") is made and entered into on 19/04/24, by and between:

Julie Tan, a post-graduate student in the School of Allied Health at Curtin University, Perth, Western Australia, from now on referred to as the "Student" or "Author".

Professor Deborah Hersh, Speech Pathology, School of Allied Health, Curtin University, Perth, Western Australia; Assoc. Professor **Naomi Cocks**, Speech Pathology, School of Allied Health, Curtin University, Perth, Western Australia; Dr **Christina Fernandes**, School of Allied Health Science and Practice, Adelaide University, Adelaide, Australia; and Dr **Mary Claessen**, Speech Pathology Australia, Melbourne, Victoria, collectively referred to as the "Supervisors" or "Academic Supervisors".

Background:

1. The student is pursuing a Master of Science (MSc) degree in Speech Pathology under the supervision of the Academic Supervisors.
2. The research conducted by the Student for her MSc thesis may result in scholarly articles suitable for publication in academic journals.

Agreement Terms:

1. Ownership and Authorship:

- a. It is understood that the primary ownership of any scholarly articles resulting from the research conducted by the Student for her MSc thesis shall reside with the student.
- b. The determination of authorship on any publication(s) resulting from this research shall be decided based on the guidelines and criteria set forth by the International Committee of Medical Journal Editors (ICMJE) or equivalent standard in the field of Speech Pathology.
- c. The Student shall be the first author on any publication(s) resulting from her MSc thesis research, and the Academic Supervisors shall be listed as secondary authors.

2. Intellectual Property:

- a. The Student retains the intellectual property rights associated with her research work, including the right to use, reproduce, and distribute the findings for academic and non-commercial purposes.
- b. The Academic Supervisors shall have the right to use the research findings for academic and educational purposes, including incorporating them into their scholarly works, provided proper attribution is given to the student.

3. Publication and Communication:

- a. The Student agrees to keep the Academic Supervisors informed of any submissions and publications resulting from her MSc thesis research.
- b. The Academic Supervisors agree to provide feedback and guidance to the student throughout the publication process.

4. Acknowledgement:

a. The Student agrees to acknowledge the support and guidance provided by her Academic Supervisors in any publications resulting from her MSc thesis research.

5. Dispute Resolution:

In the event of any disputes arising from this Agreement, the parties agree to first attempt to resolve the matter through mutual discussion and negotiation.

Miscellaneous:

1. This Agreement represents the entire understanding between the parties concerning the subject matter hereof and supersedes all prior agreements and understandings.
2. This Agreement may be amended or modified only in writing and signed by both parties.

IN WITNESS of which, the parties hereto have executed this Authorship Agreement as of the date first written above.

Julie Tan

Post-graduate Student
School of Allied Health
Curtin University, Perth, Western Australia

Professor Deborah Hersh

Speech Pathology, School of Allied Health
Curtin University, Perth, Western Australia

Assoc. Professor Naomi Cocks

Speech Pathology, School of Allied Health
Curtin University, Perth, Western Australia

Dr Mary Claessen

Speech Pathology Australia, Melbourne, Victoria

Dr Christina Fernandes

School of Allied Health Science and Practice
Adelaide University, Adelaide, Australia

4: Group Experiential Themes and Participants' Quotes

Group Experiential Themes	Participants' Quotes by Theme
The Importance of the Team	<p>Ava <i>“Understanding how to coach, how to be part of the team rather than coming in as an expert. I don’t think I’ve ever seen an expert model work”.</i></p> <p>Charlotte <i>“SLPs are often the first port of call”,</i></p> <p>Ella <i>“link them in with other care professionals within the community because we simply cannot work alone, we do need an OT, we do need a dietitian, we do need medical expertise”.</i></p> <p>Isla <i>“a family that is supported, talks with you about what's happening, how things are going, and whether things are working or not”.</i></p> <p>Matilda <i>“not just the allied health teams, it’s the medical, it’s the family, it’s the child, it’s the school, it’s talking to the NDIS planners”.</i></p> <p>Olivia <i>“I’ll be honest with families, that I need to talk to someone or need to find something out”.</i></p> <p>Willow <i>“think about the child and the family as individuals, and that there is no cookie-cutter approach”.</i></p>
Providing safe practice	<p>Charlotte <i>“they wanted to get their child to eat and get their life back to normal”.</i></p> <p>Ella <i>“When the mother goes home, am I putting the child at risk?”.</i></p>

Matilda *"an iceberg image where feeding is at the very top, but it's so complex underneath".*

Self-care

Amelia *"having those other professionals involved, helps us, just making sure we're on the right track".*

Ava *"we use the same muscles to talk".*

Charlotte *"I did another course...it just builds on what you're seeing...you can't unsee what you've seen in those courses".*

Ella *"Professional tribe...having a tribe...it's having a complete tribe".*

Isla *"all the channels for evidence now, are not so clear cut, we've got lots of other ways that we might find out information".*

Surviving "rocky seas"

Amelia *"signposting".*

Charlotte *"The challenge is navigating where to go next and not giving up too easily".*

Chloe *"I really do like reading different people's opinions. I think sometimes it can be quite aggressively said...on some posts. But I think it's good that the debate and the conversation is happening".*

Ella *"rocky seas"*

Grace *"there's no quality control",*

Isla *“it would have been nice to come in with some kind of knowledge initially... but ...you went in blind, essentially”.*

Matilda *“I want to know, I understand that they would want to know, so I give them signposts”,*

Olivia *“having the support above me really helped me with my decision-making”.*

Willow *“I don’t think it prepared me at all”*

Barriers to support

Ava *“finding people who understand that this is part of their role”*

Amelia *“a bit of a postcode lottery”,*

Chloe *“their first plan is not as likely to have funding for PFD, unless they are tube fed, and not even when they are tube-fed”.*

Ella *“we are under-resourced and underfunded; I get GPs referring for two sessions. It takes me two sessions just to figure out what's going on”.*

Grace *“a band-aid service”.*

Isla *“organisations won't often cover costs of Professional Development. They want you doing billable hours”.*

Mia *“you'll have four different clinicians all recommending different things”.*

Olivia *“I was expected to know a lot about feeding...the bosses would come to me saying, well you should know about this, I'd say, well, I'm not sure, it's really complex”.*

Willow *“Over and over again, positions are expecting new grads to deal with really complex feeding”.*

Reference List

- Aldridge, V. K., Dovey, T. M., Martin, C. I., & Meyer, C. (2010). Identifying clinically relevant feeding problems and disorders. *Journal of Child Health Care*, 14(3), 261-270. <https://doi.org/10.1177/1367493510370456>
- Allen, R. I., & Petr, C. G. (1996). Toward developing standards and measurements for family-centered practice in family support programs. In *Redefining family support: Innovations in public-private partnerships* (pp. 57-85). Baltimore, MD, US: Paul H. Brookes Publishing Co.
- Arvedson, J. C. (2008). Assessment of pediatric dysphagia and feeding disorders: Clinical and instrumental approaches. *Developmental Disabilities Research Reviews*, 14(2), 118-127. <https://doi.org/10.1002/ddrr.170>
- Arvedson, J., Clark, H., Lazarus, C., Schooling, T., & Frymark, T. (2010). The effects of oral-motor exercises on swallowing in children: An evidence-based systematic review. *Developmental Medicine and Child Neurology*, 52(11), 1000-1013. Retrieved from <https://www.proquest.com/scholarly-journals/effects-oral-motor-exercises-on-swallowing/docview/762226625/se-2>
- Attrill, S., Foley, K., Gesesew, H. A., & Brebner, C. (2023). Allied health workforce development for participant-led services: Structures for student placements in the National Disability Insurance Scheme. *BMC Medicine*, 23(1), 95. <https://doi.org/10.1186/s12916-023-02778-4>
- Auburn, E., Gott, M., & Hoare, K. (2021). Experiences of an insider researcher - interviewing your own colleagues. *Nurse Researcher*, 29(3), 22-28. <https://doi.org/10.7748/nr.2021.e1794>
- Bailey, R. L., Stoner, J. B., Angell, M. E., & Fetzer, A. (2008). School-based speech-language pathologists' perspectives on dysphagia management in the schools. *Language*,

Speech, and Hearing Services in Schools, 39(4), 441-450.

[https://doi.org/10.1044/0161-1461\(2008/07-0041\)](https://doi.org/10.1044/0161-1461(2008/07-0041))

Baxter, R. D., Merkel-Walsh, R., Baxter, B. S., Lashley, A., & Rendell, M. R. (2020). Functional improvements of speech, feeding, and sleep after lingual frenectomy tongue-tie release: A prospective cohort study. *Journal of Clinical Pediatrics*.

<https://doi.org/10.1177/0009922820928055>.

Bazeley, P., & Jackson, K. (Eds.). (2013). *Qualitative Data Analysis with NVivo* (annotated ed.). SAGE. ISBN: 1446281418, 9781446281413

Benfer, K. A., Weir, K. A., Bell, K. L., Ware, R. S., Davies, P. S. W., & Boyd, R. N. (2014). Oropharyngeal dysphagia in preschool children with cerebral palsy: Oral phase impairments. *Research in Developmental Disabilities*, 35(12), 3469-3481.

<https://doi.org/10.1016/j.ridd.2014.08.029>

Berlin, K. S., Hobart Davies, W., Lobato, D. J., & Silverman, A. H. (2009). A biopsychosocial model of normative and problematic pediatric feeding. *Children's Health Care*, 38(4), 263-282. <https://doi.org/10.1080/02739610903235984>

Bertrand, V., Tavolacci, M. P., Bargiacchi, A., Leblanc, V., Déchelotte, P., Stordeur, C., & Bellaïche, M. (2024). Analysis of feeding and eating disorders in 191 children according to psychiatric or gastroenterological recruitment: The PEDIAFED cohort study. *European Eating Disorders Review*, 32(3), 589-605. <https://doi.org/10.1002/erv.3063>

Brannick, S. F., Wolford, G. W., Wolford, L. L., Efron, K., & Buckler, J. (2022). What is clinical evidence in speech-language pathology? A scoping review. *American Journal of Speech-Language Pathology*, 31(6), 2943-2958.

https://doi.org/10.1044/2022_ajslp-22-00203

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. <https://doi.org/10.1191/1478088706qp063oa>

- Braun, V., & Clarke, V. (2021). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and Psychotherapy Research, 21*(1), 37-47.
<https://doi.org/10.1002/capr.12360>
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge, MA: Harvard University Press.
- Bryant-Waugh, R., Markham, L., Kreipe, R. E., & Walsh, B. T. (2010). Feeding and eating disorders in childhood. *International Journal of Eating Disorders, 43*(2), 98-111.
<https://doi.org/10.1002/eat.20795>.
- Bowen, M. (1978). *Family therapy in clinical practice*. NY and London: Jason Aronson.
- Burgess, A., Purdy, S., & Jackson, B. (2016). Allied health professionals' perspectives of working with dysphagia in a rural paediatric team. *The New Zealand Medical Journal, 129*(1435), 87-89. Retrieved from <https://www.proquest.com/scholarly-journals/allied-health-professionals-perspectives-working/docview/1793543542/se-2?accountid=10382>
- Carter, B., Simons, J., Bray, L., & Arnott, J. (2016). Navigating uncertainty: Health professionals' knowledge, skill, and confidence in assessing and managing pain in children with profound cognitive impairment. *Pain Research & Management: The Journal of the Canadian Pain Society*. <https://doi.org/10.1155/2016/8617182>
- Cayley, W. E. (2023). Expecting uncertainty. *Family Medicine, 55*(5), 286-288.
<https://doi.org/10.22454/FamMed>
- Chilman L, Kennedy-Behr A, Frakking T, Swanepoel L, Verdonck M. Picky Eating in Children: A Scoping Review to Examine Its Intrinsic and Extrinsic Features and How They Relate to Identification. *International Journal of Environmental Research and*

- Public Health*. 2021 Aug 27;18(17):9067. [https://doi: 10.3390/ijerph18179067](https://doi.org/10.3390/ijerph18179067).
PMID: 34501656; PMCID: PMC8431657.
- Cockerill, H., van den Engel-Hoek, L., & Harding, C. (2016). Assessing children's swallowing: Parent and professional perceptions. *Tizard Learning Disability Review*, 21(3), 117-125. <https://doi.org/10.1108/TLDR-08-2015-0033>
- Commonwealth of Australia. (2013). *National Disability Insurance Scheme Act 2013*. Canberra: Australian Government. <https://www.legislation.gov.au/Details/C2012B00230>
- Commonwealth of Australia. (2019). *National Disability Insurance Agency. Corporate plan 2019*. <https://www.ndis.gov.au/about-us/publications/corporate-plan>
- Cooke, G., Tapley, A., Holliday, E., Morgan, S., Henderson, K., Ball, J., van Driel, M., Spike, N., Kerr, R., & Magin, P. (2017). Responses to clinical uncertainty in Australian general practice trainees: A cross-sectional analysis. *Medical Education*, 51, 1277-1288. <https://doi.org/10.1111/medu.13408>
- Cortese, C., Truscott, F., Nikidehaghani, M., & Chapple, S. (2020). Hard-to-reach: the NDIS, disability, and socio-economic disadvantage. *Disability & Society*, 36(6), 883–903. <https://doi.org/10.1080/09687599.2020.1782173>
- Cowpe, E., Hanson, B., & Smith, C. H. (2014). What do parents of children with dysphagia think about their multidisciplinary teams? A qualitative study. *British Medical Journal Open*, 4(10). <https://doi.org/10.1136/bmjopen-2014-005934>.
- Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory into Practice*, 39(3), 124-130. <http://www.jstor.org/stable/1477543>
- Crist, W., & Napier-Phillips, A. (2001). Mealtime behaviors of young children: A comparison of normative and clinical data. *Journal of Developmental and Behavioral Pediatrics*, 22(5), 279-286. <https://doi.org/10.1097/00004703-200110000-00001>

- Davies, W. H., Satter, E., Berlin, K. S., Sato, A. F., Silverman, A. H., Fischer, E. A., & Rudolph, C. D. (2006). Reconceptualizing feeding and feeding disorders in interpersonal context: The case for a relational disorder. *Journal of Family Psychology, 20*(3), 409-417. <https://doi.org/10.1037/0893-3200.20.3.409>
- Dempsey, I., Keen, D., Pennell, D., O'Reilly, J., & Neilands, J. (2009). Parent stress, parenting competence and family-centred support to young children with an intellectual or developmental disability. *Research in Developmental Disabilities, 30*(3), 558-566. <https://doi.org/10.1016/j.ridd.2008.08.005>
- Dollaghan, C. A. (2007). *The handbook for evidence-based practice in communication disorders*. Brookes.
- Dong, Z., Ye, J., Xiao, M., & You, H. (2023). Ineffectiveness of watchful waiting on mouth breathing in children with obstructive sleep apnea. *Cranio: The Journal of Cranio-mandibular & Sleep Practice, 22*(1-8). <https://doi.org/10.1080/08869634.2023.2180984>
- Dovey, T. M., Isherwood, E., Aldridge, V. K., & Martin, C. I. (2010). Typology of feeding disorders based on a single assessment system. *ICAN: Infant, Child, & Adolescent Nutrition, 2*(1), 52-61. <https://doi.org/10.1177/1941406409360038>
- Dunst, C. J., Trivette, C. M., & Hamby, D. W. (2007). Meta-analysis of family-centered helping practices research. *Mental Retardation and Developmental Disabilities Research Reviews, 13*(4), 370-378. <https://doi.org/10.1002/mrdd.20176>
- Elliot, C., Hopwood, N., Moraby, K., Crockett, N., Wright, S., Vanos, K., Furey, K., Hammond, A., Handley, S., Dalby-Payne, J., Dadich, A., Gottschalk, B., Ooi, C. Y., & Woolfenden, S. (2024). New consensus definition on defining and measuring care for children with paediatric feeding disorder. *Journal of Paediatrics and Child Health, 60*(2-3), 58-66. <https://doi.org/10.1111/jpc.16534>

- Engel, G. L. (1982). The biopsychosocial model and medical education. *New England Journal of Medicine*, 306(13), 802-805. <https://doi.org/10.1056/nejm198204013061311>
- Estrem, H. H., Pados, B., Thoyre, S., Knafl, K., McComish, C., & Park, J. (2016). Concept of pediatric feeding problems from the parent perspective. *MCN: The American Journal of Maternal/Child Nursing*, 41(4), 212-220.
<https://doi.org/10.1097/NMC.0000000000000249>
- Estrem, H. H., Thoyre, S. M., Knafl, K. A., Frisk Pados, B., & Van Riper, M. (2018). "It's a Long-Term Process": Description of Daily Family Life When a Child Has a Feeding Disorder. *Journal of Pediatric Health Care: official publication of National Association of Pediatric Nurse Associates & Practitioners*, 32(4), 340–347.
<https://doi.org/10.1016/j.pedhc.2017.12.002>
- Estrem, H. H., Park, J., Thoyre, S., McComish, C., & McGlothen-Bell, K. (2022). Mapping the gaps: A scoping review of research on pediatric feeding disorder. *Clinical Nutrition ESPEN*, 48, 45-55. <https://doi.org/10.1016/j.clnesp.2021.12.028>
- Evans, L., & Trotter, D. R. (2009). Epistemology and uncertainty in primary care: An exploratory study. *Family Medicine*, 41(5), 319-326. PMID: 19418279.
- Feeding Matters. (2019). Economic impact study. *Feeding Matters*. <https://www.feedingmatters.org/economic-impact-study>
- Feeding Matters. (2024). The history of PFD. *Feeding Matters*. <https://www.feedingmatters.org/the-history-of-pfd/>
- Felicetti, C., Richardson, K., & Mansolillo, A. (2020). Dysphagia management in schools: A survey of speech-language pathologists. *Perspectives of the ASHA Special Interest Groups*, 5(3), 582-591. https://doi.org/10.1044/2020_PERSP-19-00091
- Finch, E., Ward, E. C., Brown, B., Cornwell, P., Hill, A. E., Hill, A., Hobson, T., Rose, T., Scarinci, N., Marshall, J., Cameron, A., & Shrubsole, K. (2021). Setting a prioritized

agenda to drive speech-language therapy research in health. *International Journal of Language & Communication Disorders*, 56(4), 768-783.

<https://doi.org/10.1111/1460-6984.12626>

Fischhoff, J., Whitten, C. F., & Pettit, M. G. (1971). A psychiatric study of mothers of infants with growth failure secondary to maternal deprivation. *The Journal of Pediatrics*, 79(2), 209-215. [https://doi.org/10.1016/S0022-3476\(71\)80103-8](https://doi.org/10.1016/S0022-3476(71)80103-8)

Fisher, M., Freeman, T., Mackean, T., Friel, S., & Baum, F. (2020). Universal health coverage for non-communicable diseases and health equity: Lessons from Australian primary healthcare. *International Journal of Health Policy and Management*, 11(5), 690-700. <https://doi.org/10.34172/ijhpm.2020.232>

Forstner, J., & Arnold, C. (2023). Continuity of care: New approaches to a classic topic of health services research. In M. Wensing & C. Ullrich (Eds.), *Foundations of Health Services Research* (pp. 21-35). Springer, Cham. https://doi.org/10.1007/978-3-031-29998-8_21

Gadamer, H. G. (1996). *Truth and method* (2nd rev. ed.). Sheed and Ward. (Original work published 1975)

Galai, T., Friedman, G., Kalamitzky, N., Shemer, K., Gal, D. L., Yerushalmy-Feler Feler, A., Lubetzky, R., Cohen, S., & Moran Lev, H. (2023). Pediatric feeding disorders among children with parental history of feeding disorders: A distinct group of patients with unique characteristics. *European Journal of Pediatrics*, 182, 3671-3677. <https://doi.org/10.1007/s00431-023-05038-5>

Galai, T., Friedman, G., & Moses, M. (2022). Demographic and clinical parameters are comparable across different types of pediatric feeding disorder. *Scientific Reports*, 12, 8596. <https://doi.org/10.1038/s41598-022-12562-1>

- Gavidia-Payne, S. Implementation of Australia's National Disability Insurance Scheme: Experiences of Families of Young Children With Disabilities. *Infants & Young Children* 33(3):p 184-194, July/September 2020. | DOI: 10.1097/IYC.000000000000169
- Gibbs, L. (2007). What have sampling and data collection got to do with qualitative research? *Australian and New Zealand Journal of Public Health*, 31(6), 540-544.
<https://doi.org/10.1111/j.1753-6405.2007.00140.x>
- Gilroy, J., Veli-Gold, S., Wright, W., Dew, A., Jensen, H., Bulkeley, K., & Lincoln, M. (2023). Disability workforce and the NDIS planning process in regional, rural and remote regions of Australia: Scoping review. *Australian Journal of Rural Health*. Advance online publication. <https://doi.org/10.1111/ajr.13020>
- Goday, P. S., Huh, S. Y., Silverman, A., Lukens, C. T., Dodrill, P., Cohen, S. S., Delaney, A. L., Feuling, M. B., Noel, R. J., Gisel, E., Kenzer, A., Kessler, D. B., Kraus de Camargo, O., Browne, J., & Phalen, J. A. (2019). Pediatric feeding disorder: Consensus definition and conceptual framework. *Journal of Pediatric Gastroenterology and Nutrition*, 68(1), 124-129. <https://doi.org/10.1097/MPG.0000000000002188>
- Gosa, M. M., Dodrill, P., Lefton-Greif, M., & Silverman, A. (2020). A multidisciplinary approach to pediatric feeding disorders: Roles of the speech-language pathologist and behavioral psychologist. *American Journal of Speech-Language Pathology*, 29(2), 956-966. https://doi.org/10.1044/2020_AJSLP-19-00069
- Green, J., & Mears, J. (2014). The implementation of the NDIS: Who wins, who loses? *Cosmopolitan Civil Societies: An Interdisciplinary Journal*, 6(2), 25-39. <https://search.informit.org/doi/10.3316/informit.933025846543042>
- Haggerty, J. L., Roberge, D., Freeman, G. K., & Beaulieu, C. (2013). Experienced continuity of care when patients see multiple clinicians: A qualitative metasummary. *The Annals of Family Medicine*, 11(3), 262. <https://doi.org/10.1370/afm.1499>

- Han, P. K., Klein, W. J., & Arora, N. K. (2011). Varieties of uncertainty in health care: A conceptual taxonomy. *Journal of Medical Decision Making, 31*(6), 828-838.
<https://doi.org/10.1177/0272989X10393976>
- Harvey, L., Bryant-Waugh, R., Watkins, B., & Meyer, C. (2015). Parental perceptions of childhood feeding problems. *Journal of Child Health Care, 19*(3), 392-401. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/24270993>
- Heidegger, M. (1962). *Being and time*. Harper and Row.
- Hickie, I. B. (2019). The “uberisation” of mental health care: A welcome global phenomenon? *Medical Journal of Australia, 211*, 315-316. <https://doi.org/10.5694/mja2.50342>
- Higginbotham, J., & Satchidanand, A. (2019). From triangle to diamond: Recognizing and using data to inform our evidence-based practice. *ASHA Leader*. <https://academy.pubs.asha.org/2019/04/from-triangle-to-diamond-recognizing-and-using-data-to-inform-our-evidence-based-practice/>
- Hill, R. R., & Pados, B. F. (2020). Symptoms of problematic feeding in infants under 1 year of age undergoing frenotomy: A review article. *The Journal of Pediatrics, 109*(12), 2502-2514. <https://doi.org/10.1016/j.jpeds.2020.09.018>
- Hines, M., & Lincoln, M. (2016). Boosting the recruitment and retention of new graduate speech-language pathologists for the disability workforce. *Journal of Clinical Practice in Speech-Language Pathology, 18*(2), 50-54.
- Howells, S. R., Cornwell, P. L., Ward, E. C., & Kuipers, P. (2019). Understanding dysphagia care in the community setting. *Dysphagia, 34*(5), 681-691.
<https://doi.org/10.1007/s00455-018-09971-8>
- Hutchins, T. L., Gerety, K. W., & Mulligan, M. (2011). Dysphagia management: A survey of school-based speech-language pathologists in Vermont. *Language, Speech, and*

Hearing Services in Schools, 42(2), 194-206. [https://doi.org/10.1044/0161-1461\(2011/10-0057\)](https://doi.org/10.1044/0161-1461(2011/10-0057))

Jackson, B. N., Turner, L. A. T., Kevany, G. L., & Purdy, S. C. (2021). Five years of avoidant/restrictive food intake disorder: No consensus of understanding among health professionals in New Zealand. *Speech, Language and Hearing*, 1-9. <https://doi.org/10.1080/2050571X.2021.1926620>

Jeyendra, A., Rajadurai, J., Chanmugam, J., Trieu, A., Nair, S., & Schmied, V. (2013). Australian general practitioners' perspectives on their role in well-child care. *BMC Family Practice*, 14, 2. <https://doi.org/10.1186/1471-2296-14-2>

Johnston, J. L., & Bennett, D. (2019). Lost in translation? Paradigm conflict at the primary–secondary care interface. *Medical Education*, 53(1), 56-63. <https://doi.org/10.1111/medu.13758>

Johnson, S., Matthews, R., Draper, E., Field, D. J., Manktelow, B. N., Marlow, N., Smith, L. K., & Boyle, E. M. (2016). Eating difficulties in children born late and moderately preterm at 2 y of age: A prospective population-based cohort study. *American Journal of Clinical Nutrition*, 103(2), 406–414. <https://doi.org/10.3945/ajcn.115.121061>

Jones, E., Southwood, H., Cook, C., & Nicholson, T. (2020). Insights into paediatric tube feeding dependence: A Speech-language pathology perspective. *International Journal of Speech-Language Pathology*, 22(3), 327–337. <https://doi.org/10.1080/17549507.2020.1754910>

Jones, A., Wilson, I., McClean, S., Kerr, D., & Breen, C. (2022). Review of Education: An international journal of major studies in education. *Review of Education*, 10(2), e3364. <https://doi.org/10.1002/rev3.3364>

Jordan, Z., Lockwood, C., Munn, Z., & Aromataris, E. (2019). The updated Joanna Briggs Institute Model of Evidence-Based Healthcare. *International Journal of Evidenced*

Based Healthcare, 17(1), 58-71. <https://doi.org/10.1097/XEB.0000000000000155>.

PMID: 30256247

Kedesdy, J. H., & Budd, K. S. (1998). Feeding disorders in infants and children. *Journal of Infant Mental Health*, 19(3), 290–297.

Kokorelias, K. M., Gignac, M. A. M., Naglie, G., & Cameron, J. I. (2019). Towards a universal model of family centered care: A scoping review. *BMC Health Services Research*, 19(1), 564. <https://doi.org/10.1186/s12913-019-4394-5>

Kovacic, K., Rein, L. E., Szabo, A., Kommareddy, S., Bhagavatula, P., & Goday, P. S.

(2021). Pediatric Feeding Disorder: A Nationwide Prevalence Study. *The Journal of Pediatrics*, 228, 126-131.e3. <https://doi.org/10.1016/j.jpeds.2020.07.047>

Krom, H., de Winter, J. P., & Kindermann, A. (2017). Development, prevention, and treatment of feeding tube dependency. *European Journal of Pediatrics*, 176(6), 683-688. <https://doi.org/10.1007/s00431-017-2908-x>

Kyzar, K. B., Turnbull, A. P., Summers, J. A., & Gómez, V. A. (2012). The relationship of family support to family outcomes: A synthesis of key findings from research on severe disability. *Research and Practice for Persons with Severe Disabilities*, 37(1), 31–44. <https://doi.org/10.2511/027494812800903247>

LaMantia, A. S., Moody, S. A., Maynard, T. M., Karpinski, B. A., Zohn, I. E., Mendelowitz, D., Lee, N. H., & Popratiloff, A. (2016). Hard to swallow: Developmental biological insights into pediatric dysphagia. *Developmental Biology*, 409(2), 329-342.

<https://doi.org/10.1016/j.ydbio.2015.11.011>

Lamm, K., Kristensson Hallström, I., & Landgren, K. (2023). Parents' experiences of living with a child with Paediatric Feeding Disorder: An interview study in Sweden. *Scandinavian journal of caring sciences*, 37(4), 949–958. <https://doi.org/10.1111/scs.13070>

- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, 3(2), 102-120.
<https://doi.org/10.1191/1478088706qp062oa>
- Lazard, L., & McAvoy, J. (2020). Doing reflexivity in psychological research: What's the point? What's the practice? *Qualitative Research in Psychology*, 17(2), 159–177.
<https://doi.org/10.1080/14780887.2017.1400144>
- Lefton-Greif, M. A., & Arvedson, J. C. (2016). Pediatric feeding/swallowing: Yesterday, today, and tomorrow. In *Seminars in Speech and Language*, 37(4), 298-309. Thieme Medical Publishers. <https://doi.org/10.1055/s-0036-1587702>
- Lefton-Greif, M. A., Okelo, S. O., Wright, J. M., Collaco, J. M., McGrath-Morrow, S. A., & Eakin, M. N. (2014). Impact of children’s feeding/swallowing problems: Validation of a new caregiver instrument. *Dysphagia*, 29(6), 671-677.
<https://doi.org/10.1007/s00455-014-9560-7>
- Levitt, H. M., Bamberg, M., Creswell, J. W., Frost, D. M., Josselson, R., & Suárez-Orozco, C. (2018). Journal article reporting standards for qualitative primary, qualitative meta-analytic, and mixed methods research in psychology. *American Psychologist*, 73(1), 26-46. <https://doi.org/10.1037/amp0000151>
- Liamputtong, P. (2013). *Research methods in health: Foundations for evidence-based practice* (2nd ed.). South Melbourne, Vic.: Oxford University Press.
- Lukens, C. T., & Silverman, A. H. (2014). Systematic review of psychological interventions for pediatric feeding problems. *Journal of Pediatric Psychology*, 39(8), 903–917.
<https://doi.org/10.1093/jpepsy/jsu040>
- McKenzie, K., & Smith-Merry, J. (2023). Responding to complexity in the context of the national disability insurance scheme. *Social Policy and Society*, 22(1), 139-154.
<https://doi.org/10.1017/S1474746422000562>

- Manikam, R. P., & Jay, A. (2000). Pediatric feeding disorders. *Journal of Clinical Gastroenterology*, *30*(1), 34-46. <https://doi.org/10.1097/00004836-200001000-00009>
- Marshall, J., Ware, R., Ziviani, J., Hill, R. J., & Dodrill, P. (2015). Efficacy of interventions to improve feeding difficulties in children with autism spectrum disorders: A systematic review and meta-analysis. *Child: Care, Health and Development*, *41*(2), 278-302. <https://doi.org/10.1111/cch.12157>
- Marshall, J., Hill, R. J., Ware, R. S., Ziviani, J., & Dodrill, P. (2016). Clinical characteristics of 2 groups of children with feeding difficulties. *Journal of Pediatric Gastroenterology and Nutrition*, *62*, 161-168. <https://doi.org/10.1097/MPG.0000000000000914>
- Martins, Y., Young, R. L., & Robson, D. C. (2008). Feeding and eating behaviors in children with autism and typically developing children. *Journal of Autism and Developmental Disorders*, *38*(10), 1878-1887. <https://doi.org/10.1007/s10803-008-0583-5>
- Mays, N., & Pope, C. (2000). Qualitative research in health care. Assessing quality in qualitative research. *British Medical Journal*, *320*(1), 50-52. <https://doi.org/10.1136/bmj.320.7226.50>
- McKenzie, K., & Smith-Merry, J. (2023). Responding to complexity in the context of the national disability insurance scheme. *Social Policy and Society*, *22*(1), 139-154. <https://doi.org/10.1017/S1474746422000562>
- Mehta, N. M., Corkins, M. R., Lyman, B., Malone, A., Goday, P. S., Carney, L. N., Monczka, J. L., Plogsted, S. W., & Schwenk, F. (2013). Defining pediatric malnutrition: A paradigm shift toward etiology-related definitions. *Journal of Parenteral Enteral Nutrition*, *37*, 460-481. <https://doi.org/10.1177/0148607113479972>
- Miles, M. B., Huberman, A. M., & Saldana, J. (2014). *Qualitative data analysis: A methods sourcebook* (3rd ed.). Thousand Oaks, CA: Sage.

- Modi, N., & Ross, E. (2000). The current practices, training and concerns of a group of hospital-based speech therapists working in the area of dysphagia. *South African Journal of Communication Disorders*, 47(1), 3-14. <https://doi.org/10.4102/sajcd.v47i1.217>
- Needham, C. (2013). The boundaries of budgets: Why should individuals make spending choices about their health and social care? In J. Butcher & D. Gilchrist (Eds.), *The Three Sector Solution: Delivering Public Policy in Collaboration with Not-for-profits and Business* (pp. 319-336). Australia: ANU Press.
<https://doi.org/10.22459/TSS.07.2016.15>
- Neely-Barnes, S. L., & Dia, D. A. (2008). Families of children with disabilities: A review of literature and recommendations for interventions. *Journal of Early and Intensive Behavior Intervention*, 5(3), 93–107. <https://doi.org/10.1037/h0100425>
- Nelson, K. E., Lacombe-Duncan, A., Cohen, E., Nicholas, D. B., Rosella, L. C., Guttman, A., & Mahant, S. (2015). Family experiences with feeding tubes in neurologic impairment: A systematic review. *Pediatrics*, 136(1), 140-151.
<https://doi.org/10.1542/peds.2014-4162>
- Nickless, T., Davidson, B., Finch, S., Gold, L., & Dowell, R. (2024). Aligned or misaligned: Are public funding models for speech-language pathology reflecting recommended evidence? An exploratory survey of Australian speech-language pathologists. *Health Policy OPEN*, 6, 100117. <https://doi.org/10.1016/j.hopen.2024.100117>
- Nickless, T., Gold, L., Dowell, R., & Davidson, B. (2023). Public purse, private service: The perceptions of public funding models of Australian independent speech-language pathologists. *International Journal of Speech-Language Pathology*, 25(3), 462–478.
<https://doi.org/10.1080/17549507.2023.2213864>

- Nizza, I., Farr, J., & Smith, J. A. (2021). Achieving excellence in interpretative phenomenological analysis (IPA): Four markers of high quality. *Qualitative Research in Psychology, 18*(3), 369-386. <https://doi.org/10.1080/14780887.2020.1854404>
- Noel, R. J. (2023). Avoidant restrictive food intake disorder and pediatric feeding disorder: The pediatric gastroenterology perspective. *Current Opinion in Pediatrics, 35*(5), 566-573. <https://doi.org/10.1097/MOP.0000000000001267>
- Norman, V., Zühlke, L., & Morrow, B. (2024). Care burden and support needs of caregivers of infants and children with CHDs and dysphagia. *Cardiology in the Young*. Advance online publication. <https://doi.org/10.1017/S1047951124000271>
- O'Donoghue, C. R., & Dean-Claytor, A. (2008). Training and self-reported confidence for dysphagia management among speech-language pathologists in the schools. *Language, Speech, and Hearing Services in Schools, 39*(2), 192-198. [https://doi.org/10.1044/0161-1461\(2008/019\)](https://doi.org/10.1044/0161-1461(2008/019))
- Okada, J., Wilson, E., Wong, J., Luo, M., Fiechtner, L., & Simione, M. (2022). Financial impacts and community resources utilization of children with feeding difficulties. *BMC Pediatrics, 22*(1), 508. <https://doi.org/10.1186/s12887-022-03566-x>
- O'Riordan, M., Dahinden, A., Aktürk, Z., Ortiz, J. M. B., Dagdeviren, N., Elwyn, G., & Thesen, J. (2011). Dealing with uncertainty in general practice: An essential skill for the general practitioner. *Quality in Primary Care, 19*(3), 175-181. <https://doi.org/10.12968/eqpc.2011.19.3.175>
- Pados, B.F., Hill, R.R., Yamasaki, J.T., Litt, J.S., Lee, C.S. (2021). Prevalence of problematic feeding in young children born prematurely: a meta-analysis. *BMC Pediatric Mar* 6;21(1):110. [https://doi: 10.1186/s12887-021-02574-7](https://doi:10.1186/s12887-021-02574-7).
- Pedron-Giner, C., Calderon, C., Martinez-Costa, C., Borraz-Gracia, S., & Gomez-Lopez, L. (2014). Factors predicting distress among parents/caregivers of children with

- neurological disease and home enteral nutrition. *Child: Care, Health and Development*, 40(3), 389-397. <https://doi.org/10.1111/cch.12038>
- Pereira, M. B. B., Pereira, V. B. P., Pereira, V. G. F., Paula, V. M. B., Caetano, A. P. F., & Amaral, W. N. (2022). Randomized trial of a photography-aided behavioural intervention to reduce risk factors for caries and malocclusion in high-risk infants. *International Journal of Dental Hygiene*, 20(3), 471-478. <https://doi.org/10.1111/idh.12507>
- Piazza, C. C., Fisher, W. W., Brown, K. A., Shore, B. A., Patel, M. R., Katz, R. M., & Blakely-Smith, A. (2003). Functional analysis of inappropriate mealtime behaviors. *Journal of Applied Behavior Analysis*, 36(2), 187-204. <https://doi.org/10.1901/jaba.2003.36-187>
- Pringle, J., Drummond, J., McLafferty, E., & Hendry, C. (2011). Interpretative phenomenological analysis: A discussion and critique. *Nurse Researcher*, 18(3), 20-24. <https://doi.org/10.7748/nr2011.04.18.3.20.c8459>
- Proctor, K. B., Mansoura, M., Rodrick, E., Volkert, V., Sharp, W. G., & Kindler, J. M. (2024). The relationship between food selectivity and stature in pediatric patients with avoidant-restrictive food intake disorder – An electronic medical record review. *Journal of Eating Disorders*, 12, 64. <https://doi.org/10.1186/s40337-024-01020-0>
- Psaila, K., Schmied, V., Fowler, C., & Kruske, S. (2014). Discontinuities between maternity and child family health services: Health professional's perceptions. *BMC Health Services Research*, 14, 4-12. <https://doi.org/10.1186/1472-6963-14-4>
- Raatz, M., Marshall, J., Ward, E. C., Dickinson, C., Frederiksen, N., Reilly, C., & Fernando, S. (2023). Understanding training needs in pediatric feeding for allied health professionals: An Australian perspective. *American Journal of Speech-Language Pathology*, 32(2), 452-468. https://pubs.asha.org/doi/abs/10.1044/2022_AJSLP-22-00232

- Rangarathnam, A., & Desai, R. (2021). A preliminary survey of dysphagia practice patterns among speech-language pathologists in India. *Journal of Indian Speech Language & Hearing Association*, 34(2), 259-272. https://doi.org/10.4103/jisha.JISHA_20_19
- Reibling, N., & Wendt, C. (2012). Gatekeeping and provider choice in OECD healthcare systems. *Current Sociology*, 60(4), 489-505. <https://doi.org/10.1177/0011392112438333>
- Reilly, S., Oates, J., & Douglas, J. (2004). *Evidence-based practice in speech pathology*. London: Whurr.
- Robey, R. R., & Schultz, M. C. (1998). A model for conducting clinical-outcome research: An adaptation of the standard protocol for use in aphasiology. *Aphasiology*, 12(9), 787-810. <https://doi.org/10.1080/02687039808249567>
- Robinson, O. C. (2014). Sampling in interview-based qualitative research: A theoretical and practical guide. *Qualitative Research in Psychology*, 11(1), 25-41. <https://doi.org/10.1080/14780887.2013.801543>
- Rosen, R. (2021). Prevalence of feeding disorders: A tough reality to swallow. *The Journal of Pediatrics*, 228, 13-14. <https://doi.org/10.1016/j.jpeds.2020.08.070>
- Rumbach, A., Coombes, C., & Doeltgen, S. (2018). A survey of Australian dysphagia practice patterns. *Dysphagia*, 33(2), 216–226. <https://doi.org/10.1007/s00455-017-9849-4>
- Saldana, J. (2016). *The coding manual for qualitative researchers* (3rd ed.). SAGE Publications. <https://doi.org/10.4135/978152971049>
- Samara, M., Johnson, S., Lamberts, K., Marlow, N., & Wolke, D. (2010). Eating problems at age 6 years in a whole population sample of extremely preterm children. *Developmental Medicine & Child Neurology*, 52, 16–22. <https://doi.org/10.1111/j.1469-8749.2009.03512.x>
- Schalock, R. L., Luckasson, R., & Tassé, M. J. (2021). An overview of intellectual disability: Definition, diagnosis, classification, and systems of supports (12th ed.). *American*

Journal of Intellectual Developmental Disability, 126(6), 439-442.

<https://doi.org/10.1352/1944-7558-126.6.439>

Sharp, W. G., Volkert, V. M., Scahill, L., McCracken, C. E., & McElhanon, B. (2017). A systematic review and meta-analysis of intensive multidisciplinary intervention for pediatric feeding disorders: How standard is the standard of care? *The Journal of Pediatrics*, 181(Supplement C), 116-124.e114. <https://doi.org/10.1016/j.jpeds.2016.10.002>

Sharp, W., Silverman, A., Arvedson, J., Bandstra, N., Clawson, E., Berry, R., McElhanon, B., Kozlowski, A., Katz, M., Volkert, V., Goday, P., & Lukens, C. (2022). Toward better understanding of pediatric feeding disorder: A proposed framework for patient characterization. *Journal of Pediatric Gastroenterology and Nutrition*, 75(3), 351-355. <https://doi.org/10.1097/MPG.0000000000003519>

Shields, B., Wacogne, I., & Wright, C. M. (2012). Weight faltering and failure to thrive in infancy and early childhood. *British Medical Journal*, 345, 1-7. <https://doi.org/10.1136/bmj.e5931>

Silverman, A.H., Erato, G., Goday, P. (2021) The relationship between chronic paediatric feeding disorders and caregiver stress. *Journal of Child Health Care*. Mar;25(1):69-80.[https://doi: 10.1177/1367493520905381](https://doi:10.1177/1367493520905381).

Smith, J. A. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review*, 5(1), 9-27. <https://doi.org/10.1080/17437199.2010.510659>

Smith, J. A., & Nizza, I. E. (2022). *Essentials of interpretative phenomenological analysis*. American Psychological Association. <https://doi.org/10.1037/0000259-000>

Smith, J. A., & Osborn, M. (2007). Pain as an assault on the self: An interpretative phenomenological analysis of the psychological impact of chronic benign low back pain. *Psychology & Health*, 22(5), 517–534. <https://doi.org/10.1080/14768320600941756>

- Smith-Merry, J. N., Hancock, A., Bresnan, I., Yen, J., Gilroy, G., & Llewellyn, G. (2018). Mind the gap: The National Disability Insurance Scheme and psychosocial disability. Final report: Stakeholder identified gaps and solutions. University of Sydney: Lidcombe.
- Speech Pathology Australia. (2020). *Professional standards for speech pathologists in Australia*. <https://www.speechpathologyaustralia.org.au/Members/libraryviewer?ResourceID=409>
- Speech Pathology Australia. (2012). *Dysphagia position paper* (Publication No. SPA PP-2012-001). Speech Pathology Australia. <https://www.speechpathologyaustralia.org.au/Members/libraryviewer?ResourceID=125>
- Speyer, R., Cordier, R., Sutt, A. L., Remijn, L., Heijnen, B. J., Balaguer, M., Pommée, T., McInerney, M., & Bergström, L. (2022). Behavioural interventions in people with oropharyngeal dysphagia: A systematic review and meta-analysis of randomised clinical trials. *Journal of Clinical Medicine*, *11*(3), 685. <https://doi.org/10.3390/jcm11030685>
- Spitz, R. A. (1945). Hospitalism: An inquiry into the genesis of psychiatric conditions in early childhood. *The Psychoanalytic Study of the Child*, *1*, 53-74.
- Silverman, A. H., Erato, G., & Goday, P. (2021). The relationship between chronic paediatric feeding disorders and caregiver stress. *Journal of Child Health Care*, *25*(1), 69-80. <https://doi.org/10.1177/1367493520905381>
- Siktberg, L. L., & Bantz, D. L. (1999). Management of children with swallowing disorders. *Journal of Pediatric Health Care*, *13*(5), 223-229. [https://doi.org/10.1016/S0891-5245\(99\)90003-2](https://doi.org/10.1016/S0891-5245(99)90003-2)
- Simione, M., Dartley, A. N., Cooper-Vince, C., Martin, V., Hartnick, C., Taveras, E. M., & Fiechtner, L. (2020). Family-centered Outcomes that Matter Most to Parents. *Journal*

of Pediatric Gastroenterology and Nutrition., 71(2), 270–275.

<https://doi.org/10.1097/MPG.0000000000002741>

- Tan, J., Cocks, N., & Claessen, M. (2021). Mothers' perspectives of support for their child, diagnosed with feeding/swallowing disorders. *Journal of Speech, Language and Hearing*, 25(1), 17–28. <https://doi.org/10.1080/2050571X.2021.1904734>
- Tan, J., Hersh, D., Claessen, M., Fernandes, C., & Cocks, N. (2024). A Band-Aid service: Speech-Language Pathologists' Perspectives on the challenges they face to support Children with PFD and Their Families [Manuscript currently under review].
- Taylor, J. (2011). The intimate insider: Negotiating the ethics of friendship when doing insider research. *Qualitative research*, 11(1), 3-22.
<https://doi.org/10.1177/1468794110384447>
- Teoh, H. J., & Darvell, M. (2021). Reducing paediatric outpatient waitlists: A proposed allied health multidisciplinary approach. *Open Journal of Preventive Medicine*, 11, 63-70.
<https://doi.org/10.4236/ojpm.2021.112006>
- Thompson, K.L., Romeo, C., Estrem, H.H., Pederson, J., Peterson, M., Delaney, A.L., Ra-
baey, P., Sharp, W.G. (2024). Preparedness of Speech Language Pathologists and Oc-
cupational Therapists to Treat Pediatric Feeding Disorder: A Cross-Sectional Sur-
vey. *Dysphagia*, 1-13 <https://doi.org/10.1007/s00455-024-10718-x>
- Tracy, S. J. (2010). Qualitative quality: Eight “big-tent” criteria for excellent qualitative re-
search. *Qualitative Inquiry*, 16(10), 837-851.
<https://doi.org/10.1177/1077800410383121>
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative re-
search (COREQ): A 32-item checklist for interviews and focus groups. *International
Journal for Quality in Health Care*, 19(6), 349-357.
<https://doi.org/10.1093/intqhc/mzm042>

- Tower, K. D. (1994). Consumer-centered social work practice: Restoring client self-determination. *Social Work, 39*(2), 191–196. <http://www.jstor.org/stable/23717208>
- Turner, P. (2018). The changing landscape of healthcare. In *Talent Management in Healthcare*. Palgrave Macmillan, Cham. https://doi.org/10.1007/978-3-319-57888-0_2
- Voniati, L., Papaleontiou, A., & Georgiou, R. (2021). The effectiveness of oral sensorimotor intervention in children with feeding disorders. *Current Developmental Disorder Report, 8*, 201–211. <https://doi.org/10.1007/s40474-021-00236-y>
- Wade, D. T., & Halligan, P. W. (2017). The biopsychosocial model of illness: A model whose time has come. *Clinical Rehabilitation, 31*(8), 995-1004. <https://doi.org/10.1177/0269215517709890>
- World Health Organization. (2007). *International Classification of Functioning, Disability, and Health: Children and Youth Version: ICF-CY*. World Health Organization. <https://www.who.int/classifications/icf/en/357>
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health, 15*(2), 215–228. <https://doi.org/10.1080/08870440008400302>
- Zickgraf, H., & Mayes, S. D. (2018). Psychological, health, and demographic correlates of atypical eating behaviors in children with autism. *Journal of Developmental and Physical Disabilities, 31*(3), 399–418. <https://doi.org/10.1007/s10882-018-9645-6>

“Every reasonable effort has been made to acknowledge the owners of copyright material. I would be pleased to hear from any copyright owner who has been omitted or incorrectly acknowledged.”

