Examining health care practices for young children with complex feeding difficulties and their families: What's the problem represented to be?

By

Sandra Mortimer

Thesis
Submitted to Flinders University
for the degree of

Doctor of Public Health

College of Medicine and Public Health
28 September 2021

TABLE OF CONTENTS

Abstract vi
Declaration ix
Acknowledgements x
Conference Presentations and Dissemination of Research xii
List of Figures xiv
List of Tables xv
Terminology and Abbreviations xvi
Chapter 1 Introduction 1
  1.1 Introduction 1
  1.2 Rationale for this study 1
  1.3 Background 4
    1.3.1 Complex feeding difficulties 5
    1.3.2 Health care context 6
  1.4 Research significance 9
  1.5 Structure of the thesis 10
Chapter 2 Literature Review 13
  2.1 Introduction 13
  2.2 Narrative review process 13
  2.3 Existing approaches to complex feeding difficulties 15
    2.3.1 Biomedical 16
    2.3.2 Biopsychosocial 16
    2.3.3 Relational 17
    2.3.4 Behavioural 17
  2.4 Constructions of complex feeding difficulties in existing literature 18
    2.4.1 Feeding vs eating and their establishment 18
    2.4.2 Feeding difficulties 20
    2.4.3 Feeding disorders 21
    2.4.4 Prevalence, cause and presentation 22
  2.5 Significance of caring and gender roles 25
    2.5.1 Impacts on carers 25
    2.5.2 The role of gender 28
  2.6 Constructions of best practice approaches to complex feeding difficulties 29
    2.6.1 Multidisciplinary teams 29
    2.6.2 Intervention environments 31
    2.6.3 Intensive versus weekly therapy 31
    2.6.4 Intervention approaches 32

2.6.5 Behavioural approaches 32
2.6.6 Involvement of carers 33
2.7 Summary of findings 36
2.8 Conclusion 37
Chapter 3 Methodology 39
3.1 Introduction 39
3.2 Rationale for approach 39
3.2.1 Methodological implications 41
3.3 What's the problem represented to be? approach 42
3.4 Relevance to clinical setting 43
3.5 Sample 44
3.6 Site location 50
3.7 Position of researcher 50
3.8 Research design 53
3.9 Methods 56
3.10 Data analysis and synthesis 62
3.11 Ethical considerations 67
3.12 Trustworthiness 67
3.13 Conclusion 68
Chapter 4 What's the Problem of Complex Feeding Difficulties Represented to be in the Clinical Practices of the Paediatric Feeding Assessment Team? 70
4.1 Introduction 70
4.2 Document analysis 70
4.3 Results of document data analysis: What's the problem represented to be? 71
4.3.1 Question 1: What's the problem of young children's complex feeding difficulties represented to be in the clinical practices of the Paediatric Feeding Assessment Service through the documents they have developed? 71
4.3.2 Question 2: What presuppositions or assumptions underlie this problem representation? 72
4.3.3 Question 3: How has this representation of the problem come about? 73
4.3.4 Question 4: What is left unproblematic in this problem representation? Where are the silences? Can the problem be thought about differently? 76
4.3.5 Question 5: What effects (discursive, subjectification, lived) are produced by this representation of the problem? 77
4.3.6 Question 6: How/where has this representation of the problem been produced, disseminated, and defended? How could it be questioned, disrupted and replaced? 78
4.4 Results of clinician interview data set analysis: What's the problem represented to be? 79

4.4.1 Question 1: What's the problem of young children's complex feeding difficulties represented to be in the clinical practices of the Paediatric Feeding Assessment Service through their interviews? 79
4.4.2 Question 2: What presuppositions or assumptions underlie this problem representation?....84
4.4.3 Question 3: How has this representation of the problem come about? 85
4.4.4 Question 4: What is left unproblematic in this problem representation? Where are the silences? Can the problem be thought about differently? 86
4.4.5 Question 5: What effects (discursive, subjectification, lived) are produced by this representation of the problem? 88
4.4.6 Question 6: How/where has this representation of the problem been produced, disseminated, and defended? How could it be questioned, disrupted and replaced?....89
4.5 Integrated analysis results: Clinician responses - What's the problem represented to be? 91
4.6 Conclusion 92
Chapter 5 How is this Problem Representation Experienced by the Carers? 94
5.1 Introduction....94
5.2 Results of carer data set analysis: What's the problem represented to be?....94
5.2.1 Question 1: How is this problem representation experienced by the carers attending the Paediatric Feeding Assessment Service?....94
5.2.2 Question 2: What presuppositions or assumptions underlie carers' experience of this problem representation?....97
5.2.3 Question 3: How has this representation of the problem come about? 100
5.2.4 Question 4: What is left unproblematic in this problem representation? Where are the silences? Can the problem be thought about differently? 100
5.2.5 Question 5: What effects (discursive, subjectification, lived) are produced by this representation of the problem? 102
5.2.6 Question 6: How/where has this representation of the problem been produced, disseminated and defended? How could it be questioned, disrupted and replaced?....103
5.3 Conclusion 107
Chapter 6 Discussion: Health as Care - Clinicians' Representations and Carers' Experiences of Complex Feeding Difficulties 109
6.1 Introduction....109
6.2 Problematising and discourse analysis....109
6.3 Comparison of clinician problem representations and carers' experiences and the implications of this for service responses....110
6.3.1 Biomedical discourse 110
6.3.2 Governmentality 111
6.3.3 Clinical practices as problematisations....113
6.3.4 Cultural factors....115

6.3.5 Regulatory discourse of shame 116
6.3.6 The silence of trauma 117
6.3.7 Feeding and eating 119
6.4 Effects on service responses 119
6.5 Challenges for change and improvement 122
6.6 Health as care 123
6.6.1 Role of clinician 124
6.6.2 Role of the team 125
6.6.3 Reflective practice 127
6.6.4 Role of client 129
6.7 Conclusion 130
Chapter 7 Conclusions: Implications of the Adapted What's the Problem Represented to be Model and a Logic of Care for Clinical Research, Teaching and Practice 131
7.1 Introduction 131
7.2 A different approach 131
7.3 The adapted What's the problem represented to be? model 132
7.4 The adapted model applied to the Paediatric Feeding Assessment Service 134
7.5 Benefits of the model 138
7.5.1 Critical reflection 138
7.5.2 Teaching 139
7.6 Quality of research 141
7.7 Recommendations for further research 144
7.8 Knowledge translation 144
7.9 Addressing research aims 146
7.10 Conclusion 147
References 149
Appendices 165
Appendix 1: Literature review summary table 165
Appendix 2: Ethics approval 171
Appendix 3: Clinician participant information and consent form 173
Appendix 4: Carer participant information and consent form 181
Appendix 5: Briefing document to help inform the redesign of the paediatric clinic waiting 190
Appendix 6: Process for clinic observations and post-observation follow up 193
Appendix 7: Interview question guides 194
Appendix 8: Vignettes 199
Appendix 9: Example of WPR coding process 209
Appendix 10: Adapted WPR version for clinical practice 221

Appendix 11: Summary of research findings for participants 228

ABSTRACT

This research makes a practical and theoretical contribution to the consideration of health care practices informed by the messy everyday realities of living and working with young children with complex feeding difficulties (CFDs). These children require specialised medical and allied health care and multiple health service encounters over extended periods of time, often from birth. My review of the literature identified best practice recommendations to respond to children with CFDs and their families holistically, applying an interdisciplinary approach and considering biological, psychological, and social aspects of care. However, programs and approaches emphasised the physical and behavioural aspects of children's care and reflected a dominant biomedical and behavioural construction of the issue. The literature review highlighted the lack of critical epistemological approaches in this field and the importance of considering how a problem is constructed as a way of understanding the solutions that are proposed. It also highlighted that there was limited research that examined both carer and clinician perspectives, shed light on interdisciplinary team practice or addressed the everyday lives and needs of the carers and children. I addressed these gaps in this research by employing a poststructural methodological approach to examine the clinical practices associated with caring for these children informed by both the carers and the clinicians. I examined the clinical practices of a paediatric feeding assessment service (PFAS) located within a tertiary hospital in Adelaide to achieve the following three aims:

1. To critically examine and compare how the problem of complex feeding difficulties is being represented in clinical practices and experienced by carers,
2. To analyse how problem representations influence experiences and practices of health care, and
3. To reflect on the contribution and extension of the What's the problem represented to be? (WPR) approach to clinical practices.

As part of my original contribution to knowledge I applied and adapted the poststructural theoretical and analytic WPR framework developed by Carol Bacchi (2009) for policy analysis to this clinical health care setting. I took the stance that clinical practices are problematisations, in that they create particular understandings of what a clinical problem is. I applied the WPR methodology to deconstruct the ways that the clinical issue of complex feeding difficulties was problematised and the effects of this on carers, children, clinicians, and practices. I then examined

these findings through a ‘health as care’ lens informed by the work of Annemarie Mol (2008). This enabled me to examine and describe good health care practices at the level of the clinician, client, and team. I also developed an adapted WPR approach to clinical practices that can be applied in tertiary education and clinical practice settings to support critical review and reflection of health care practices and team functioning for current and future clinicians.

I conducted in-depth interviews, home and clinic observations with carers and clinicians over a seven-month period. I then analysed this data by applying the WPR methodology. I identified the implied problem representation by closely examining how this clinical issue was discussed, described, and framed in clinical practices and service documents. I then compared the clinician and carer data to identify the effects of this problem representation. A CFD was represented as a serious physical problem that affects a child’s ability to put on weight. The implied ‘problem’ was the weight of the child. This drove a focus on the child’s weight which resulted in silences surrounding the traumatic, emotional, and everyday life effects of living with CFDs and carers’ knowledge and expertise. The client/clinician relationship, power imbalances and the effects of team practices were some of the unexamined constructs that were highlighted.

I identified the broad structural factors that made it possible for this problem representation to come about. Some of these included neoliberal influences on health care policy; biomedical dominance; social and cultural discourses of food, mothering, normality; funding models and structures; team and clinical practices reflecting technologies of governing. I also examined the effects of this problem representation on carers and clinicians. Some of these included carers needing to become highly specialised medical technicians to manage their child’s physical needs and distance themselves emotionally from the daily pain and suffering of their child. Carers’ sense of their own wellbeing became inextricably connected to their child’s weight. Clinicians experienced overwork and lack of autonomy in an underfunded service. They were constrained in their practices but found ways to subvert the systems and build positive relationships with each other and their clients which influenced the carers’ experiences of health care.

I applied the adapted WPR model to the PFAS and identified specific recommendations to system responses, environments, and practices. These included reconceptualising the client as central to the team, supporting empowerment, relationships and trust between carers and children; carers and clinicians; and between clinicians; and reflecting on, understanding, and valuing the everyday experiences of carers and children. I was able to describe the aspects of interprofessional team

functioning that were most valued by carers and highlight clinical practices and their potential risks, in particular, the risk of reducing clients' agency to act and speak for themselves. This practical application of the adapted WPR model suggested that it offers a useful tool to support critical review and reflection of health care practices. I developed a guide to using the adapted WPR model to help bridge the gap between policies and practice with sensitivity and care. This adapted model provides a structure and process to help deconstruct and examine clinical practices and their effects and makes a contribution towards improving health care practices and outcomes.

DECLARATION

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

Signed: SMortimer

Date: 28 May 2021

ACKNOWLEDGEMENTS

I would firstly like to acknowledge that I live, work, and learn on the lands of the Kaurna people and pay my respects to Elders past, present and emerging. I believe we can learn so much from Aboriginal and Torres Strait Islander knowledges and practices, resilience, and strength.

I would also like to acknowledge and thank the clinicians and carers who shaped, strengthened, and embraced this research with generosity and openness allowing me to develop deep insights into their experiences which have been invaluable to this research. Spending time with you in your clinics and homes was an absolute privilege. The messy everyday work and life experiences I witnessed stayed with me as I wrote my thesis and motivated me to strive towards developing a model for review of clinical practices that did not lose sight of the everyday complexities of caring for and working with people.

I began this research process in 2014 when I took a breath, looked at my life and thought, now is a good time. It seemed that my children were old enough and my parents were young enough to present me with a window of opportunity. Since then, it feels like almost everything that could happen, has happened in my life and just when things were settling down a little for me and my family in 2020, the world delivered another challenge in the form of COVID-19. Over the last years I have juggled personal and family crises, illness, anxiety, stress, sick pets, sick children, sick parents, death, new life, renovations, a full-time demanding job, and doctoral research. I have experienced some of the lowest moments in my life and some of the highest. I have experienced so many health care encounters across the full range from community to emergency departments, aged care to antenatal services. In so many of these encounters, health *care* was lacking. This really reinforced for me how important this research was and how much people and relationships matter. I have been blessed to have nurturing, respectful, and supportive people in my life.

These include my supervision team, Professor Colin MacDougall, Dr Jessie Shipman and Dr Brian Coppin, whose combination of knowledge, wisdom, care, and thoughtfulness made such a difference to the outcome of this research. Thank you to Colin whose unique supervisory style helped me overcome my perfectionism and hone my writing so that I could be productive in my limited time. Your ability to gently challenge me and provide just the right feedback, combined with your kindness got me through when I really did not think I could continue. Thank you, Brian, for your enthusiasm for this project and for helping me navigate and understand the acute

hospital system. And to Jessie, thank you for your ever-present practical and emotional support and passion for this research. Your belief in me and willingness to go above and beyond (all the way through maternity leave) is so appreciated. Your approach to research and people provides a beautiful blend of care and knowledge and your understanding of the importance of relationships was balm to my often-overwrought soul.

Thank you also to my treasured friends, Linda Charleton, Danika Fromm, Georgie Enders, and Terrie Mortimer, who I am also lucky enough to have as a sister. You provided balance and light relief and supported me throughout this epic journey even though you really did not understand why I was doing this! You made me laugh and were there when I cried. You are the most amazing clinicians and your approach and commitment to the families you work with inspires me.

I also want to acknowledge the occupational therapy team at Flinders University. I am proud to call these people my colleagues and friends. Thank you to Professor Stacey George, Ellice Willcourt, Ali Dymmott and Renee Mitchell. Your support was invaluable. You cheered me on, laughed with me, and lightened the load of this incredibly demanding job.

And finally, most preciously, my family. To Dominic, thank you for your unending support and encouragement, for picking up the practical aspects of household management to enable me to focus on this study. To my four daughters, Shaez, Aisha, Tahnae and Indi; incredible, strong, passionate, and caring young women. Your belief and pride in me helped me keep going. Wanting to make things better for you is one of my key motivators. To my granddaughter Ada, born March 2020, thank you for reminding me that there was life beyond work and study and providing me and our family with so many moments of absolute joy. Thank you all for your support and sacrifice while this took over. I look forward to having more energy and time to be able to spend with you all.

No professional editing service has been utilised in the development of this thesis.

CONFERENCE PRESENTATIONS AND DISSEMINATION OF RESEARCH

Mortimer, S.K. (2021). Interdisciplinary team practice: what parents of children with complex feeding difficulties value and need. Electronic poster. Accepted for presentation at Occupational Therapy Australia 28th National Conference and Exhibition in July 2021.

Mortimer, S.K. (2021). A qualitative study adapting the "What's the problem represented to be?" approach to complex feeding difficulties. Oral paper presentation. Accepted for presentation at Occupational Therapy Australia 28th National Conference and Exhibition in July 2021.

Mortimer, S.K. (2019). How understanding the problem can drive the solutions: a qualitative case study of carers of young children with complex feeding difficulties. In Occupational Therapy Australia 28th National Conference and Exhibition. Sydney: *Australian Occupational Therapy Journal, 66*, S1. Special Issue: "Together Towards Tomorrow", July 2019, p53. https://doi.org/10.1111/1440-1630.12585

Mortimer, S.K. (2018). Collaborative practice with carers of young children with complex feeding difficulties. Oral presentation. National Occupational Therapy Paediatrics Symposium. Sydney, NSW, November 2018.

Mortimer, S.K. (2018). Tube as trauma: caring for a young child with complex feeding difficulties. Oral presentation. International Childhood Trauma Conference. Melbourne, Victoria August 2018.

Mortimer, S.K. (2017). Examining carer and clinician perspectives of tertiary health responses for young children with complex feeding difficulties: Preliminary findings. Flinders Medical Centre Paediatric Grand Round. September 2017.

Mortimer, S.K. (2015). What is it about Family Mealtimes that supports young children's development? Results from a scoping review. Electronic poster. Occupational Therapy Australia, 26th National Conference and Exhibition. Melbourne, Victoria. Jul 2015. Australian Occupational Therapy Journal, 62: 8–33. https://doi.org/10.1111/1440-1630.12211_1

Mortimer, S.K. (2015). What can clinicians learn from a critical policy analysis in the area of early childhood practice? Oral presentation. Occupational Therapy Australia, 26th National Conference and Exhibition. Melbourne, Victoria. Jul 2015. *Australian Occupational Therapy Journal, 62:* 68–117. https://doi.org/10.1111/1440-1630.12212_1

LIST OF FIGURES

Figure 3.1 The research process 56
Figure 3.2 WPR approach to policy analysis 63
Figure 3.3 Analytic Process 65
Figure 7.1 WPR model adapted to clinical practices 133
Figure 7.2 Adapted WPR model applied to PFAS..134

LIST OF TABLES

Table 0.1 Key terms and abbreviations.......... xvi
Table 2.1 Keywords used in searching academic databases 13
Table 2.2 Types and locations of articles 15
Table 3.2 Carer participant options 46
Table 3.3 Carer participants' level of involvement in research 48
Table 3.4 Carer demographic information.......... 49
Table 3.5 Required information and aligned methods 55
Table 3.6 Summary of data collected 58
Table 3.7 Summary of clinician interview data analysis 66
Table 3.8 Carer interview data summary.......... 66
Table 7.1 Addressing the quality of this research through application of the criteria proposed by Popay et al. (1998) 143

TERMINOLOGY AND ABBREVIATIONS

Throughout this thesis, I have used the term carer when referring to the primary caregiver who may be the child's parent, carer, or foster carer. I have also used the term client when referring to a client, patient, or consumer. The following abbreviations have been used;

Table 0.1 Key terms and abbreviations

Abbreviation	Term
WPR	What's the problem represented to be?
CFD	complex feeding difficulty
CFDs	complex feeding difficulties
PFA	paediatric feeding assessment
PFAT	paediatric feeding assessment team; includes the people and their clinical practices.
PFAS	Paediatric Feeding Assessment Service; includes the environment and the processes.
PR	problem representation
GP	general practitioner
OT	occupational therapist
PEG	percutaneous endoscopic gastrostomy- a procedure to place a feeding tube through the skin and into the stomach to provide nutrients and fluids
ARFID	avoidant/restrictive food intake disorder
RSS	Russell-Silver syndrome

Chapter 1 **INTRODUCTION**

1.1 Introduction

Care for young children with complex feeding difficulties (hereafter CFDs) is embedded in the health system. These children are at risk and often seriously ill from their inability to consume enough nutrients to grow and thrive. They require specialised medical and allied health help, needing to be examined, monitored, and fed. They rely on hospitals, technologies, and equipment. These children and their families experience significant challenges in the present and are at risk of experiencing preventable physical, cognitive, psychological, social, and emotional difficulties in the future. They require multiple health care encounters from birth. These families spend much of the early days, weeks, months, and years of their children's lives in and out of hospitals at a time when growth and development is so important and while they are working out how to be a family, how to relate to and care for each other. I wanted to closely examine and understand the health care encounters and clinical practices surrounding these children and families. From a public health perspective, I was interested in understanding the systems operating around these children, their carers, and their clinicians and how these affect the care they receive.

1.2 Rationale for this study

This research examined the clinical practices of a Paediatric Feeding Assessment Service (PFAS) located within a tertiary hospital in Adelaide to achieve the following three research aims:

1. To critically examine and compare how the problem of CFDs is being represented in clinical practices and experienced by carers.
2. To analyse how problem representations influence experiences and practices of health care.
3. To reflect on the contribution and extension of the What's the problem represented to be? (WPR) approach (Bacchi, 2009) to clinical practices.

To do this I examined the clinical practices associated with caring for young children with CFDs informed by both their carers and clinicians. I first applied and adapted the Foucault- influenced poststructural theoretical and analytic framework, What's the problem represented to be? (WPR) developed by Carol Bacchi (Bacchi, 2009) to this clinical health care setting and deconstructed the ways that the clinical issue of CFDs is problematised and the impact of this. I then explored the implications for clinical practices informed by the work of Annemarie Mol (Mol, 2002, 2008) whose praxiographic approach is based on extensive ethnographic studies immersed within health care facilities. In doing so this research offers a novel approach and theoretical contribution to the consideration of health care practices.

This research was situated within social and political climates that challenge health systems, and the clinicians working within them, to provide effective service responses. A detailed account of this context is discussed below but, in short, this refers to the pressures experienced by health services, and passed on to clinicians, to provide the best and most economical service responses in the fastest time. My interest in this research arose from my own experiences as; a clinician; a direct user of health services; an advocate for my family in their experiences of health care; and a university lecturer teaching allied health students. I worked in health care systems across South Australia (SA) and New South Wales (NSW) for more than twenty years as an occupational therapist (OT). The majority of this time was spent working with children and families in community settings. I saw and experienced the impact on families when services did not or could not respond to their needs in a holistic, caring, timely or flexible manner. I also live with a chronic health condition which involves ongoing experience of pain, and requires prescription medication, general practitioner (GP) and specialist medical care and regular access to allied health services. I have experienced the frustration of being seen as a condition or a presenting issue rather than being seen holistically as a person. Additionally, I have four daughters and a partner with ongoing medical issues, and ageing parents. I have supported all of them through multiple health service encounters and needed to advocate for their care. I now teach at a university in an occupational therapy program and work with future health professionals to support them to understand the role they can play in improving health care delivery for the people they will serve.

I brought these experiences to my research and they motivated my interest in examining health service encounters. I was driven by a fundamental consideration – if you don’t really understand the problem, how can you come up with the best solutions? In my work as a clinician and educator I have seen how much time and energy, students and practitioners apply to developing solutions, examining the evidence to guide what will work best for their clients, but they rarely focus on examining the problem and how it has come to be seen as a problem. I was interested in the ways that this then influenced experiences of health ‘care’ and whether that was very ‘care*ful*’. I was interested in the inadvertent ways our clinical practices and processes can be directly or indirectly ‘care*less*’. This might be through missing key information by not asking the right questions, through only addressing one aspect of the problem, through the ways we make people wait, feel and act as part of our clinical service responses.

I was keen to achieve a practical outcome and to maximise the relevance of my research and the likelihood of practice and policy change. To achieve this, I applied knowledge exchange principles in my research. Knowledge exchange is defined as an interactive interchange of knowledge between research users and research producers (Kiefer et al., 2005). There is strong evidence that an explicit focus on developing partnerships that operate from the beginning of the research process and involve the end users throughout are more likely to produce research findings that are transferable to practice and policy (Australian Primary Health Care Research Institute, 2011; Cuthill, O'Shea, Wilson, & Viljoen, 2014; Graham et al., 2006; Greig, Entwistle, & Beech, 2012; Huberman, 1994; Walter, Davies, & Nutley, 2003). Additionally, knowledge exchange partnerships are considered essential to investigate multifaceted social and health challenges (Lavis, Posada, Haines, & Osei, 2004; Ward, Smith, House, & Hamer, 2012).

As I was contemplating the focus of my research, I was fortuitously introduced to the members of the Paediatric Feeding Assessment team (PFAT). They had heard about work I had presented at the 2015 National Occupational Therapy conference reporting on the results of a literature review examining family mealtimes and their influence on young children’s development. I was invited to speak with them and in doing so commenced a collaboration that has been a key part of this research. This team comprised a dietician, OT, speech pathologist and paediatrician. They shared a passion for the area of CFDs and were working to create the best model of care possible with very limited resourcing. They worked with young children with CFDs and their families and were striving to provide a consultative and streamlined clinical response across inpatient and outpatient settings. They were excited to work with me to improve the quality of the services they provide. I spent time and effort establishing effective and trusting relationships and consistent with knowledge exchange principles this was essential to the success of my research (Graham et al., 2006; Innvær, Vist, Trommald, & Oxman, 2002; McIntyre, Jackson Bowers, Kalucy, Beacham, & Raven, 2014; Nath, 2007; Ward et al., 2012). While developing the research proposal and submitting the ethics application, we established a positive knowledge exchange partnership. This partnership allowed me access to the workings of the team which included observing multiple individual, joint, and clinic sessions, follow up discussions and team meetings. The PFAT has shaped, strengthened, and embraced this research with generosity and openness. Their willingness to work with me presented an excellent opportunity to examine the health encounters between a group of clients experiencing significant health challenges and a specialised interdisciplinary team.

I was particularly interested in how CFDs were understood by the clinicians and the carers of the young children experiencing these difficulties and how this then influenced the delivery and experience of service responses. As will be discussed in more detail in Chapter 3, this line of enquiry required a methodology that would uncover assumptions and focus more on understanding what the perceived problems are and how they came to be so, rather than seeking 'solutions'. I was interested in the ways a problem is perceived or constructed, how this comes to be and the impacts of this. My review of the literature brought my attention to poststructuralism and the WPR approach. As will be described in Chapter 3, this approach is widely used in policy analysis and, in more recent years, its role has expanded to consider implications for broad practices in health, justice, and education sectors. However, it has not previously been applied to examine specific clinical practices, that is, actions and interactions of a clinical service delivery team and the impact of these on their clients.

The composition of my supervision team was an important part of my research and reflexivity. I chose supervisors from outside my discipline who helped me to challenge my assumptions and biases and supported me in applying a critical methodology. My principal supervisor, Professor Colin MacDougall, is a professor in public health with extensive experience in unpacking structural inequalities. My secondary supervisor, Dr Jessie Shipman, is a medical sociologist with expertise in qualitative research with families that informs policy and practice. My third supervisor, Dr Brian Coppin, is a senior paediatrician and Clinical Director of the Department of Paediatrics and Child Health at the hospital where this research occurred. He provided contextual information and facilitated access to the team and site. He also took on the role of clinical expert and acted as a sounding board to test my ideas and check conclusions throughout the research process. Together this supervision team helped me to think critically and carefully as I applied this research methodology. They also helped me to remain accountable and connected to the people affected by this research.

1.3 Background

I needed to understand the context within which this research was taking place to understand the system challenges the team and families were experiencing and the pressures and expectations that existed in their everyday work and lives. This section provides background regarding CFDs and the broader Australian health system context within which service responses to address these existed.

1.3.1 Complex feeding difficulties

The term CFDs used in this thesis is not a diagnostic category. It is a term that was defined for me by the parameters of who is seen by the PFAT. Hence the term refers to the team's referral criteria which includes:

> Infants and children with complex medical conditions and syndromes, oral aversion with or without an identified medical problem, failure to thrive – organic and non-organic, and feeding problems associated with developmental delay and/or congenital anomalies. (PFAT referral criteria)

Approximately 3% to 10% of children experience CFDs, meaning they have difficulty consuming adequate nutrition by mouth and require medical intervention (Manikam & Perman, 2000; Sharp, Volkert, Scahill, McCracken, & McElhanon, 2017). These occur in up to 80% of children with additional health concerns and physical disabilities (Davis et al., 2013; Manikam & Perman, 2000). CFDs represent one of the most common conditions that carers seek support from paediatricians to address (Lukens & Silverman, 2014). The incidence of CFDs in young children is continuing to rise as medical advancements improve the life expectancy of infants and children with complex medical conditions (Gosa, Dodrill, Lefton-Greif, & Silverman, 2020). Without intervention, symptoms of CFDs tend to worsen over time resulting in significant health and behavioural issues that may have been prevented with early identification and intervention (Lukens & Silverman, 2014).

Difficulties in eating can have a significant impact on very young children's ongoing growth, development and general health (Sanchez, Spittle, Allinson, & Morgan, 2015). Adequate nutrition is essential for brain development and is the foundation for healthy early childhood development (Shonkoff, 2010). The consequences of CFDs in early childhood are significant and can include growth failure, susceptibility to chronic illness, and even death (Manikam & Perman, 2000). CFDs also impact significantly on a child's family, in particular on the relationships between family members, the emotional state of children and carers, the family's identity generally (Fiese, Foley, & Spagnola, 2006; Satter, 1995), and the carer's identity in particular (Wilken, 2012).

The development and maintenance of a healthy feeding process requires a complex interaction between physiological factors (especially the functioning of the cardiac, respiratory and digestive systems), sensorimotor functions, and parental and child factors (Krom, de Winter, & Kindermann, 2017). Eating is one of the most important skills that a baby must learn to survive (Davis et al., 2013). However, the skills and co-ordination of body systems required for eating and processing food are complex, interconnected and influenced not only by the young child but also their carer and the environment in which they live (Manikam & Perman, 2000; Pérez-Escamilla, Segura-Pérez, & Lott, 2017). This means there are many opportunities for things to go wrong in the process of learning to eat and feed. Additionally, children with CFDs frequently require enteral or tube feeding to support their nutritional intake to sustain growth and development which can result in side effects and complications (Krom et al., 2017; Lively, McAllister, & Doeltgen, 2020). Consequently, children experiencing CFDs and their carers have a wide range of presenting concerns, complicated medical and developmental histories and may require the services of a myriad of different health professionals across different aspects of the health care system; inpatient, outpatient and community, GPs, specialists such as paediatricians, allergists, gastroenterologists and allied health practitioners including OTs, speech pathologists, dieticians, psychologists (Norris, Spettigue, & Katzman, 2016). It is estimated that children with CFDs account for 1-5% of preventable paediatric hospitalisations and have frequent emergency department visits (Begotka, Long, Goday, & Silverman, 2018; Spratling & Lee, 2020). The health care that children with CFDs and their families receive is often disjointed (Norris et al., 2016). Children with CFDs and their carers are high users of health care services which makes them worthy recipients of research attention and means that understanding their needs and experiences may make a valuable contribution to public health research.

1.3.2 Health care context

Responses to health issues and delivery of health care services occur within complex health care systems and funding arrangements. It is important to understand these systems to be able to contextualise this research. This next section describes the Australian, South Australian, and international health care contexts and the impacts of these on the environment in which the service responses for young children with CFDs and their carers were occurring.

According to the Australian Institute of Health and Welfare's 2018 report on the state of Australia's health, spending on health in Australia has grown by approximately 50% in real terms over the past decade, while Australia's population has grown by approximately 17%. Australia spends 9.6% of gross domestic product on health which is more than the Organisation for Economic Co-operation and Development (OECD) average of 9.0% (Australian Institute of Health and Welfare., 2018). The Australian health care system operates within a mixed model of private and public health care services (Krassnitzer, 2019). In Australia, governments fund two-thirds (67%, or $115 billion) of all health spending, and non-government sources fund the rest (33%, or

$56 billion). Individuals contribute to more than half (17%, or $29 billion) of the non-government funding (Australian Institute of Health and Welfare., 2018).

The Australian health system is complex and fragmented (Hall, 2015), with involvement of all levels of government; national, state and territory, and local. The National Healthcare Agreement is an agreement between the Australian Government and state and territory governments that outlines the role and responsibilities of the parties involved (Australian Institute of Health and Welfare., 2018). The Australian government is responsible for Medicare, Australia's universal health care system, which provides free or subsidised health care across public hospitals, GP and some allied health and nursing services. The Pharmaceutical Benefits Scheme provides subsidised access to some medicines. The Australian government also provides a means tested rebate to support the cost of private health insurance. Additionally, there are 31 primary health networks across Australia funded by the Australian government and responsible for assessing and responding to the health needs in their local area and coordinating care across the different systems (Australian Government, 2019).

The PFAT was located within a publicly funded tertiary hospital in SA. Services within public hospitals in Australia are free. Most of the families accessing the team also received services through publicly funded specialists such as gastroenterologists, neonatologists, ear, nose and throat specialists, allergists and allied health clinicians including OTs, speech pathologists and dietitians who were also employed by the tertiary hospital. There were long wait times for high demand publicly funded services such as gastroenterology. Carers often made the difficult choice to access these services privately to reduce the wait times. There were very limited options for community based publicly funded services to respond to the health care needs of young children with CFDs and these services were comprised of allied health clinicians and only provided services until the child turned four. Funding for this tertiary hospital was based on a national activity-based model whereby the hospital receives funding for the specific services it provides and each of these services has a set price based on its characteristics (Krassnitzer, 2019). This requires stringent coding of patients and activities. The way patients were coded influenced their associated funding which influenced the types of services that could be provided.

In 2015, as this research project was commencing, SA Health launched a new 'Transforming Health' agenda which aimed to consolidate health services and maximise the value of every health encounter (Delivering Transforming Health – The Next Steps, 2015). With the election of the state

Liberal government in 2019, Transforming Health was decommissioned, and a new reform agenda launched that included changes to the state government health system governance. The newly named Minister for Health and Wellbeing was responsible for ensuring the public health system met the requirements of the South Australian community through planning and implementing a system of health services that was comprehensive, coordinated and readily accessible to the public; ensuring hospitals and other health services were operated in an efficient and economical manner; and ensuring the proper allocation of health resources (Department for Health and Wellbeing, 2019). I collected data during the Transforming Health agenda at a time when services and staffing within this tertiary hospital was being closely scrutinised. My analysis and discussion regarding implications reflected and considered the new reform agenda whereby justifications for new service models or approaches needed to present very strong business cases and were unlikely to be approved unless they could show cost savings.

The Australian health care system is also part of and influenced by the international context. The world is also facing multiple health challenges. According to the World Health Organization (2019), these include: outbreaks of vaccine-preventable diseases like measles and diphtheria; the health impacts of climate change including poor air quality; increasing reports of drug-resistant pathogens; growing rates of obesity and physical inactivity; and multiple humanitarian crises. The rates of noncommunicable diseases, such as diabetes, cancer and heart disease have significantly risen, driven by five major risk factors: tobacco use, physical inactivity, the harmful use of alcohol, unhealthy diets and air pollution (World Health Organization, 2019). According to the Australian Institute of Health and Welfare (2018), p.5, "[a] major aim of any health system is to prevent disease and other ill health and injury and to maintain health—not just to treat illness". A focus on the quality and timeliness of health care services is required to be able to achieve this (Australian Institute of Health and Welfare., 2018). This requirement was occurring within an Australian health system that was experiencing significant challenges include; an ageing population with increasing demands on health services; increasing rates of chronic disease; costs of investment in medical and health research; making the best uses of emerging health technologies; and health data generation and use (Australian Government, 2019). Additionally the following health challenges are shared with countries around the world; the rising cost of the health system; the ability to respond to new health issues; inequality in access to health services and hospital waiting times (Australian Government, 2019) .

As Braithwaite (2018) describes health care systems are highly complex;

> No other industry or sector has the equivalent range and breadth—such intricate funding models, the multiple moving parts, the complicated clients with diverse needs, and so many options and interventions for any one person's needs. Patient presentation is uncertain, and many clinical processes need to be individualised to each patient. Healthcare has numerous stakeholders, with different roles and interests, and uneven regulations that tightly control some matters and barely touch others. The various combinations of care, activities, events, interactions, and outcomes are, for all intents and purposes, infinite. (p 1)

Across the multiple levels of health care provision and funding, and within this context of increasing demand for and cost of health care services, there is a clear imperative to provide health care more efficiently and effectively while maintaining safety and quality (Australian Institute of Health and Welfare., 2018). The complexity of structures and funding models in Australia has been described as "a complex set of overlapping and fragmented responsibilities" (Hall, 2015, p. 495) and reported as contributing to the difficulties of enacting reform (Australian Government, 2014; Braithwaite, Runciman, & Merry, 2009; Hall, 2015). The complexity of this challenge requires us to think differently (Braithwaite, 2018), and this presents an opportunity to examine different approaches and paradigms when considering health care reform (Braithwaite et al., 2009; Van Bueren, Klijn, & Koppenjan, 2003). In outlining principles for enacting change in such complex systems, Braithwaite (2018) posits that "we must pay much more attention to how care is delivered at the coalface" (p. 2). Braithwaite reflects that clinicians successfully handle complex situations in their everyday practice and that if we "better appreciate how clinicians handle dynamic situations throughout the day, constantly adapting, and getting so much right, we can begin to identify the factors and conditions that underpin that success" (Braithwaite, 2018, p. 3) and then learn from these in the application to broader system change. Braithwaite and Goulston (2004) further encourage a bottom-up approach whereby clinicians and consumers lead the process of reform rather than politicians and senior bureaucrats. This provided credibility and support to research focussing on the level of clinical practices. It also supported an approach that examined health problems more critically.

1.4 Research significance

As described above, young children with CFDs and their families are a particularly vulnerable group who experience significant challenges in the present and are at risk of experiencing a number of preventable physical, psychological, social, and emotional difficulties (Aldridge et al., 2018; Mitchell, Farrow, Haycraft, & Meyer, 2013; Oliveira et al., 2015; Sanchez et al., 2015). They also represent a group with complex health care needs who are high service users and experience multiple health care encounters within the context of a complex, ever more constrained, health care system. This is an area that is significantly under researched, with a recent review focusing on children under 13 years of age, concluding that knowledge about epidemiology, prognosis, outcomes and treatment interventions for children with CFDs is extremely limited (Bryant-Waugh, 2013).

Public health seeks to understand systems and support system change to enable greater empowerment and participation of individuals in their own health experience thereby promoting greater health (Baum, 2008). The outcome of this research has the potential to contribute to public health research and health care reform by providing new mechanisms for a critical review of clinical practices within health care settings. This research adapted and extended the WPR approach (Bacchi, 2009), a poststructural theoretical and analytic framework that is well established in policy analysis and applied it to a specific clinical situation within a tertiary hospital setting. I applied the WPR model (Bacchi, 2009) to determine how the problem of CFDs is represented by the clinicians and experienced by the carers of Paediatric Feeding Assessment Service. I analysed how these problem representations (PRs) influenced experiences and practices of health care. This was further supported by Annemarie Mol's praxiographic work on examining health care practices (Mol, 2002, 2008). Throughout the research, I employed a partnership approach with clinicians to ensure knowledge exchange processes were meaningful and relevant. The outcome of this research was a novel mechanism for analysing clinical health care practices. I proposed an adapted WPR model to support the review and reflection of clinical practice in health care settings. The WPR method adapted to clinical practices appears to have merit. The application of this approach to other areas of clinical practice, and the trialling of the adapted WPR model as a tool to support practice change warrant further research.

1.5 Structure of the thesis

Chapter 1: Introduction

This chapter provides the context for this research and introduces me as a researcher, the clinical issue, and the broad structural environments in which this was positioned. The research aims and the significance of this research to public health is outlined.

Chapter 2: Literature Review

In Chapter 2 I present a review of the literature related to young children with CFDs and their carers to offer insight into how this clinical issue is constructed and understood. Current service responses to CFDs were also examined. I then analysed the current state of research and identified gaps in the literature. I conclude the chapter by discussing how this research was informed by the literature review and how it addressed some key gaps in the current evidence base.

Chapter 3: Methodology

Chapter 3 provides a detailed rationale for and explanation of the epistemology, theoretical perspective, and methodology for this novel research approach. I describe the WPR theoretical and analytic framework and make the case for its application to clinical settings. I outline my position as a researcher and the research design I employed. I describe the multiple methods that were used to ensure rich data and outline the process of data analysis and synthesis. I conclude the chapter by explaining the ethical considerations and addressing the trustworthiness of the research design.

Chapter 4: What is the problem of complex feeding difficulties represented to be in the clinical practices of the Paediatric Feeding Assessment Team?

In Chapter 4 I address the first part of research aim 1; to critically examine how the problem of CFDs is being represented in clinical practices by presenting the findings of the analysis of document and interview data with clinicians.

Chapter 5: How is the problem representation experienced by the carers?

Chapter 5 presents the findings from the analysis of carer observation and interview data. I examine the carers' experiences of the PR identified in Chapter 4. This addresses the second part of research aim 1; to critically examine how the problem of CFDs is being experienced by carers.

Chapter 6: Discussion: Health as care; clinicians' representations and carers experiences of CFDs

In Chapter 6 I discuss these results in relation to the theoretical underpinnings of this research. The first part of Chapter 6 brings together the analysis of carer and clinician data and completes research aim 1; to critically examine and compare how the problem of CFDs is being represented in clinical practices and experienced by carers. In the rest of the chapter, I analyse and discuss how this PR influences the service responses of the PFAS and examine the implications of this for service responses more broadly. Mol's work on the logic of care is applied to bring another layer to this analysis and foreground the clinical practices of health care. This addresses my second research aim; to analyse how PRs influence experiences and practices of health care.

Chapter 7: Conclusions: Implications of the adapted What's the Problem Represented to be? model and a logic of care for clinical research, teaching and practice

Chapter 7 addresses my third research aim; to reflect on the contribution and extension of the WPR approach (Bacchi, 2009) to clinical practices. I discuss the contribution of the WPR approach to clinical practises and present a proposed adaptation to the model to support this application. Recommendations for its use and applicability in health care and tertiary education settings are discussed. The processes by which research findings will be disseminated to influence future practices is outlined. This chapter concludes my thesis with a discussion of the quality of this research and opportunities for further research.

Chapter 2 LITERATURE REVIEW

2.1 Introduction

This chapter describes the narrative review process undertaken to inform the development of my research aims and methodology. This review was an iterative process that began prior to finalising the research aims and continued throughout the data collection, data analysis and synthesis stages of the study. Narrative reviews aim to summarise previously published research and identify new study areas and gaps in research (Ferrari, 2015). I undertook a narrative review as they are considered of particular value in providing a research overview and rationale for a particular study approach (Ferrari, 2015). My aim was to examine the ways CFDs are constructed ie defined, described, framed, and conceptualised, within the current literature, and identify research gaps to best position my research.

2.2 Narrative review process

I applied a systematic search strategy that focused on key words summarised in table 2.1.

Table 2.1 Keywords used in searching academic databases

feeding difficult*	AND	young child*	AND	approach*	AND NOT	adolescent
feed*		child*		“best practice”		adult
eat*		baby		team*		breastfeed*
“ARFID”		infant		practice		lactat*
“avoidant/restrictive food intake disorder”		parent*				developing country
		carer				
		mother*				

The following databases were used for literature searching as they reflect the interdisciplinary nature of the research focus; Scopus, PubMed, CINAHL, ProQuest and PsycINFO. The focus of this study was young children under five years experiencing CFDs but not requiring parenteral nutrition in a developed country with access to tertiary health care services including interdisciplinary medical and allied health care specialties such as neonatology, gastroenterology, allergy, paediatrics. I therefore applied limits to exclude studies focused on breast feeding, parenteral nutrition, school aged children or older, developing countries and were not published in English. In acknowledging that much of the research in this area covers a broader age range, literature was included if the age range included children under five years. Research from 2015 -2020 was identified following a major change in labelling and diagnosis within the feeding difficulties literature that occurred as part of updates to official diagnostic criteria in 2013 in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) (American Psychiatric Association, 2013). In line with principles of reviewing literature, I identified additional papers through reference list and citation searching and incorporated these into the review to add further information and context (Aveyard, 2014). So, while the initial focus was on literature published between 2015 and 2020, I identified and included earlier work of relevance in this review.

The initial part of this review examined the ways CFDs are constructed or considered. In doing this I outlined and analysed how the key terms feeding, eating, feeding difficulties, and feeding disorders are presented in the literature. This section examined a wide range of literature identified through the search strategy outlined above including, systematic and narrative literature reviews, expert opinion pieces, descriptive work and clinical research of varying methodologies. The second part of this review examined current best practice responses based on these characterisations. This section considered evidence that was based on clinical research, systematic reviews and meta-analyses, scoping and narrative reviews.

A total of 44 articles that specifically focused on young children with CFDs and/or their carers were included in this review. A detailed table summarising the key characteristics of these articles is included as Appendix 1. A summary table of the types and locations of studies included is presented here (Table 2.2). Of the 32 studies with participants, the main focus of research was the experiences of children themselves (17/32), with nine studies focused on carer perspectives (Aponte, Brown, Turner, Smith, & Johnson, 2019; Begotka et al., 2018; Franklin & Rodger, 2003; Garro, Thurman, Kerwin, & Ducette, 2005; Greer, Gulotta, Masler, & Laud, 2007; Petersen, Kedia, Davis, Newman, & Temple, 2006; Russell, Jewell, Poskey, & Russell, 2018; Silverman, Erato, & Goday, 2020; Spratling & Lee, 2020), an additional five that focused on mothers (Craig, 2005; Craig & Scambler, 2006; Craig, Scambler, & Spitz, 2003; Hewetson & Singh, 2009; Winston, Dunbar, Reed, & Francis-Connolly, 2010) and one on grandparent experiences (Tapera, Harwood, & Anderson, 2017).

Table 2.2 Types and locations of articles

<table>
<tr><td colspan="5">**22 primary research articles:**
• 11 quantitative; **(Aldridge et al., 2018; Begotka et al., 2018; Garro et al., 2005; Greer et al., 2007; Marshall, Hill, Wallace, & Dodrill, 2018; Marshall, Hill, Ware, Ziviani, & Dodrill, 2015; Maximino et al., 2016; Mazze et al., 2019; Silverman et al., 2020; Taylor, Purdy, Jackson, Phillips, & Virues-Ortega, 2019; Williams et al., 2017)**
• 4 mixed methods design; (Backman, Granlund, & Karlsson, 2019; Petersen et al., 2006; Russell et al., 2018; Winston et al., 2010)
• 7 qualitative; (Craig, 2005; Craig & Scambler, 2006; Craig et al., 2003; Franklin & Rodger, 2003; Hewetson & Singh, 2009; Spratling & Lee, 2020; Tapera et al., 2017)</td></tr>
<tr><td colspan="5">**10 literature reviews:**
• 1 systematic review and meta-analysis; (Sharp et al., 2017)
• 4 systematic literature reviews; (Howe & Wang, 2013; Lukens & Silverman, 2014; Saini, Kadey, Paszek, & Roane, 2019; Sharp, Jaquess, Morton, & Herzinger, 2010)
• 2 scoping reviews; (Aponte et al., 2019; Lively et al., 2020)
• 3 narrative literature reviews; (Kerzner et al., 2015; Krom et al., 2017; Silva, Costa, & Giugliani, 2016).</td></tr>
<tr><td colspan="5">**12 expert opinion:**
(Borowitz & Borowitz, 2018; Davies et al., 2006; Eddy et al., 2019; Edwards et al., 2015; Goday et al., 2019; Gosa et al., 2020; Keren, 2016; Manikam & Perman, 2000; McComish et al., 2016; Norris et al., 2016; Sharp & Stubbs, 2019; Yang, 2017)</td></tr>
<tr><td colspan="5">**Country (number of papers)**</td></tr>
<tr><td>USA (22)</td><td>Australia,
UK
(4)</td><td>International,
Canada
(3)</td><td>Brazil,
New Zealand
(2)</td><td>Korea,
Sweden,
South Africa,
The Netherlands
(1)</td></tr>
</table>

2.3 Existing approaches to complex feeding difficulties

I identified diversity in the ways the clinical issue of CFDs was constructed. In examining this, I reviewed the 44 articles and categorised their constructions of the problem as: biomedical, biopsychosocial, relational, or behavioural. Two other literature reviews applied similar categorisations to describe intervention approaches. Howe and Wang (2013) in their systematic review of effective intervention approaches for young children, identified three intervention categories as (1) behavioural interventions, (2) parent-directed and educational interventions, and (3) physiological interventions. Lively et al. (2020), in their scoping review of international tube weaning approaches, identified three predominant approaches as behavioural, biomedical or child and family centred. In examining how the clinical issue of CFDs was constructed, I added an additional category of biopsychosocial to capture the more holistic framing that also incorporated a focus on daily life experiences and broader structural factors. While there was some overlap between these categories, especially biomedical and psychological, the decision as to which category to assign was based on multiple readings to determine the primary focus of the methodology, approach, and the way a CFDs was described and framed. The details of this is presented as Appendix 1 and summarised below.

2.3.1 Biomedical

The biomedical category primarily considered the physical impacts on the child and included a focus on the medical, physiological, and skills aspects of the child and their feeding. The carer's role in this, if defined at all, was posed as one of supporting the medical and physical processes of feeding. While the importance of the parent-child relationship in supporting the feeding process may have been discussed this was not the primary focus of describing, evaluating, or intervening. Behavioural responses were frequently considered as part of this framing but were not the sole focus. Of the 44 articles reviewed, 13 were categorised as biomedical. Half of the expert opinion articles (6/12) framed CFDs through a biomedical lens (Eddy et al., 2019; Edwards et al., 2015; Gosa et al., 2020; Norris et al., 2016; Sharp & Stubbs, 2019; Yang, 2017). This reflects the dominance of the biomedical model in shaping clinical opinion and health care research in this field. These represented multidisciplinary perspectives including paediatric gastroenterology, paediatrics, and speech pathology. Six of the 32 primary research and literature review articles were categorised in this way (Krom et al., 2017; Maximino et al., 2016; Mazze et al., 2019; Sharp et al., 2010; Sharp et al., 2017; Williams et al., 2017). Research within this biomedical category was informed by a positivist epistemological approach and employed quantitative methodology.

2.3.2 Biopsychosocial

Biopsychosocial framing considered the broader ecocultural environments and how they influenced a child and their abilities to feed or eat. This considered the carer and child, their daily life experiences and activities, and broader family, social and cultural environmental considerations as influencers on CFDs. Seventeen of the 44 articles were categorised as biopsychosocial. Four of these were expert opinion articles (Borowitz & Borowitz, 2018; Goday et al., 2019; Manikam & Perman, 2000; McComish et al., 2016) and represented multidisciplinary perspectives including speech pathology, nursing, dietetics, psychology, and paediatric gastroenterology. Thirteen of the 32 primary research and literature review articles were categorised as biopsychosocial (Backman et al., 2019; Craig, 2005; Craig & Scambler, 2006; Craig et al., 2003; Garro et al., 2005; Hewetson & Singh, 2009; Howe & Wang, 2013; Petersen et al., 2006; Russell et al., 2018; Spratling & Lee, 2020; Tapera et al., 2017; Winston et al., 2010). These articles reflected a constructionist epistemological position, qualitative methodology and the majority explored carer perspectives (9/13), with only two focussing on intervention-based research. They reflected a wide range of discipline perspectives including paediatric gastroenterology, paediatrics, speech pathology, occupational therapy, nursing, medical sociology, and psychology.

2.3.3 Relational

Relational framing focused predominantly on the bi-directional relationship between the child and their carer and how this influenced the child's feeding patterns and capacities. This category considered the relationship between the child and their carer and the 'feeding relationship' as core to understanding and intervening with CFDs. Five of the 44 articles were categorised as relational. Two expert opinion articles were identified in this category, representing the disciplines of psychology, paediatrics and infant mental health (Davies et al., 2006; Keren, 2016). Davies et al. (2006) first proposed that CFDs be constructed as a relational and multisystemic process in 2006 to challenge the then dominant biomedical construction of the problem as located within the child. Additionally, three literature review articles were also categorised as relational (Kerzner et al., 2015; Lively et al., 2020; Silva et al., 2016) and incorporated the disciplines of speech pathology, paediatric gastroenterology and paediatrics.

2.3.4 Behavioural

The final category, behavioural, constructed the problem as the child's learned responses to feeding, eating and food. Behavioural management strategies were considered necessary to promote eating new foods, acceptance of foods with different textures, increase caloric intake, and reduce negative feeding and mealtime behaviours. A behavioural approach also considered the carer's behaviour and their impact on the child's behaviour. While other aspects may have been considered including medical, developmental, and relational, the primary focus was the behaviour of the child and/ or carer. There were no expert opinion articles identified in this category, but there were ten primary research and literature review articles (Aldridge et al., 2018;

Aponte et al., 2019; Begotka et al., 2018; Greer et al., 2007; Lukens & Silverman, 2014; Marshall et al., 2018; Marshall et al., 2015; Saini et al., 2019; Silverman et al., 2020; Taylor et al., 2019), all of which focused on intervention research and involved predominantly psychology and speech pathology as lead authors of multidisciplinary teams. These articles were informed by a positivist epistemological approach and applied quantitative methodology to examine clearly defined aspects of the condition.

Categorising the ways that CFDs were framed provided a useful way of mapping the existing research and helped me to identify that a biopsychosocial consideration of CFDs made the most sense in addressing such a complex issue and this informed my research design by ensuring I included carers and asked questions of both clinicians and carers that reflected this holistic approach and paid attention to the impacts on everyday life.

2.4 Constructions of complex feeding difficulties in existing literature

2.4.1 Feeding vs eating and their establishment

I identified only two examples where feeding and eating were explicitly delineated and described. One of these was from an infant mental health perspective (Keren, 2016) and one from a paediatric perspective (Yang, 2017). They both described that, in the context of young children, feeding was considered to be an interaction between the child and their caregiver, while eating comprised actions relating to nutritional intake via the mouth that are performed autonomously by the child and include reaching for food, opening the mouth and swallowing (Keren, 2016; Yang, 2017). Gosa et al. (2020) define feeding from a speech pathology perspective as “the process of getting liquids and foods to the mouth and then accepting them for ingestion” p.957. Other than these examples, the terms feeding and eating, and their use appeared to be largely unexamined and assumed within the feeding difficulties literature. Given that it is difficult to study or address an undefined problem, I wondered about the implications of these terms and their use for carer understandings and clinician goals and priorities for services. All the services are referred to as feeding services or feeding teams. This flagged the need for an approach that pays attention to these terms and their meanings and examines how they have come to be understood and the assumptions and differences that may be at play between carers and clinicians of children with CFDs.

Silva et al. (2016) more typically represented the literature by implicitly outlining the important role of the interaction between carer and child in the process of feeding/learning to eat. Infants and very young children are dependent on a carer to feed them due to their physiological immaturity (Silva et al., 2016) and developmental status. The carers' own life habits, parenting style, interactions with their child (Silva et al., 2016) and relationship with food (Manikam & Perman, 2000) inform this process, as does the broader sociocultural influences which include family, friends, school and media (Silva et al., 2016). Cultural practices also affect feeding practices (Tapera et al., 2017) as do attitudes to food and eating and expectations regarding nurturing (Petersen et al., 2006). Feeding and learning to eat occur in social contexts (Backman et al., 2019; Manikam & Perman, 2000) and are strongly influenced by the interactions between the child and carer (Silva et al., 2016).

Children communicate their preferences and satiety through behavioural responses that need to be interpreted and responded to by the carer (Manikam & Perman, 2000; Pérez-Escamilla et al., 2017; Silva et al., 2016). It is in this space of learning to read and respond to the cues of the young child, referred to as responsive feeding, that much research has been conducted. Responsive feeding has been defined as "a process that involves reciprocity between the child and caregiver during the feeding process. It is based on the following 3 steps: (1) the child signals hunger and satiety through motor actions, facial expressions, or vocalizations; (2) the carer recognizes the cues and responds promptly in a manner that is emotionally supportive, contingent on the signal, and developmentally appropriate; and (3) the child experiences a predictable response to signals" (Pérez-Escamilla et al., 2017, p. 225). Responsive feeding is considered very important in setting up a child's healthy relationship to food and eating and supporting the development of self-regulation whereby a child monitors and responds to their own cues of hunger and satiety (Cooke, Higgins, & McCrann, 2017).

Environmental influences are important in helping establish feeding practices. These were framed as more proximal influences such as the setup of the home environment, limiting distractions, ensuring the child is seated comfortably with sufficient support, and appropriate carer and family modelling of eating healthy foods (Cooke et al., 2017; Manikam & Perman, 2000; Pérez-Escamilla et al., 2017). Additionally, there are sensitive periods in a baby's first few months of life during which they are receptive to certain flavours and textures and their exposure during this time appears to influence preferences later in childhood (Borowitz & Borowitz, 2018; Pérez-Escamilla et al., 2017). Repeated exposures to foods may be required for acceptance of some foods (Pérez-Escamilla et al., 2017). Of much less consideration in the literature were the broader structural factors such as access to food, employment, financial security, societal pressure (Tapera et al.,

2017) and the socio-political influences of gender, race, class and culture on the process of feeding (Craig & Scambler, 2006). This drew my attention to the need for further research regarding the impact of these broader structural factors.

Feeding processes gradually develop from reflexes in newborns to voluntary actions on the part of the child which emerge around 6 months of age (Borowitz & Borowitz, 2018; Krom et al., 2017). These voluntary actions are based on developmental processes of the motor, sensory, cognitive and communication systems that continue to develop over the first year of life (Borowitz & Borowitz, 2018). Feeding is a complex developmental skill that requires the integration of breathing, sucking, swallowing, the achievement of overall motor stability, and the processing of a wide range of incoming visual, tactile, gustatory, olfactory and auditory stimuli (Howe & Wang, 2013). The typical feeding process also involves a hunger-satiation system that consists of three phases: (1) the preoral phase in which the child feels hungry, leading to appetite and nutritional intake; (2) the oro-pharyngeal phase in which the foods are prepared in the mouth, transported from tongue to pharynx, and swallowed; and (3) the gastro-intestinal phase in which satiation and digestion occur (Krom et al., 2017). Children learn most of the oro-motor, hunger-satiety response and social skills required to eat and drink during their first year of life. If opportunities for oral feeding are disrupted for any reason during this critical window of learning, then the development of these foundational skills may be impacted (Gosa et al., 2020). The development of typical healthy feeding processes requires a complex interaction between the child's physiological systems (in particular the cardiac, respiratory and digestive systems), sensorimotor functions, personality, temperament and preferences, and the carer, and the environment (Borowitz & Borowitz, 2018; Krom et al., 2017; Silva et al., 2016).

This section of the review provided me with a sound background understanding of the complex range of factors impacting the development of young children's feeding and eating and signposted the value of multidisciplinary teams in this space. It also started me questioning why some of the broader environmental and carer/family factors received less attention when so little of feeding and eating establishment is within the control of the child.

2.4.2 Feeding difficulties

The term 'feeding difficulties' is used within the literature to capture the broad range of eating difficulties in childhood including; low appetite, insufficient quantity, variety, or type of foods, refusal to eat, disinterest in food, behavioural responses to food and mealtimes that include tantrums, agitation, anxiety, distractions, disengagement, negotiations and parental, but especially, maternal distress and dissatisfaction (Kerzner et al., 2015; Maximino et al., 2016; McComish et al., 2016). There is recognition that 20-30% of all children experience these issues, and that they present on a spectrum from mild to severe (Cooke et al., 2017; Kerzner et al., 2015). Carers frequently report concerns with their children's eating (Borowitz & Borowitz, 2018), with one study reporting more than 50% of mothers of children under 2 years claimed that their children ate poorly (Carruth, Ziegler, Gordon, & Barr, 2004). Nevertheless, most feeding problems resolve in the first two years of life without requiring medical intervention (Cooke et al., 2017; Sharp et al., 2010).

2.4.3 Feeding disorders

The term 'feeding disorder' is more typically used within the literature to identify a severe problem. The DSM-IV diagnosis of feeding disorder of infancy or early childhood was relabeled as avoidant/restrictive food intake disorders (ARFID) in the DSM-5 (American Psychiatric Association, 2013; Sharp & Stubbs, 2019). This change brought eating and feeding disorders into one category and emphasised that, regardless of diagnostic features, an individual's challenges with food and eating may emerge in and persist from infancy through to adulthood (Sharp & Stubbs, 2019). The ARFID label was introduced within the psychiatric/medical fields to more appropriately reflect the breadth and diversity of this condition and to bring to the forefront the relevance and importance of the child's approaches to food and eating rather than an emphasis on what the child weighs (Aldridge et al., 2018; Bryant-Waugh & Kreipe, 2012). However, the introduction of this label has been met with debate. Goday et al. (2019) contend that the ARFID classification does not capture a multidisciplinary perspective or reflect the true nature of CFDs. They also propose that an ARFID diagnosis specifically excludes children whose primary challenge is a skill deficit, which they contend is not consistent with the reality of clinical presentations for these children (Goday et al., 2019). They propose instead the term Paediatric Feeding Disorder and define this 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). They assert that this diagnostic term would better support multidisciplinary intervention and more accurately capture the full range of concerns associated with feeding disorders and their functional implications, "most importantly, the impact on participation in daily family and community life" (Goday et al., 2019, p.125).

Eddy et al. (2019) commented on the division between the feeding disorders and eating disorders communities in the uptake of the term ARFID and expressed concern that the proposal by Goday et al. (2019) would further divide the field. Sharp and Stubbs (2019) suggest that as ARFID is now part of psychiatric terminology and is increasingly recognised by the wider paediatric health professional community, work should be prioritised to bridge this divide and further differentiate subtypes of ARFID (Sharp & Stubbs, 2019). Eddy et al. (2019, p. 362) further refined and operationalised the research and clinical implications for ARFID and defined ARFID eating as;

> characterized by food avoidance and/or restriction, involving limited volume and/or variety associated with one or more of the following: weight loss or faltering growth (e.g., defined as in anorexia nervosa, or by crossing weight/growth percentiles); nutritional deficiencies (defined by laboratory assay or dietary recall); dependence on tube feeding or nutritional supplements (≥50% of daily caloric intake or any tube feeding not required by a concurrent medical condition); and/or psychosocial impairment.

These recent publications on the categorisation of CFDs reflect debates in the field that appear to be based on fundamental but unexamined assumptions about health and illness and the contributing factors and impacts of these. Eddy et al. (2019) appear to represent a more biomedical construction of health and illness and it's impacts on the person who is experiencing the condition's body and, to a much lesser extent, mind. By contrast, Goday et al. (2019) represent a more biopsychosocial perspective of health as a mechanism for participation in everyday life and reflect a more holistic consideration of the body and mind impacts for the person experiencing the condition, their family and community. Goday et al's (2019) approach appears to be more inclusive of the range of ways a complex feeding disorder can develop. This conceptualisation is further described by Silverman et al. (2020) who argue that an ARFID diagnosis is more appropriate for predominantly behavioural feeding-related problems, whereas the Paediatric Feeding Disorder diagnosis, better reflects the medical and developmental complexity of children. Goday et al.'s (2019) approach provided me with a key foundation to build upon in terms of developing a more comprehensive and nuanced understanding of CFDs in young children.

Although the feeding difficulties referred to in this thesis would align more closely to the terms paediatric feeding disorder or ARFID as represented in the literature, I have chosen to use the term CFDs as it reflects the focus and values of the PFAT. It also reflects a useful umbrella term that can encompass the whole range of presenting problems and acknowledges carers' concerns (Kerzner et al., 2015) without pathologising or aligning with one side of a current and evolving categorisation debate.

2.4.4 Prevalence, cause and presentation

Prevalence of CFDs in children under five years of age is difficult to determine because of the range of ways this is categorised. Given the relative newness of the category ARFID, there are very limited data available to determine its prevalence in young children (Norris et al., 2016). There is consensus that feeding disorders occur in 25-35% of typically developing children (Manikam & Perman, 2000; Silverman, 2015), and in up to 80% of children with additional health concerns and development delays (Manikam & Perman, 2000; Petersen et al., 2006; Saini et al., 2019). CFD represent one of the most common conditions that carers seek support from paediatricians to address (Keren, 2016; Lukens & Silverman, 2014). Severe feeding difficulties are estimated to occur in 3-10% of children (Manikam & Perman, 2000; Sharp et al., 2017) and occur with much greater prevalence in children with significant physical disabilities (26%-90%) and medical illness and prematurity (10%-49%) (Manikam & Perman, 2000).

CFDs are considered to be highly heterogeneous (Sharp & Stubbs, 2019) and have multiple causes, involving an interplay of medical, nutritional, behavioural, psychological, social and environmental factors (Kerzner et al., 2015; Manikam & Perman, 2000). There are a number of medical and/or developmental conditions which are considered to predispose a child to more severe feeding disorders (Borowitz & Borowitz, 2018). These medical conditions impact on a child's ability to perform the activities required for feeding because of:

- Structural abnormalities of the face, oral cavity, or aerodigestive system
- Neuromuscular dysfunction/incoordination
- Inadequate strength and/or rapid fatigue/lack of endurance
- Inability to coordinate suck/swallow/breathe normally as a result of respiratory distress
- Nausea and/or discomfort during the feeding process (Borowitz & Borowitz, 2018).

This framing of the activities required for feeding reflects a biomedical construction and emphasises this as a physical task that does not consider the carer-child relationship, social or other environmental factors that may impact on the process of feeding. This contrasts with other constructions of CFDs as a "relational disorder between the feeder and the child" (Kerzner et al., 2015, p. 345), with both carer and child impacting on the development and ongoing issues (Goday et al., 2019). Gosa et al. (2020) frame this slightly differently again and identify certain clinical populations as being more likely to experience CFDs. These include those born prematurely, or born with developmental delays, cardiac disease, pulmonary disease, neurologic disease or disorders, or craniofacial disorders (Gosa et al., 2020). Begotka et al. (2018) add in behavioural and sensory problems with their classifications including structural/anatomic, neurodevelopmental, cardio/cardio-respiratory, gastrointestinal, metabolic, allergy/immune, endocrine, behavioural, and sensory problems.

Children with CFDs present with complicated histories and risk factors that include a variety of developmental (Saini et al., 2019), medical and psychiatric factors affecting nutritional intake (Manikam & Perman, 2000; Norris et al., 2016). Infants and young children with CFDs may also present with a broad range of issues or concerns including delayed cognitive and emotional development, compromised immune functioning (Sharp et al., 2017), stress, fear, reacting to stress or trauma, reacting to messages about foods; restricting or avoiding foods to avoid pain, choking, vomiting, adverse taste or texture experiences or reacting to parental stress and stress at mealtimes (Norris et al., 2016). These CFDs are difficult to diagnose and treat due to the range of contributing factors and presentations (Greer et al., 2007). As discussed in chapter one, this wide range of presentations and histories means that children experiencing these issues may require frequent hospitalisations (Sharp et al., 2017) and be seen by many different health professionals across different aspects of the health care system including general practice, community and acute care (Norris et al., 2016).

Many children with CFDs have spent significant periods of time unwell and receiving medical treatment for conditions that involve pain and discomfort (Borowitz & Borowitz, 2018; Marshall et al., 2018). In this context, feeding quickly becomes associated with pain, stress and discomfort for both child (Borowitz & Borowitz, 2018; Sharp et al., 2017) and carer (Franklin & Rodger, 2003; Hewetson & Singh, 2009). Early feeding experiences often occur in abnormal sensory environments (eg hospital wards or clinics), disrupting carer-child interactions that support bonding and responsive feeding patterns and interfering with the everyday typical encounters with food and eating including the social, sensory and exploratory aspects (Borowitz & Borowitz, 2018). They may also disrupt crucial opportunities to develop foundational mouth and movement (oro-motor) skills required for feeding and eating (Gosa et al., 2020). These early life moments can result in long lasting physical and emotional behaviours and responses to food and eating that persist even when the painful condition may have resolved (Borowitz & Borowitz, 2018; Marshall et al., 2018; Sharp et al., 2017) and yet there is very little research focused on how to improve these health care environments and pay attention to these important factors. These findings informed the observation components of the study design and helped me structure my research to consider the role that an interdisciplinary team could play in responding to these disruptions.

2.5 Significance of caring and gender roles

2.5.1 Impacts on carers

CFDs occur within and affect the whole family (Manikam & Perman, 2000). A relational construction of CFDs brings the carer and the importance of the child-carer relationship to the forefront and posits that both parties contribute to the development of, and responses to, feeding and both need to be involved in any intervention (Goday et al., 2019; Greer et al., 2007; Kerzner et al., 2015). There is a risk in this framing, of the carer being considered, by others and themselves, as part of the 'problem'. This places them in a position of vulnerability and potential judgement that was not addressed in the literature. Thus, examination of the risk of judgement and blame from health professionals was identified as a research gap. I therefore employed methods that were inclusive of carers' perspectives and paid particular attention to power differentials and the potential for exacerbating carers' experiences of blame and judgement (see Chapter 3).

Caring for a child with any chronic illness or disability is highly stressful and presents risks to the carer for a range of additional health and wellbeing challenges (Bourke-Taylor, Jane, & Peat, 2019; Bourke-Taylor, Howie, Law, & Pallant, 2012). Additional stressors come with caring for a child with CFDs including the pressures carers, and especially mothers, experience as a result of societal expectations associating competent parenting with provision of adequate nourishment (Craig, 2005; Greer et al., 2007; Silverman et al., 2020). When feeding does not happen with ease it can cause significant impacts on parental stress, guilt, self-esteem, self-efficacy and confidence (Craig et al., 2003; Franklin & Rodger, 2003; Garro et al., 2005; Goday et al., 2019; Greer et al., 2007; McComish et al., 2016; Silverman et al., 2020).

Silverman et al. (2020) built on from the work of Greer et al. (2007) and Garro et al. (2005) and examined the levels of carer stress present in 840 carers of children with CFDs using four recognised standardised assessment measures (Parent Stress Index- Short Form, Mealtime Behaviour Questionnaire, Child Development Inventory and Child Behaviour Checklist). They identified specific risk factors for parenting stress as the presence of mealtime behaviour problems, both externalizing (oppositional or aggressive behaviours) and internalizing behaviours (mood or anxiety) and the degree of developmental delay(s) experienced by the child (Silverman et al., 2020). They confirmed that the more emotionally dysregulated a child is around eating and mealtimes the greater the levels of carer stress (Silverman et al., 2020). This study, exemplifying a behavioural approach, analysed stress based on a certain construction of stress informed by the use of particular measurement tools and methodological approach. There was limited exploration of what this meant for carers or clinicians at a practical level. Garro et al. (2005)'s study took a more biopsychosocial approach; reflected in their choice of measures that included the Parent Stress Index- Short Form, but also the Family Inventory of Life Events and Changes and Coping Health Inventory for Parents. These additional measures offered a more holistic and family focused view of stress and consideration of the impact of caring for a child with CFDs. Their results provided useful implications for clinical practice that included the importance of working collaboratively with the family to understand the stressors they may be experiencing (Garro et al., 2005). This study provides an example of a positivist methodology that through choice of research instruments and study design reflected a biopsychosocial perspective.

Most of the literature regarding carer perspectives of CFDs involved carers of children requiring tube feeding. Many children with CFDs require naso-gastric (n-g) or gastrostomy tube (GT) feeding to support adequate nutritional intake (Lively et al., 2020; Manikam & Perman, 2000). Naso-gastric tube feeding is most often considered a short term measure, with GT feeding considered a longer term solution (Craig & Scambler, 2006). Weaning from tube feeding is known to be a difficult process (Krom et al., 2017; Manikam & Perman, 2000) and tube dependency has significant health and economic consequences (Krom et al., 2017). Most of the studies in this area were of either qualitative or mixed methods design and reflected a constructionist epistemological position and a biopsychosocial framing of CFDs with key themes identified as experiences of stigma and pressure to uphold societal expectations around the provision of food and the associated role of nurturing (Craig, 2005; Craig & Scambler, 2006; Hewetson & Singh, 2009; Petersen et al., 2006; Spratling & Lee, 2020).

Carers expressed a strong sense of failure and incompetence as nurturers when GT insertion was required to feed their child (Petersen et al., 2006). . Reflecting a normative discourse (Craig, 2005), carers reported feeling that eating by mouth was 'natural' and that their child was rendered "somewhat 'less human'"(Petersen et al., 2006 p. 716) when they were unable to eat in this way. The strength of this belief and the societal value of eating together as a family (Evans & Rodger, 2008; Russell et al., 2018) was attested to by the high proportion of carers who continued to orally feed their child despite specific medical advice that this placed their child at risk (Petersen et al., 2006). This highlighted the importance of family mealtimes and the impact of CFDs and tube feeding on stress levels and relationships between family members negotiated through mealtimes (Russell et al., 2018).

Mothers reported fearing for their child's survival and experienced guilt, stress, and difficulties bonding with their child because they were so focused on feeding them and getting enough nutrients into their child (Franklin & Rodger, 2003; Hewetson & Singh, 2009). This also impacted on their time use and meant they had little time left to care for themselves or undertake leisure activities (Winston et al., 2010). This then often resulted in feelings of frustration, rejection, anger and guilt and was very much tied to a sense of failing as a mother (Franklin & Rodger, 2003). Additionally, feeding a child with CFDs required significantly longer time and often the need to negotiate tubes, pumps, syringes, calculate calories and balance timing of feeds as well as attending multiple health appointments (Craig, 2005; Winston et al., 2010). Carers consistently reported feeling overwhelmed with the amount they needed to do to support their child and that services were often unaware and unresponsive to these challenges (Russell et al., 2018; Winston et al., 2010). They highlighted the need for greater understanding of the everyday impacts of caring for a child with CFDs, their own emotional support needs and provision of associated practical and targeted support (Craig et al., 2003; Franklin & Rodger, 2003; Hewetson & Singh, 2009; Petersen et al., 2006; Russell et al., 2018; Winston et al., 2010).

Craig (2005) explored and challenged the prevalent psychological discourse surrounding feeding children with CFDs as one of grief and loss and presented a more nuanced analysis that considered the social constructions of mothering and feeding and the implications of these as a way of making sense of the guilt, disgust, isolation and conflict that mothers reported feeling as they worked to renegotiate their role of mother and find new ways to relate to their child through the feeding process (Craig & Scambler, 2006). Caring for a child with CFDs was further described as a transformative experience where joy, love and empowerment coexisted with grief, sorrow and disempowerment (Hewetson & Singh, 2009). Craig's work with her colleagues (Craig, 2005; Craig & Scambler, 2006) employed a feminist poststructural epistemological approach that offered a mechanism to consider how feeding practices and mothers' experiences were influenced by broad social and cultural practices and dominant constructions of mothering. It provided a way of going beyond what mothers said, to consider why they may have said this.

This section of the literature review highlighted the value of understanding carers' stress and working with families to identify and address specific stressors and coping strategies that support their everyday lives. Understanding the patterns, routines and implications of daily life when caring for a young child with CFDs will help identify stressors at individual and system levels to ensure services are supportive, responsive and tailored to individual needs and circumstances

(Craig, 2005; Craig & Scambler, 2006; Craig et al., 2003; Hewetson & Singh, 2009; Winston et al., 2010). Reviewing the work of Craig and colleagues (Craig, 2005; Craig & Scambler, 2006) brought my attention to poststructuralism and helped me consider epistemological and methodological choices that matched my interest in exploring a more holistic framing of CFDs.

2.5.2 The role of gender

The majority of the studies that focused on carers and their responses to children's eating concerns were focused on mothers. As indicated in the literature summary table in Appendix 1, of the 14 studies that focussed on carers, five specified mothers as the participants, but three of the nine remaining studies had all female participants and the majority of participants in the mixed studies were female. In one study, 91% of carers who verified their responsibility for food choice and feeding were mothers (Carruth et al., 2004) and more recently in a study examining carer stress levels, 92% of the 840 participants were mothers (Silverman et al., 2020). In one of the first studies to examine carer perspectives of feeding their medically compromised children, both parents perceived feeding and nurturing to be primarily the responsibility of the mother and, on the occasions where fathers played a greater role, it was attributed to particular paternal characteristics such as patience or persistence (Franklin & Rodger, 2003). The fathers in this study viewed their role as providing discipline at mealtimes and supporting mothers to be able to feed their child (Franklin & Rodger, 2003).

This focus on mothers in the literature reflects the broader gendered nature of caring for children, provision of food and managing health (Craig & Scambler, 2006; Warin, Jay, & Zivkovic, 2019). This is emphasised even more in the area of feeding and nurturing a child where mothers often consider their difficulties with feeding their child to be a reflection of their competency and capacity to be a good mother (Craig & Scambler, 2006; Hewetson & Singh, 2009). This is associated with broader social and cultural constructions of the ideal mother as one who naturally nurtures and feeds her child with love and care (Craig & Scambler, 2006; Hewetson & Singh, 2009; Woodward, 2003). There is significant value in research that unpacks these constructs and goes beyond naming these as concerns and explores why, however examination of gender as a social construct in the area of CFDs received very little attention. The exception to this was the work of Craig and colleagues (Craig, 2005; Craig & Scambler, 2006). As already mentioned, they employed a feminist poststructural approach that offered a depth of analysis including considerations of gender. This added further support to the value of a poststructural epistemological and methodological approach to research in this field and helped me refine my research aims.

2.6 Constructions of best practice approaches to complex feeding difficulties

Despite the high prevalence and significant impacts associated with CFDs, there is a lack of strong evidence to guide clinical practice in this area (Lively et al., 2020; Marshall et al., 2015). Contributing factors to this include, a wide range of intervention approaches and a lack of well-designed intervention studies (Lively et al., 2020; Marshall et al., 2015). As previously discussed, there are also diverse ways of categorising CFDs and attempts to refine and unify the field are currently under debate (Eddy et al., 2019; Goday et al., 2019). This section examines 'best practice' intervention approaches that are described within the literature.

2.6.1 Multidisciplinary teams

In the absence of clear and consistent clinical guidelines, it is generally accepted that effective interventions for CFDs need to target the cause of the problem and this requires a multidisciplinary team approach to assessment and ongoing intervention (Borowitz & Borowitz, 2018; Gosa et al., 2020). Each discipline in the multidisciplinary team is considered to play a vital and distinct contribution to understanding the issues and developing a collaborative intervention plan (Gosa et al., 2020). The primary goal of multidisciplinary intervention approaches was typically consistent with framing CFDs as behavioural, biomedical, biopsychosocial or relational. For example, studies with a behavioural framing considered intervention goals to be related to specific behaviours such as increasing dietary variety, reducing undesirable mealtime behaviours (Marshall et al., 2015) or managing carer stress levels (Greer et al., 2007). Goals identified in biomedical research focused on the child achieving safe, age or developmentally appropriate feeding skills and adequate nutrition and growth through positive mealtime experiences (Borowitz & Borowitz, 2018; Gosa et al., 2020). Studies from a biopsychosocial perspective considered the child's developmental stage, nutritional status, participation and carers goals when developing intervention plans (Goday et al., 2019). Relational research additionally addressed the carers' capacity to respond to the child throughout the feeding experience (Davies et al., 2006; Keren, 2016; Kerzner et al., 2015).

There was strong support for a multidisciplinary team approach to working with young children with CFDs across all four approaches. One paper indicated that a multidisciplinary team approach was only needed in complex cases (Eddy et al., 2019) but the majority of the systematic reviews and clinical research supported a multidisciplinary approach regardless of severity (Begotka et al., 2018; Edwards et al., 2015; Marshall et al., 2018; Mazze et al., 2019; Sharp et al., 2017; Williams et al., 2017). There was variance in the membership of multi-disciplinary teams reported in the literature (see Appendix 1). Gosa et al. (2020) were the only authors to identify carers as essential members of the multidisciplinary team.

Given the complexity and range of presentations for children with CFDs and their families outlined previously, a multidisciplinary, coordinated care approach is essential for accurate diagnosis, timely interventions, and positive outcomes (Gosa et al., 2020; Maximino et al., 2016; McComish et al., 2016; Sharp et al., 2017). It also enables children and carers to see more than one discipline in a single visit and has additional benefits of reducing trips to services and the associated costs and burdens of carparking, travel and time, improving communication between the various disciplines and the family, and streamlining services for the family (Maximino et al., 2016; McComish et al., 2016). Presenting compelling evidence, a meta-analysis of 11 studies involving 593 participants determined that intensive multidisciplinary treatment was effective for young children with CFDs. (Sharp et al., 2017). The overall effect size for percentage of children successfully tube weaned was 71% and the benefits of the programs appeared to persist with up to 80% of children tube free at follow up and experiencing increased oral intake, improved mealtime behaviours and reduced parenting stress.

Despite this clear endorsement of multidisciplinary teamwork, only one definition was found where a team was described as “one that works together and collaboratively in different contexts” p.330, which was then referred to as an interdisciplinary approach (Maximino et al., 2016). The terms multidisciplinary and interdisciplinary were used interchangeably in this literature and were not well defined or described. Reference was made to the concept of a ‘well-functioning interdisciplinary team’ (McComish et al., 2016; Williams et al., 2017) but other than a description of the composition of the team, there was limited explanation as to what this meant. Factors identified as important in working as a team and optimising assessment and intervention outcomes were communication within the multidisciplinary team, integration of expertise across domains (Edwards et al., 2015) and the use of interdisciplinary clinical decision making and collaboration (Williams et al., 2017) however these were not described. There appears to be assumptions that a ‘well-functioning team’ is a known and understood construct. This influenced my research design by ensuring I paid close attention to how the multidisciplinary team functioned in my observations and asked both carers and clinicians about their perspectives of this construct in my interviews to help address this gap.

2.6.2 Intervention environments

Intervention environments described in the literature can be broadly classified as outpatient, day treatment, or inpatient. Outpatient services are more accessible and less expensive than other options (Lukens & Silverman, 2014) but offer low frequency treatment and are less likely to involve multidisciplinary input, specialised skills and knowledge (Begotka et al., 2018). Day treatment models allow for greater frequency of contact, tighter control over the feeding environment and increased multidisciplinary team access (Lukens & Silverman, 2014). These intensive programs have daily treatment sessions for at least five days (Lukens & Silverman, 2014). Inpatient hospitalisation is most suited for medically unstable and severely affected children as it allows for the greatest environmental control, the closest medical supervision as well as intensive multidisciplinary involvement (Lukens & Silverman, 2014). Home as an intervention environment was not prominent in the literature reviewed. One study reported on the results of a home-based behavioural treatment for tube dependency (Taylor et al., 2019) and one study examined mealtime behaviours in the home (Aldridge et al., 2018). Lukens & Silverman (2014) concluded that inpatient and day treatment programs have the most evidence for positive treatment outcomes, but this finding reflects the paucity of research conducted across different settings. These findings influenced my research design by ensuring asked questions about and observed the services provided in home environments and the ways that health service responses influenced outcomes in the home.

2.6.3 Intensive versus weekly therapy

There is mixed evidence regarding the value of intensive versus weekly therapy options. One American study compared the outcomes of a five week multidisciplinary intensive outpatient feeding therapy program to a once weekly single discipline therapy option and reported positive results for the intensive therapy approach (Williams et al., 2017). It was not possible, however, to identify if the improvements were based on the intensity of the approach or the multiple disciplines involved. In contrast, an Australian randomised control study found no significant differences between intensive or weekly therapy (Marshall et al., 2018). These studies reflected a biomedical framing and a positivist epistemological approach focused on understanding clearly defined aspects of the condition, and carers' views were not sought.

In their systematic review of psychological interventions for CFDs, Lukens and Silverman (2014) found that in an outpatient setting, weekly interventions comprised of appetite manipulation and behavioural therapy based on operant conditioning were effective in decreasing tube dependency;

however, it was unclear as to the relative contributions of each treatment component. The results of this review indicated that for some children weekly outpatient therapy may decrease the need for more intensive intervention (Lukens & Silverman, 2014). Other intensive programs reported being designed for children who had not made progress with weekly therapy (Begotka et al., 2018).

2.6.4 Intervention approaches

Recommendations for 'best practice' intervention approaches to respond to young children with CFDs included: interdisciplinary/ multidisciplinary approaches, a focus on nutritional, behavioural and skill focussed interventions, the active involvement of carers, parent education (Begotka et al., 2018; Lukens & Silverman, 2014; Marshall et al., 2015; Sharp et al., 2017; Williams et al., 2017), transition plans and follow up to ensure gains are sustained (Sharp et al., 2017), family centred care (McComish et al., 2016) and a focus on carer stress levels (Greer et al., 2007). Many of the successful programs described in the literature were based on biomedical and behavioural framings and included variations of a medical, motor and behavioural approach which addressed the complexity of feeding difficulties as follows: 1) medical; evaluating and managing underlying medical issues that can cause feeding problems (e.g., gastroesophageal reflux, constipation, food intolerances/allergies); 2) motor; treating delays or challenges in oral, sensory, gross and fine motor skills and supporting optimal positioning for feeding; and 3) behaviour; addressing negative feeding behaviour through the use of behavioural interventions and strategies (Borowitz & Borowitz, 2018; Howe & Wang, 2013; Lukens & Silverman, 2014; Manikam & Perman, 2000; McComish et al., 2016). Providing a more biopsychosocial perspective, Goday et al. (2019) recommended that intervention approaches should focus on medical, nutritional, psychological and feeding skills and consider the impact on carers and children and their participation in everyday life. Grounded in an ecocultural theoretical approach, and also reflecting a biopsychosocial framing, the work of Backman et al. (2019), recommended a focus on communicative, social and emotional aspects of therapy as well as strategies that enable participation in everyday life.

2.6.5 Behavioural approaches

Reflecting the predominance of intervention literature from a positivist epistemological position, behavioural interventions are the most researched and thus form the strongest evidence base. The results of a well-designed scoping review of international tube weaning approaches identified 32 papers of which 13 described a behavioural approach to tube weaning (Lively et al., 2020). Of these 13 studies, study designs included five case series, one randomised controlled trial, four cohort studies, one observational, and two case studies. Behavioural approaches were carried out by a psychologist or behavioural therapist who initiated strict feeding regimes with the child. Carer involvement was limited to when the child had begun to make gains with oral intake and their negative mealtime behaviours had been reduced (Lively et al., 2020). Furthermore, the results of a systematic review of literature to evaluate the effectiveness of feeding interventions for young children found that behavioural interventions were effective in improving children's appetite, acceptance of food, oral intake and mealtime behaviours (Howe & Wang, 2013).

Behavioural approaches predominant in the literature fell into two groups; operant conditioning and more recently systematic desensitisation (Marshall et al., 2018; Marshall et al., 2015). Operant conditioning was the most common form of behavioural intervention and was described as top-down, prompt-and-reward style of intervention (Marshall et al., 2015) that used a range of techniques including reinforcement, punishment and escape extinction and was externally driven, meaning the child needed to take a bite to receive an external reward (Marshall et al., 2018). Systematic desensitisation is emerging in the literature as a newer behavioural approach that is described as bottom-up, play-based, modelling style of intervention (Marshall et al., 2015). This approach involves gradual exposure to a feared stimulus in a relaxing environment and is internally driven, meaning the child is invited to look, smell, touch, then taste and eat but only does so on their own volition (Marshall et al., 2018).

Some studies have reported positive outcomes from programs based on operant conditioning (Lukens and Silverman (2014). Programs were typically tailored to specific patient conditions and all used operant conditioning behavioural interventions, conducted three or more therapy sessions a day and provided some degree of parent training. They concluded that these programs supported promising treatment effects across both child mealtime behaviour and nutrition (Lukens & Silverman, 2014). An Australian randomised control study found no significant differences between outcomes when comparing operant conditioning and systematic desensitisation behavioural approaches (Marshall et al., 2018).

2.6.6 Involvement of carers

Some programmes emphasised the role of the carer as pivotal to the process of supporting a child with CFDs (Aponte et al., 2019; Gosa et al., 2020; McComish et al., 2016) although this was not uniform. When carers were mentioned, it was deemed important to take their concerns seriously and respond promptly to avoid the common progression to entrenched and difficult to address feeding difficulties (Kerzner et al., 2015; Lukens & Silverman, 2014; Manikam & Perman, 2000). A team philosophy that aims to upskill and empower carers and supports them to be the key 'feeders' of their children appeared to be important (Marshall et al., 2018; Sharp et al., 2017). This approach emphasised building the knowledge, skills and capacities of carers to be able to understand and support their child's feeding needs (McComish et al., 2016; Williams et al., 2017). These papers reflected the dyadic nature of feeding, and the importance of the relationship between the carer and the child, and considered working with carers and children more likely to promote improvement in children's mealtime behaviours and overall feeding outcomes (Howe & Wang, 2013; Kerzner et al., 2015). As an example Kerzner et al. (2015) considered a successful outcome to be one where carers understood their child's feeding difficulty, had received information about supporting mealtimes and feeding practices related to their specific feeding style, understood the goals and felt confident to carry out the selected intervention.

The results of a systematic literature review examining the effectiveness of interventions used in occupational therapy to improve feeding outcomes for young children indicated that educational interventions aimed at carers were moderately to strongly effective in improving children's physical growth, development, increasing the feeding competence for children and carers and strengthening the parent-child relationship (Howe & Wang, 2013). These types of interventions focused on providing carers with information on how to facilitate appropriate feeding behaviours. They were however unable to determine which form of delivering parent education was preferred (Howe & Wang, 2013). Approaches aimed at building capacity in carers were considered highly beneficial and cost effective ways of supporting carers to feed their children on a daily basis in their home environments and reduce reliance on specialist help (Aponte et al., 2019).

Some approaches, typically within the relational or biopsychosocial categories, referred to partnering with the family to improve outcomes (McComish et al., 2016) and saw carers as part of the 'solution' and valued their voice in assessment and intervention. Other programs and approaches, within the behavioural and biomedical categories, presented carers as part of the 'problem' and described their "maladaptive" or "suboptimal" interactions with their children as resulting in behavioural and feeding concerns (Begotka et al., 2018; Mazze et al., 2019). One study characterised psychosocial factors as child feeding avoidance behaviours and "suboptimal" carer feeding strategies which they further described as carers using force feeding (14.5%) and distractions (47.1%) to make their child eat. The most commonly used distractions identified were television (25.4%) and mobile screens (15.9%) (Mazze et al., 2019). These ways of viewing carer involvement resulted in programs that focused on behavioural approaches that taught carers how to feed their child ‘properly’. An example of this is a 5-day intensive outpatient parent training protocol described and evaluated by Begotka et al. (2018). This study utilised carer completed measures that showed pre-to-post improvements in carer-child mealtime interactions, decreased problematic mealtime behaviours, and improved carer use of effective mealtime strategies. Decreases in carer distress and carer perceptions of their child as difficult were also found (Begotka et al., 2018). There were, however, no studies identified that specifically included carer perspectives of these types of behavioural programs. Given the findings of research examining carer perspectives, outlined in section 2.5.1, that they feel blamed and guilty for not being able to feed their child ‘properly’, this is an important gap that my study will address by examining both carer and clinician perspectives.

An analysis of medical records conducted by Backman et al., 2019 demonstrated a predominance of therapist goals and interventions focused on the child’s body functions rather than the child more holistically. This research challenged health professionals to consider the everyday experiences of their clients rather than focus on their presenting problems in isolation. Their findings indicated that true family centred care would consider participation in everyday activities and in particular mealtimes as a meaningful goal for therapy for children with CFDs (Backman et al., 2019). A partnership approach to working with carers that included more emphasis on really understanding their concerns and beliefs about feeding, their unique coping styles, creating more tailored family-centred interventions, and allowing carers to make decisions is warranted (Garro et al., 2005; Hewetson & Singh, 2009; Petersen et al., 2006). Findings indicated a lack of professional focus on supporting families to adapt to everyday life or to consider their social, psychological or environmental needs and instead a strong emphasis on managing the physical aspects of care and recovery including nutrition and weight gain (Backman et al., 2019; Petersen et al., 2006; Russell et al., 2018). Carers identified factors that helped them to cope as; parental sharing of childcare duties, learning to let go of expectations, accepting help, and building good relationships with health professionals (Franklin & Rodger, 2003; Hewetson & Singh, 2009). This complements best practice clinical evidence indicating successful multidisciplinary teams build strong engagement with families and carers (Williams et al., 2017) and partner with families (McComish et al., 2016).

Another type of program favoured in the literature focused on a home feeding program with written goals where techniques were expected to be practiced at home in between sessions

(McComish et al., 2016; Williams et al., 2017). Carers’ experiences of a similar style of program while adjusting to GT feeding indicated that the expectations of health professionals were often unrealistic and not aligned with their unique needs (Russell et al., 2018). Caregivers experienced health professionals as “being removed from the realities of what is going on in the home” (Russell et al., 2018, p. 33) which resulted in additional burden, frustration and stress with many carers feeling very overwhelmed. Comparisons like this between research focusing on carer perspectives and research focussing on clinician perspectives highlights gaps and mismatches. This helped me to position my study to address this lack of carers’ perspectives on the types of effective programs. It also reinforced my decision to examine both carer and clinician perspectives.

2.7 Summary of findings

I undertook a narrative review to provide an overview of the current literature, identify gaps in research and new study areas (Ferrari, 2015). CFDs in young children is an under-researched field that encompasses a wide range of disciplines and understandings and is currently experiencing debate regarding categorisation. There is strong consensus that CFDs in young children are recognised as a heterogeneous condition that encompass a wide range of clinical presentations (Manikam & Perman, 2000; Sharp & Stubbs, 2019) and that there is a need for further clarity and refinement in the field and further mechanisms to support critical reflection and provide guidance and structure for clinical practice and ongoing research (Goday et al., 2019; Lively et al., 2020; Marshall et al., 2015; Sharp & Stubbs, 2019).

As a mechanism for summarising the literature, I categorised the ways CFDs were constructed and identified four categories, biomedical, behavioural, relational and biopsychosocial, as described in section 2.3. Examining the ways CFDs were conceptualised in the literature in this way helped me identify research gaps and raised numerous questions. As examples, I wondered why some aspects of behaviour were prioritised for research and others were not. I wondered about the messiness and complexity of living with a child with CFDs and why the impact of this on everyday life was so often overlooked. I wondered why certain disciplines were so prevalent in the research. I wondered why some voices were so absent. I wondered about the relationship of this to power and to what is considered true and real.

There is a predominance of positivist research aimed at understanding clearly defined narrow aspects of CFDs. While there were several studies employing a social constructionist approach and attempting to make meaning of people’s experiences, the majority of the intervention research was conducted within a positivist paradigm using quantitative methodology. Despite strong recommendations throughout the literature to address this issue holistically applying a multidisciplinary approach and considering biological, psychological and social aspects of care for children with CFDs, and the needs of their families, the literature on programs and approaches typically reflected an emphasis on the physical and behavioural aspects of the child's care and a dominant biomedical and behavioural construction of the issue.

A number of key constructs were unexamined, assumed or overlooked. These included feeding versus eating, the role of broader sociocultural influences including gender on how CFDs develop and are experienced, what comprised a 'well- functioning' multidisciplinary team, a focus on and response to the carers' physical and emotional needs and the emotional and psychological wellbeing of the children and carers. There was minimal research examining carer perspectives and these were rarely sought when evaluating the effectiveness of intervention approaches. There was no research identified in this field that brought together carer and clinician perspectives. Additionally, there was a focus on interventions that considered feeding difficulties in isolation from the everyday impacts of these difficulties for the children and their families. In an area that is highly stigmatised, research examining carers' experiences of judgement and blame from health professionals and the impact of this on seeking and receiving support was identified as another gap in the literature. Comparing research focusing on carer perspectives and research focusing on clinician perspectives highlighted gaps and mismatches in evidence-based practice in this field. This indicated that further research including carers' perspectives on the types of 'effective' programs is needed. It also highlighted the value of research that seeks to examine and consider both carer and clinician perspectives.

2.8 Conclusion

This review has identified a need for an epistemological approach that extended the current main approaches; one being a positivist framing of research that focused on defined aspects of CFDs; the other being a social constructionist approach that examined carers' perspectives. Reviewing the work of Craig and colleagues (Craig, 2005; Craig & Scambler, 2006) brought my attention to poststructuralism and informed my epistemological and methodological choices. Poststructuralism matched my interest in exploring a more holistic framing of CFDs and provided a way to unpack and critically examine the clinical issue of CFDs and address the research gaps identified. This informed my epistemology, and the development of my research aims. As will be discussed in

Chapter 3, I employed a Foucauldian- influenced poststructural approach and undertook a qualitative study that examined both carer and clinician perspectives and included in-depth interviews and observational data across clinic and home settings. This provided holistic attention to the impacts on everyday life, power differentials and the potential for exacerbating carers' experiences of blame and judgement. It also allowed me to closely study the functioning of an interdisciplinary team. The rationale for this approach, research design and methods are described in the next chapter.

Chapter 3 **METHODOLOGY**

3.1 Introduction

This chapter will provide a detailed justification and explanation for the epistemology and methodological approach employed in this research. The research process will be outlined, as will the process of gathering, organising, analysing, and synthesising the data. Ethical considerations and the trustworthiness of this research will be discussed. The results of my literature review indicated that there was a need for an epistemological approach that extended the current positivist and social constructionist approaches to address gaps in understanding some of the key concepts that emerged from examining how CFDs were currently constructed, thought about and acted upon. This led me to consider a methodological approach that could unpack the way we think about clinical issues and how that influences the ways we respond to them.

3.2 Rationale for approach

My research aims were:

1. To critically examine and compare how the problem of CFDs is being represented in clinical practices and experienced by carers.
2. To analyse how problem representations influence experiences and practices of health care.
3. To reflect on the contribution and extension of the What's the problem represented to be? (WPR) approach (Bacchi, 2009) to clinical practices.

To address these aims I required an ontological and epistemological approach that enabled me to critically examine how this clinical issue was represented as a problem. I called upon a poststructural ontology that views social reality as an ongoing state of becoming shaped by power and politics (Chia, 1996) and examined "reality-constituting practices" (Chia, 1996, p. 31) within a clinical health care setting. I studied clinical health care practices as political practices that influence the ways knowledge comes to be understood as truth (Bacchi & Goodwin, 2016) In this context, knowledge is considered as an effect of power relations rather than something to be gained or exchanged (Bacchi & Goodwin, 2016). Consistent with this approach, Mol (2002) focuses on "knowledge practices"p.5 and holds that "ontology is not given in the order of things, but that, instead, ontologies are brought into being, sustained, or allowed to wither away in common, day-to-day, sociomaterial practices."(Mol, 2002, p. 6). Mol's work provides an excellent justification for applying this ontological perspective to a health care setting because ontologies "inform and are informed by our bodies, the organization of our health care systems, the rhythms and pains of our diseases, and the shape of our technologies"." (Mol, 2002, p. 7).

I employed a poststructural approach to examine the unexamined and help challenge assumptions that can be missed in a purely social constructionistic approach. I was aware that cultural and social meanings can be hidden and taken for granted by the "tyranny of the familiar" (Crotty, 1998, p. 59), a process whereby we make assumptions that the way we do things are the ways they are done by everyone. Culturally and socially constructed meanings can also reinforce and mask particular power structures (Crotty, 1998). I therefore adopted a Foucault-influenced poststructural theoretical approach to support a critical deconstruction of CFDs. A poststructural approach offers a way to interrogate and examine truth claims and the systems that allow truth to be privileged or silenced and to challenge the uncontested ideas of truth and knowledge by considering them as social products that reflect specific contexts, circumstances and influences (Bacchi, 2009). Poststructuralism as an approach therefore takes on a sceptical rather than a relativist stance on knowledge claims (Bacchi & Goodwin, 2016). Foucauldian based analyses of health care settings provide an alternative way of examining health conditions and health care practices and enable a critical perspective that challenges assumptions and offers new insights.(See examples including Annerstedt & Glasdam, 2019; Austin, 2019; Davis et al., 2019; Gardner, 2017; Hodges, Martimianakis, McNaughton, & Whitehead, 2014; Maynard, 2020; Rowland & Kuper, 2018; Tierney, 2004)

Annemarie Mol's work is based on extensive ethnographic studies immersed within health care facilities. She observed and interviewed patients and clinicians working with and experiencing diabetes (Mol, 2008) and atherosclerosis (Mol, 2002) within major hospitals in The Netherlands to more fully understand health care practices and living with a disease or condition. She strongly emphasises the importance of health care teams working collaboratively to understand and support a person living with a disease to live their everyday life in the best way possible. She analysed health care practices in order to compare "patient choice" (the logic of choice) and "good care" (the logic of care) (Mol, 2008). Mol uses the term logic in a philosophical context to refer to events and processes that fit together in a creative and fluid way. This is similar to Foucault's use of discourse which refers to "knowledge, what is "within the true"" (Bacchi & Bonham, 2014, p. 174). A Foucault-influenced poststructural approach applies an analysis of discursive practices, to give access to the rules that explain how it becomes possible to say or know certain things; ''the rules governing a knowledge" (Cousins & Hussain, 1984, p. 94).

I argue that synthesising these two approaches allowed me to address my research aims. A poststructural approach based on WPR offered the mechanism to question the taken for granted nature of the clinical problem of CFDs. Mol’s work in considering a logic of care provided the mechanism for discussing the results of the WPR analysis that brought the clinicians, carers, and children back to the forefront. This methodological approach provided a way for me to address the gaps identified in the literature review on CFDs described in Chapter 2, and examine both clinician and carers perspectives of working with and caring for a young child with CFDs from a holistic view that kept the impacts on everyday living front and centre. I was also able to examine health care encounters and the workings of an interdisciplinary team through this lens.

3.2.1 Methodological implications

This ontological position has methodological implications. Qualitative research that relies on interviews and participant observation, relies on the concept of research subjects as sources of experiential knowledge. A poststructural approach challenges the notion that these participants’ experiences give access to ‘the truth’. The literature reflects the contested role that ethnographic methods such as interviews and participant observation play in poststructural research. One line of argument is that ethnography plays an important role in governmentality studies to ensure that the voices of those affected and their everyday experiences are considered (Brady, 2014; McKee, 2009). McKee describes governmentality studies as top down accounts of governing practices that ignore the “messy empirical actualities”(McKee, 2009, p. 473) of lived realities. She states that the reliance of most governmentality studies and poststructural analysis on text-based policy documents is a limitation for “those researchers interested in the effects of power at the micro-level and the lived experience of subjection” p. 474. McKee and other scholars including O'Malley, Weir, and Shearing (1997) propose that a top-down solely discursive analytic approach contradicts Foucault’s perspective of power and the role social relations play within this. Brady (2014) further argues that by including interview and observation data within analysis researchers are forced to consider the “multiplicity and dynamics of everyday social life” p13 which offers greater insights into the complexity of power relations and practices and the actual processes through which subjectivities are formed. Mol’s praxiographic work adds further perspective to this debate by stating that people’s identities “do not precede their performances, but are constituted in and through them” (Mol, 2002, p. 38). Praxiography is based on the concept that ‘the social’, ‘the cultural’, and ‘the political’ are based primarily in implicit knowledge and meaning and reflected through practices (Bueger, 2014).

The role of interviews within poststructural research is also contested (St Pierre, 2011). Bonham and Bacchi (2017) summarise the concerns expressed within poststructural literature and assert that the use of interview data runs the risk of making assumptions about the subject as an autonomous, stable, meaning-making subject and ignoring the factors and structures that have enabled this to be the case. A Foucault-influenced poststructural view considers subjects as multiple, relational and in continual process of developing and becoming (St Pierre, 2011) and therefore challenges the concept of lived experience as a fixed thing to be examined and treated as true. According to Foucault, we must consider how a subject has been produced (Foucault, 1988, p. 15). Consistent with this approach, and similar to the work by Bay, Haynes, and Western (2019) in their poststructural analysis of social workers' critical reflection practices, findings from my research were "not taken as evidence of actual practices by the study participants but as ways of making sense and meaning about their practices"(Bay et al., 2019, p. 944).

Mol investigated the knowledges incorporated in practices, in the daily events and activities occurring within both home and hospital settings, rather than articulated in words or images printed on paper (Mol, 2002). This work further bridges the divide between a theoretical and top-down approach to understanding practices and a real-world approach that incorporates a critical perspective of lived experiences. This provided my research with a framework for going beyond examining people's perspectives (an interpretive approach) whilst still adhering to a poststructural requirement to avoid the recreation of the subject as an autonomous choosing subject (Bacchi & Bonham, 2016). This provided a methodologically consistent and sound mechanism to examine "how living with an impaired body is done in practice" (Mol, 2002, p. 15).

3.3 What's the problem represented to be? approach

Bacchi's WPR approach (Bacchi, 2009) is a Foucault-influenced poststructural theoretical and analytical framework that formed the basis of this research. Informed by this approach, I applied a model of analysing and understanding PRs to help understand clinical service practices and responses to young children with CFDs and their carers from both clinician and carer perspectives. This provided a mechanism to critically consider; the ways in which this particular clinical issue was constructed or represented as a 'problem'; the underlying assumptions underpinning this; and the effects of this on service responses.

Bacchi's WPR approach is well recognised in critical policy analysis and widely used in health policy analysis (see as examples; Barnett, Dilkes-Frayne, Savic, & Carter, 2018; Browne-Yung, Ziersch, Baum, Friel, & Spoehr, 2020; Flacks, 2019; George, Mackean, Baum, & Fisher, 2019; Henderson et al., 2019; Shrewsbury, Mogensen, & Hu, 2018). It has been identified as a positive tool for supporting public health analysis for students and researchers at a theoretical and policy level (Coveney & Putland, 2012). Core to this approach is the underlying assumption that a policy sets out to address a problem. This presumed ‘problem’ is often implicit and unexamined (Bacchi, 2009) and the WPR model asserts that these ‘problems’ need to be made explicit and closely examined and provides a process for doing so. Bacchi challenges us to move the focus from "‘problem’ *solving* to ‘problem’ *questioning"* (Bacchi, 2009, p. vii) to enable more nuanced and considered responses. This approach provides both a theoretical and analytic mechanism for examining data and processes of knowledge construction, in particular, the relationship between knowledge and power (Bacchi, 2009) and insight, how we are governed.

Governmentality research is based on the work of Foucault (1978), and examines mechanisms that govern and control individual and societal behaviour (Lawless, Coveney, & MacDougall, 2014). In a poststructural context, government involves more than political parties and legislative actions (Bacchi & Goodwin, 2016), it refers broadly to any form of activity that aims to “shape, guide, or affect the conduct of people” (Bacchi & Goodwin, 2016, p. 5). Foucault defined the term government as the “conduct of conduct” (Gordon, 1991, p. 2). Governmentality research focuses on examining the mechanisms of governing that act and interact in often unseen or taken-for-granted ways to manage the conduct of individuals and populations. Government includes “numerous sites, agencies, and “ways of knowing” that interrelate in important ways to shape social rules” (Bacchi & Goodwin, 2016, p. 5).

Bacchi (2009) contends that we are governed through problematisations, through the ways problems are constructed and represented. She further contends that “policies are problematisations…“*they make a ‘problem’ exist* as a particular type of ‘problem’” (Bacchi, 2009, p. 263) These problematisations serve as framing mechanisms, they reduce complexity and focus attention (Bacchi, 2009) but unless we carefully examine how these are constructed, we risk missing key information, perspectives or considerations that may be shaping the ‘solutions’. The WPR process provides the mechanism to do this by interrogating the data through a series of six questions that critically examine how problems are thought about and acted upon rather that accepting the problem as a given.

3.4 Relevance to clinical setting

While this approach is widely used in policy analysis, I have only come across one other paper that applied this model directly to clinical practice. Lawless et al. (2014) examined infant mental health policy and practice responses using Bacchi's approach (Lawless et al., 2014) and a governmentality lens. Njenga (2019) also applied this model to examine the policy and management of obese pregnant women in rural SA but her focus was on applying the results of a policy analysis using the WPR model to interviews with clinicians to make policy and practice recommendations. My research applied this approach more directly to a clinical setting; to the consideration of how the representation of a clinical problem impacts on service delivery responses. Bacchi suggests that the WPR model has the potential to extend beyond policy analysis and be used to examine theoretical stances more generally (Bacchi, 2009). In applying this model to clinical work, I propose that clinical practices can similarly be seen as problematisations. Through the same process of problematisation, clinical practices create particular understandings of what the problem is. These are referred to as PRs. Applying this model, to a clinical setting provided a novel way to examine clinical services. Informed by Bacchi's model, I problematised the PRs uncovered in documentation and clinical practices of young children with CFDs through observing and interviewing carers and clinicians. I based the analysis on interview transcripts, field work notes, and service documentation rather than formal policy documents. The WPR methodology provided the mechanism to critically consider; the ways in which this particular clinical issue was represented as 'a problem'; the assumptions underpinning this; and the effects of this on carers, children, clinicians, and service responses.

This approach is relevant to clinical services in a tertiary hospital as the delivery of health care services is a form of governing that requires and privileges certain knowledges and creates subjects of patients, carers, doctors, and clinicians, who behave in particular ways that help establish and maintain social control. Health care services draw the parameters for acceptable standards of health and set the rules for how to act to respond to and maintain these. Therefore, it is both consistent and valuable to understand clinical practices through this lens. This will be discussed in more detail in Chapter 6.

3.5 Sample

I used purposive sampling to recruit participants who were attendees at and members of the PFAS (Hesse-Biber, 2017). The participants were recruited because of their experiential, personal and systems knowledge about young children with CFDs and their health service responses. This research particularly sought to examine and compare both clinicians' and carers' experiences to be able to meet the research aims and so representatives of both groups were needed.

As this research was based on knowledge exchange principles, relationships were established with the members of the PFAT first. This team was comprised of clinicians from the disciplines of occupational therapy, speech pathology, nutrition/ dietetics, and paediatrics. They were all invited to participate and provided with a participant information and consent form (see Appendix 3). All four of the clinicians agreed to participate and returned the signed consent forms before research began. These clinicians had between 18months and 12 years' experience working in paediatric feeding and were all parents.

As discussed in Chapter 1, I entered into a knowledge exchange partnership with the team, and they helped shape the research questions and methods. This was done specifically to increase the relevance of the research by working closely with the end users of the research throughout the research process and building multiple check in points into the research design (Kothari & Wathen, 2013). The team also helped develop a sampling strategy and facilitated recruitment of the carers. To assist in this process, the team provided insider knowledge as to the structure and functioning of the service, the typical attendees, and the typical pattern of involvement with the service. This then informed the development of the sampling strategy.

Attendees at the service were reported to be from a diverse range of family configurations (single parent, grandparents, foster parents) and from a range of ethnic, cultural, and socioeconomic backgrounds. The pattern of engagement of families with the PFAS was highly variable and often involved many contacts with individual PFAT clinicians before attending the service for one to multiple occasions. Carers and children continued to see the members of the team jointly or individually in between the PFAT clinic days when they would see all four members of the team. They often had multiple contacts with other medical specialists including gastroenterologist, neonatologists, paediatricians, and allergists prior to and while they were involved with the PFAT. Their contact with the team was often over a protracted period of time ranging from weeks to years.

In my initial research proposal and ethics application, only mothers were to be included in the study. I took this decision for two reasons, firstly it is well recognised in the literature that mothers assume greater responsibility for caring for children with additional needs (Gill & Liamputtong, 2009; Kingston, 2007) and carry more of the burden of child caring duties and the responsibilities of feeding and nurturing children (Coveney, 2002). Secondly, it seemed that this would offer one way to focus the research. However, on reflection and in consultation with the literature and the team, I realised that it was essential for the participants to accurately reflect the diversity of the service with all its complexity and messiness. An ethics amendment was applied for and approved, and the focus broadened to include carers. This reflexive and flexible approach is supported by Yin (2018, p. 30) who advocates the need to maintain an "adaptive posture" throughout research to enhance its rigour. This means remaining flexible and responsive through the research process and especially during data collection and analysis. It is not always possible to anticipate accurate sampling processes at the beginning of the research and checking back regularly with the research question and aims and being open to modifications ensures better research outcomes (Yin, 2018).

To reflect the diversity of attendees and complexity of patterns of engagement the final inclusion criteria for this this study were:

1. Carers of children with CFDs who had had contact with at least one member of the core clinicians of the PFAT through individual or group sessions, and had attended the PFAS
2. Clinicians from the disciplines of occupational therapy, speech pathology, nutrition/ dietetics, and paediatrics who had worked as part of the PFAT.

Given the challenges of parenting a young child with CFDs, recruitment of carers was anticipated to be difficult. To reflect and respect the impact of caring for a young child with CFDs on carers' time, energy and capacity to be involved, a flexible strategy was developed to offer a range of ways carer participants could contribute to this study as shown in Table 3.2.

Table 3.1 Carer participant options

Carer participant options	Description	Recruitment process
Observation only	These carers had their typical session or sessions observed but did not participate more fully in the study.	These participants were approached by their clinicians, provided with a participant information and consent form (see Appendix 4) and consent was gained prior to their session/s being observed.
Participant	These carers had the option to be involved in all or some of the following: 1. In-depth interview 2. Clinic observation 3. Home mealtime session observation 4. Follow up interview session after home mealtime observation	These participants were approached by their clinicians, provided with a participant information and consent form (see Appendix 4) and consent was gained. I then contacted them and arranged the dates and times for the different levels of involvement. I explained the option for carers to provide progressive consent and that they could withdraw from the study at any point without any consequences.

This flexible strategy worked well. Some participants were involved initially in session observations and then also agreed to be part of the full study. Additionally, once participants were involved in the study, they often invited me to attend and observe other sessions. At the time of recruitment, there was a potential pool of 18 eligible carers to call upon and from this pool, 11 agreed to participate as follows: five agreed to participate in all aspects of the study, one agreed to participate in the in-depth interview and clinic observations, and five agreed to participate in observations only. All carer participants completed the carer participant information and consent form (Appendix 4). At the time of recruitment there were no grandparent carers or foster carers in the pool of eligible carers. Table 3.3 reflects the carer participants’ level of involvement in the research. A summary of the carer participants’ demographic details is included in Table 3.4 and reflects the range of participants involved in the interview and home observation components of this study. These tables show that a diverse range of participants and data was included in this research and that this range reflects the typical clients of PFAS, their presentation and level of involvement.

Table 3.2 Carer participants' level of involvement in research

Carer	**Role**	**Child, age**	**Research Involvement**				
		yr- years mo- months	**Interview**	**Clinic observation**	**Home MT Observation**	**Follow up Interview**	**Types of Observations**
Rachel	Mother	Ellie, 17mo	*	*	*	*	Paediatric clinic waiting room x 2, Paediatric Feeding Assessment Team (PFAT) clinic x2, Dietitian x1, Home Mealtime (MT)
Kate	Mother	Noah, 2.5yr	*	*	*	*	Speech Pathology waiting room x1, Speech Pathology x1, Home Mealtime
Karen	Mother	James, 4yr	*	*			Paediatric clinic waiting room x2, Dietitian x2
Jane	Mother	Jack, 2yr	*	*	*	*	Paediatric clinic waiting room, PFAT clinic x2, Inpatient tube wean process, PFAT team meeting to discuss inpatient tube wean, Speech Pathology and Occupational Therapy joint session, Dietitian session, Paediatrician session, Home Mealtime
Fardin	Father	Nazir, 3yr	*	*	*	*	Paediatric clinic waiting room, PFAT clinic x1, Home Mealtime
Emily	Mother	Summer, 16mo	*	*	*	*	Paediatric clinic waiting room x2, Dietitian to Dietitian handover, Home Mealtime, Dietitian and Speech Pathology X1
Bianca	Mother	Abby, 21mo		*			PFAT clinic session x1, Dietitian session, Paediatric clinic waiting room x1
Saliha & Mahir	Mother & Father	Asif, 3yr		*			Speech Pathology and Occupational Therapy joint sessions x2, Speech Pathology and Dietitian x1
Aiko	Mother	Sachi,.5mo		*			Paediatric clinic waiting room - gavage feed in waiting room, Speech Pathology and Dietitian session, Team discussion- SP, Dietitian, Paediatrician, PFAT clinic session x3
Ellen	Mother	Olivia, 19mo		*			PFAT clinic session x1
Maddie	Mother	Brooke, 19mo		*			Dietitian session, Paediatric clinic waiting room x2, Speech Pathology and Dietitian session

Table 3.3 Carer demographic information

Carer, role NB all carers were the primary carer of their child	**Child, age** yr- years mo- months	**Issues contributing to CFDs**	**Total time of N-G Tube placement in months, & status**	**Other demographic factors**
Carer 1 Rachel, Mother	Ellie, 17mo	Premature, reflux, vomiting, severe oral aversion	17months, current	Lower SES, not in employment, 5 children, twins, partner works away, lives with parents, good family support
Carer 2 Kate, Mother	Noah, 2.5yr	Enlarged tonsils, severe oral aversion	no tube yet, anticipating need for tube	Higher SES, not in employment, 2 children, partner, good family support
Carer 3 Karen, Mother	James, 4yr	Severe allergies, eosinophilic oesophagitis	few months, unable to tolerate, awaiting PEG	Mid-level SES, part time employed, single mother, 2 children, 1 with ASD, good family support
Carer 4 Jane, Mother	Jack, 2yr	Russell- Silver syndrome	15months, weaned	Higher SES, full time employed, 3 children, 1 with physical condition, twins, partner, both work FT, limited family support
Carer 5 Fardin, Father	Nazir, 3yr	No known cause, limited food intake	12months in total, 3 times, weaned	Lower SES, full time PhD student from Bangladesh, partner, 2 children, no family support in Australia → regular trips to Bangladesh
Carer 6 Emily, Mother	Summer, 16mo	Severe reflux and vomiting	15months, current- 23/24 hr slow continuous feeds, awaiting PEG	Lower SES, not in employment, 2 children, 1 with severe ASD, partner, some family support

3.6 Site location

The PFAS was located in a major tertiary hospital in Southern Adelaide. The PFA clinic operated monthly from the fourth floor in the Paediatric clinic space. The PFA clinic was the space where clients met with the PFAT (all four members) for a 1.5-2-hour session. The clients most often had contact with at least one member of the team prior to attendance at this clinic and detailed information had already been gathered about their circumstances and particular needs. This clinic operated on a consultative model, which meant that the children were still the patients of and 'under the care of' another clinician or team (be that paediatrician, gastroenterologist, neonatology team, allergy team etc). This team/ clinician was responsible for their overall care, while the PFAT consulted and offered specific advice regarding their feeding difficulties. Engagement with the PFAT often involved regular individual and/or joint sessions with the members of the team in between and in addition to attendance at the PFA clinic. Engaging in these different service encounters took place in various locations within the large hospital. Car parking was limited and expensive and the hospital was hard to navigate. An analysis of the waiting room observations undertaken over the period of data collection was written up as a briefing document to help inform the redesign of the paediatric clinic waiting room and is included as Appendix 5).

3.7 Position of researcher

Working within a knowledge exchange partnership involved some particular challenges that were similar to those experienced by researchers undertaking case study research and included negotiating roles of advocate, biographer, evaluator and interpreter (Stake, 1995). I worked to build relationships with the clinicians to really understand their practice and what they hoped to improve and learn from the research. I was invited into the role of advocate in this process. The hope from the team was that the data I gained would contribute to a business case for increased funding for the service as well as generate ideas for service improvement. I entered into this process without any knowledge as to whether the service was an effective one and so had to walk a careful line in my roles as evaluator and interpreter to explain that the data would be shared and available for advocacy but that I could not guarantee any results.

I strove to develop and maintain an authentic, honest, and non-judgemental relationship with the team throughout the research process whilst observing their practice and hearing their experiences of their practice through interviews and team meetings. I was aware that being observed could feel like being judged and as such, I was conscious of the tension between biographer, evaluator, and interpreter. To address this, I called upon my clinical skills and experience in creating a non-judgemental stance and building rapport. I worked to repair any instances where they may have felt vulnerable or judged. I kept detailed field notes of each session and noted moments of potential tension or points for clarification. I regularly shared my perspectives and worked hard to create an environment of inquiry not judgement. Following each observation session, I noted two key points for follow up and arranged a time to meet or talk with the clinician about the session. The process I followed is detailed in the methods section and included as Appendix 6: Process for Clinic Observations and Post- observation follow up. This process successfully built trust and collaboration with the clinicians. They offered me increased opportunities to observe sessions and invited me to attend meetings and informal team discussions. There was only one instance where I was requested to delete a specific reference made about the practice of another health professional that was discussed in a team meeting.

Attentive to the results of the literature review regarding carers experiences of blame and shame, and the lack of attention to power differentials within research, I worked to develop rapport and maintain authentic relationships with the carers throughout the research process. It could be argued that they were even more vulnerable to judgement as I observed their parenting and listened to their experiences of caring for their children through interviews and mealtime observations in their homes (Liamputtong, 2007). I was very mindful of the potential impact of my presence and so I intentionally structured the research process in a way that enabled me to build their trust and create a non-judgemental stance. As detailed below in Figure 3.1 the research process was designed to allow the carers a chance to get to know me in safer, more controlled ways before they agreed to be part of the research and before they needed to provide more personal information or invite me into their home. In this way the carers felt comfortable with me by the time I was interviewing them and observing and joining with their family mealtime in their homes. Similarly to my approach with the clinicians, I worked to reduce the hierarchy between myself and the participants (Hesse-Biber, 2017) and to repair any instances where the carers may have felt vulnerable or judged. I checked in with them at the end of the mealtime observations to determine whether they felt that my presence had affected the mealtime and to allow them a space to talk about the experience and add their perspectives and thoughts to what had happened within that mealtime and how that was relevant to them and their child. This was important to elicit honest responses and a true sense of their everyday lives and helped to reduce the potential for social desirability responses (Baxter & Jack, 2008).

Another challenge presented in this research was the potentially conflicting roles of biographer and interpreter for both the carers and clinicians. Biographer refers to the capturing and retelling of their stories (Hesse-Biber, 2017) and the expectation to reflect this well was often in conflict with the requirement to interpret, analyse and evaluate the data in a way that respected the voices of the participants but was also consistent with the poststructural perspective of critical deconstruction. The aim of this research was to present a “nuanced, complicated and productive” (Mazzei & Jackson, 2012, p. 746) account rather than simply capture the participants voices and to do this required a process for and recognition of the active co-production of knowledge between myself as researcher and the participants (Flynn, 2019).

The knowledge partnership approach generated genuine interest and ownership of clinicians for the project. This had to be tempered with the need to retain and respect the confidentiality of the carers. Clinicians wanted to hear regular updates but once this involved carer data – interview or home observation – it was essential not to discuss information that could inadvertently identify participants.

As mentioned in Chapter 1, I brought over 20 years’ clinical experience working as an OT with young children and families in community settings to this research. I came with values around equity and justice and a holistic perspective of health and wellbeing which sees a client as part of a broader system that includes their own mental and physical health capacities, their key relationships, and the environments they exist within including social, political and physical environmental factors. Additionally, I believe in enabling and respecting people to make the decisions that are best for themselves. Relational practice (Taylor, 2020), trauma informed care principles (Champagne, 2011) and the social determinants of health shaped my work as an OT and my research practice.

Despite my extensive clinical experience, I had never worked in a hospital setting or with young children with CFDs. So, while I brought prior knowledge, values, attitudes and beliefs with me, the environment and context in which I was researching was foreign to me. This worked well to help me take on the new role as researcher and monitor my more familiar role as clinician. As I interviewed and observed the encounters between the carers and clinicians, I felt that I was experiencing the environments and processes both through and with the participants and with fresh eyes.

Consistent with reflexive practice, I kept detailed field notes throughout the research process of the ways my social position, my values, attitudes and beliefs may have been influencing my role as researcher (Hesse-Biber, 2017). I regularly reviewed and discussed these with my supervisors. Through this process I became comfortable sharing my experiences as a mother and an experienced clinician who had worked with families with young children. This offered me some insider status that supported rapport building (Hesse-Biber, 2017). I felt it was important to share that I had not experienced difficulties with my children's eating and I had not worked in hospitals with acutely unwell children. This outsider status gave me a freedom to question situations that were often taken for granted and assumed by the participants who were so immersed in their lives as carers or clinicians of such unwell children (Hesse-Biber, 2017). By acknowledging the similarities and differences between myself and my participants I was able to build effective relationships that enabled us to work together and supported the research process.

Applying a reflexive stance was particularly important when I conducted the WPR analysis. It is challenging to move outside assumptions that make up the ways we live and think. Recognising this, Alvesson and Sandberg (2011) recommend using "problematization as a methodology for challenging the assumptions that underlie not only others' but also one's *own* theoretical position" (p 252; emphasis in original). As Bacchi (2009) states, our own perspectives and values are shaped by the PRs surrounding us and it became difficult at times to see and separate from the PRs I was trying to analyse. This was particularly so given my experience working as a clinician and as a mother. Following each analysis, I followed the process recommended by Bacchi and applied the six questions to my own PRs to examine potential assumptions influencing my analysis and to guard against the potential of missing alternative perspectives. I also sought feedback with my supervision team where we challenged each other to come up with alternate PRs.

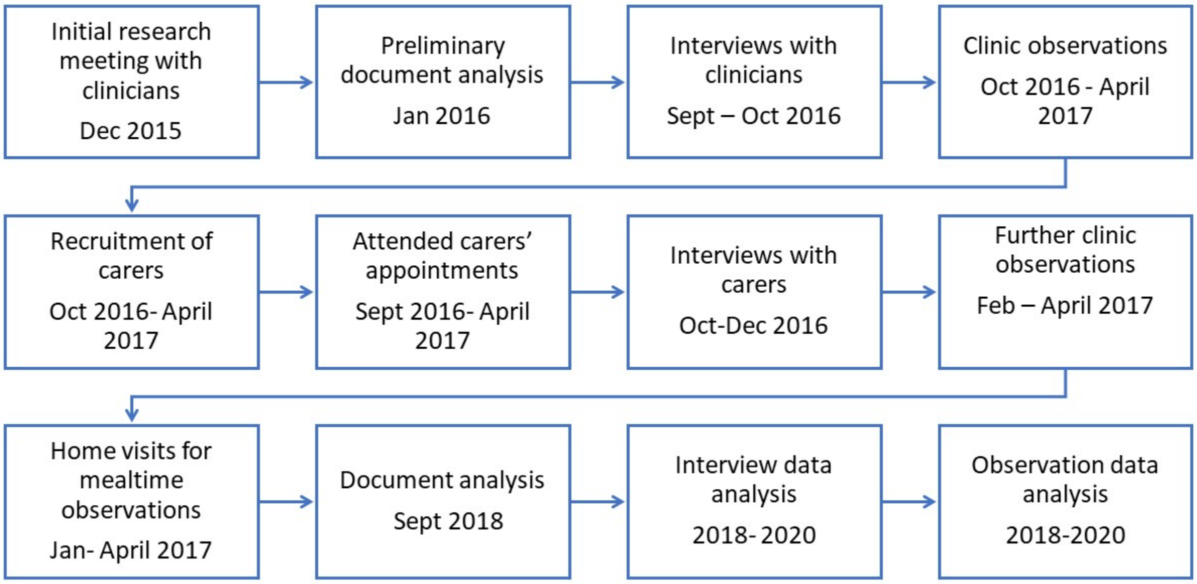
3.8 Research design

The research was designed to address the research aims by gathering in-depth data from both the carers and clinicians of the PFAS. The outcome was a rich description and interpretation of the ways the problem of children's CFDs was represented by clinicians and experienced by the carers. I chose multiple, complimentary methods that enabled me to address my research aims. An overview of the information that was required and the aligned methods is presented in Table 3.5.

The research design was based on a poststructural theoretical framework and informed by an ongoing review of the literature. The research process is outlined in Figure 3.1. This process was strategically designed to gain trust and rapport as discussed in Section 3.4 and to increase the quality and trustworthiness of the data. The initial meeting with clinicians occurred in December 2015. In this meeting a knowledge exchange partnership was established, and the team offered advice and suggestions on the research design. I had originally planned to undertake interviews only, being cognisant of the burden observations may have placed on both clinicians and carers. However, in this meeting I provided some examples of how this research could be designed including clinic and home observations. The team were very open to being observed and could see that this would add value and integrity to the research outcomes. They were also very keen to gain feedback as to how their clinical recommendations were being translated to the home environments of their clients. Based on their interest and support, and consistent with knowledge exchange principles, I then designed the research to include home and clinic observations. Data collection occurred over a seven-month period between September 2016 and April 2017. Preliminary findings were shared with participants in September 2017. Final feedback was provided to the carers and clinicians in March 2021.

Table 3.4 Required information and aligned methods

Type of Information	**Specifics required**	**Methods**
Demographic	Descriptive information about the participants	Brief survey
Perceptual and contextual information to address Research aim 1: To critically examine and compare how the problem of CFDs is being represented in clinical practices and experienced by carers .	Perspectives of the clinicians and carers– descriptions and explanations of their experiences with the PFA service, how they make senses of a complex feeding difficulty. Written documentation about the service provided to the carers	Interviews Observations – clinic and home Document analysis
Perceptual and contextual information to address Research aim 2: To analyse how problem representations influence experiences and practices of health care.	Perspectives of the clinicians and carers– descriptions and explanations of their experiences with the PFA service Observations of interactions between clinicians and carers	Interviews Observations – clinic and home
Theoretical information to address Research aim 3: To reflect on the contribution and extension of the WPR approach to clinical practices.	Ongoing review of the literature to provide a theoretical grounding and understanding of contemporary evidence	Literature review



Intermission – Sept 2017 – April 2018

Figure 3.1 The research process

3.9 Methods

As described below, I undertook multiple in-depth interviews, clinic and home observations with clinicians and carers of young children with CFDs over seven months. Sessions were audio-recorded, transcribed and detailed field notes were taken during and immediately after.

The methods used to gather data included:

1. In-depth semi-structured interviews with carers and clinicians
2. Document analysis of written information developed by the team
3. Observations: across clinic and home settings
4. Feedback with carers
5. Feedback with clinicians

Techniques included:

1. Reflexive photography
2. Vignettes

Using several methods and techniques provided strength and rigour to research findings (Curtin & Fossey, 2007; Tracy, 2010) and enabled the in-depth examination of the information exchange processes occurring within the PFA service from multiple angles and perspectives (Baxter & Jack, 2008; Stake, 2009; Thomas, 2011). Explanation of and justification for these methods and techniques follows.

Document analysis: I analysed key written documents about the Paediatric assessment service developed by the PFAT. These documents included: appointment letter, information sheet for parents, information sheet for staff, Inpatient tube wean information: process checklist, pre-admission information, discharge information sheet, Medical, Developmental and Feeding Questionnaire, recommendations, and referral form. Analysis was informed by Bacchi's (2009) WPR approach. This offered a well-established methodology (Bacchi, 2009) for document analysis to provide insight into the PRs of CFDs. Preliminary analysis of these documents helped inform the development of the interview questions for the clinicians. This process is outlined in section 3.11.

In-depth semi-structured interviews were used to determine the perspectives of both the carers and the clinicians in this study. In-depth interviews are considered an excellent way of discovering the subjective meanings and interpretations that people give to their experiences (Liamputtong, 2009). I followed a recursive model of interviewing to allow for a more natural and participant-centred interview with freedom to follow the cues of the participants (Minichiello, Aroni, & Hays, 2008). Semi-structured interview question guides were developed for both clinicians and carers and provided a consistent base for eliciting information but allowed individual flexibility for each participant (Luck, Jackson, & Usher, 2007). Examples of these are included as Appendix 7. The interview guides sought information directly related to the research question and research aims.

In-depth interviews with the carers occurred on two occasions, at initial interview, and following home mealtime observations. Data gained from these interviews provided information about experiences of the services and informed analysis regarding PRs. One in-depth interview was conducted with the clinicians to gain data on PRs.

As can be seen from Table 3.6 summarising the data collected, a total of four interviews occurred with clinicians averaging 73 minutes. These all occurred in the hospital. A total of 11 interviews occurred with carers, the six initial interviews averaged 90 minutes in duration (ranging from 66 to 131 minutes) and the five follow up interviews averaged 30 minutes. One initial carer interview took place in a single hospital room during an inpatient tube wean process with the child present. All others took place in their homes.

I wrote summaries immediately following the interviews which captured initial thoughts and responses and noted the physical environment and emotional tone of the interview. One of the clinician audio recordings failed and I wrote out responses to all the questions in full, from memory, within minutes of the end of the interview when I identified that the recorder had malfunctioned. Halcomb and Davidson (2006) supported this process and discussed that relying on detailed field notes and interview summaries written after an interview is sometimes necessary. In these instances these notes can be analysed in the same way as a transcript (Halcomb & Davidson, 2006).

Table 3.5 Summary of data collected

Type of Data Collected	**Details**	**Number of sessions**	**Number of minutes**
Observations			
Waiting Rooms	Paediatric clinic waiting room observations	12	240
	Speech Pathology waiting room observations	2	60
PFAT clinics	4 full clinic days	10	900
Individual clinicians	Dietitian sessions	7	280
	Speech Pathology sessions	1	45
	Paediatrician session	1	30
Joint clinicians	Speech Pathology and Occupational Therapy joint sessions	4	240
	Speech Pathology and Dietitian joint sessions	4	240
Inpatient tube wean process	over 4 days	3	180
Mealtime observations at home	5 families	5	600
Total observations		**49**	**2815 = 47 hours**
Interviews			
Interviews with clinicians		4	240
Interviews with carers		6	795
Follow up interviews with carers		5	150
Total Interviews:		**15**	**1185 = 20 hours**
Meetings/discussions			
PFAT meetings	Formal or informal meetings	5	240
PFAT	Discussion with inpatient staff re tube wean	1	30
Discussions with clinicians	Follow up sessions after clinic observations	9	180
Total meetings/discussions:		**15**	**450 minutes = 7.5 hours**
PFAT documentation	Appointment letter, information sheet for parents, information sheet for staff, Inpatient tube wean information for patients, Medical, Developmental and Feeding Questionnaire, recommendations, and referral form		

Reflexive photography was used with the carers as a technique to build rapport, establish them as the experts in their children's lives and offer them a creative and non-verbal way to convey information about what it was like to care for a child with a CFDs. The carers were asked to bring up to four photographs to the initial interview that they believed represented or helped shed light on their child's eating difficulties. This technique was based on photovoice which is a well-recognised participatory strategy to engage participants in expressing their own experiences through the use of photographs (Carlson, Engebretson, & Chamberlain, 2005). Of the six participants involved in the in-depth interviews, four provided photographs and these were an effective way to begin the interview as they created an immediate visual and emotional sense of the issue. While not specifically used as data in the results, these photographs helped me to connect with the carers, build rapport and prompted discussions about their experiences that are captured in the results.

I had also planned to take photographs during the mealtime observations as a way to capture the experience and as a reflective tool to prompt discussion in the post mealtime interview (Minichiello et al., 2008). However, during the first mealtime observation I changed my mind. By the time I was observing the mealtimes, I had built good rapport with the participants and they welcomed me into their homes. I joined in with the family meal and it felt inappropriate to then take photographs. I had not anticipated the level to which I would become involved with the families and become a participant observer rather than a nonparticipant observer. By entering more fully into the mealtime experience and taking detailed field notes afterwards, I gained more information than I would have by taking notes and photographs during the meal and distancing myself from the family. The mealtimes then became a relaxed experience with both parents and siblings joining in and offering their insights and perspectives. The follow up interviews then occurred more naturally, immediately following the end of the meal. This had some added benefits of reducing the time burden on the family and ensuring the experience was fresh in everyone's minds. This experience of gaining rich data through paying attention to relationship building processes was consistent with ethnographic research (Hesse-Biber, 2017). This requirement to be flexible and responsive in data collection and enter more fully into the participants' lives is mentioned frequently in the literature (Luck et al., 2007; Stake, 2009; Thomas, 2011; Yin, 2018). The position of the researcher transitioning over the course of the study from observer to observer as participant is also well established (Gray, 2013; Luck et al., 2007).

Home and clinic observations added depth to the data. Observations provide information about what people actually do in specific contexts (Saldaña, 2011). By observing interactions in both clinic and home settings, I gained an understanding of the contextual factors that were impacting on representations of CFDs, and the ways clinical services occurred across both the home and therapy settings. This then supplemented the interview data and served as a prompt for further follow up or clarification (Saldaña, 2011). Interviews alone would not have provided this level of detail and context-specific information which was particularly important in addressing the first and second research aims. Participant observation, when used in addition to interviews, can offer nuanced, rich and important data that complements interview data when researching highly stigmatised areas such as obesity and feeding/eating practices (Gunson, Warin, Zivkovic, & Moore, 2014). Participant observation enabled me to gain rich data (Luck et al., 2007) and provided detailed information about the services across both the hospital and home settings.

I conducted home mealtime observations with the carers and their children. The carers were able to interpret and determine what ‘a typical mealtime experience’ was for them and their young child. For four of the five families this was an evening meal. Three of these four included the whole family and one included the mother and children but not the father. One family invited me to observe an afternoon tea that involved the child and their sibling while the parents watched. As discussed already, being in people’s homes requires a certain level of rapport and trust to be built and exchanged between the researcher and participants, as such the home observations were structured to occur after the carers had met me through the clinic and observations and had had one in-depth interview in a setting of their choice. Informed by a similar ethnographic approach to meal time observations conducted by Warin et al. (2019), I spoke with the carers about how they would like the mealtime observation to look and feel and explained that I would be as involved in the experience as the family felt comfortable to create a sense of trust and reduce the sense of ‘sitting in judgment’. As I am vegetarian, I offered to bring my own non-meat option to substitute for the family option. I then ate with the family and we talked together. A total of 10 hours of home mealtime observations occurred.

Observations can occur along a continuum from complete participant to non-participant observer (Hennink, Hutter, & Bailey, 2010). I took on the role of both participant and non-participant observer depending on the setting and context. When observing clinic sessions, I remained in the background as a non-participant. In the carers’ homes, during the mealtime observations, I was a participant. While there is a risk that observations are skewed by the participants’ changed behaviour as a result of being observed (Orrell-Valente et al., 2007), it has been shown that this is still a worthwhile method to employ as rich, contextual data can be gained (Mol, 2008) especially in regard to the bi-directional interchanges between parents and children that are so important in understanding eating issues (Demir et al., 2012) and in understanding the complex processes occurring within and influencing mealtimes (Warin et al., 2019). Additionally, unique and valuable sensory insights can be gained through joining in a mealtime experience that are not able to be recreated through non-participant observations or interviews (Pink, 2015). Following the home observations, carers were interviewed, and I specifically asked how typical this session was and how much my presence influenced the experience. This was taken into consideration in the analysis.

I conducted PFAT clinic, individual and joint session observations with the clinicians and carers. These served as an additional layer of information to enhance in-depth interviews findings about the influences on clinicians' development of PRs and service responses. These observations provided an opportunity to immerse myself in the service and gain a more complete understanding of the experiences of the clinicians and carers. Clinicians chose the sessions that were observed. Observations were unstructured and recorded using an audio recorder. I kept detailed field notes during and after each session and noted moments of potential tension or points for clarification. Following each observation session, I noted two key points for follow up and discussed these with the clinicians. I asked three questions about the session;

1. Was this a typical session?
2. What challenges did they experience?
3. What were the positive moments they noticed?

I then shared my 2 key observations and asked them to comment on these;

1. I noticed/was really interested in (key observation 1…). Can you tell me more about what was going on there?
2. I noticed/was really interested in (key observation 2…). Can you tell me more about what was going on there?

As explained in section 3.7 this process for the clinic observations and follow up (Appendix 6.) allowed me to build trust with the clinicians.

Clinic observations totalled 47 hours and were undertaken over a seven-month period. This comprised 15 hours of PFAT clinic observations, four hours of waiting room observations, six hours of individual clinician sessions and eight hours of joint sessions. I observed each clinician in an individual or joint session at least once (Table 3.6).

Vignettes are considered a valuable way of clarifying a researcher's perspective on what has been observed (Hall, 2008). A vignette is a focused detailed narrative taken to be typical of the experiences of the person or situation being examined (Miles & Huberman, 1994). Detailed summaries were developed for all six carers who were full participants. Three of these were developed into vignettes and included as Appendix 8 to supplement Chapter 5. These three were chosen as they represented the range of carers and experiences. These vignettes provided a narrative summary based on in-depth interview and observational data. They served as analytic tools to capture and clarify my perspectives and to keep the experiences of these people front and centre in this research.

Feedback with carers

The six carers involved in the interviews were provided with a summary of the findings based on the combined carer and clinician data. This summary was designed to explain my research process and highlight the key findings and recommendations that would be provided back to the PFAT. This was emailed to the carers and they were invited to provide feedback. They were also offered to opportunity to have a follow up phone, virtual or in-person discussion of the findings. None of the carers took up this offer. Each carer was presented with a $50 gift voucher as a gesture of thanks for their involvement in the study. The original plan was to provide each carer with a summary of their own data but in discussion with the carers they all expressed interest in hearing about the overall findings of the research instead, rather than in individual summary. I then adapted my approach based on this.

Feedback with clinicians

The four clinician participants were provided with a summary of the findings based on the combined carer and clinician data. They were also provided with a copy of the adapted WPR model for practice. This was emailed to the clinicians and they were invited to provide feedback via the most convenient form for them. The original plan was to hold a face-to-face group session to create a reflective space for considering the policy and practice implications of the research findings. This was adjusted to a more flexible approach based on the clinician's preferences and COVID-19 protocols. Two of the four clinicians responded by email and two requested a face-to-face meeting. Their responses were incorporated as data in the analysis and informed the knowledge translation process.

3.10 Data analysis and synthesis

The purpose of analysis was to gain rich understandings of the how the problem of young children's CFDs was represented by clinicians and how this was experienced by carers. To do this, I employed the WPR approach to critically examine how the problem of CFDs was thought about, represented and acted upon (Bacchi, 2009). The six questions in the WPR approach provide a structured approach to do this for policy analysis (see Figure 3.2).

What’s the Problem Represented to be? (WPR) approach to policy analysis

Question 1: What’s the problem (e.g. of “gender inequality”, “drug use/abuse”, “economic development”, “global warming”, “childhood obesity”, “irregular migration”, etc.) represented to be in a specific policy or policies?

Question 2: What presuppositions or assumptions underlie this representation of the problem (*problem representation*)?

Question 3: How has this representation of the problem come about?

Question 4: What is left unproblematic in this problem representation? Where are the silences? Can the problem be thought about differently?

Question 5: What effects (discursive, subjectification, lived) are produced by this representation of the problem?

Question 6: How/where has this representation of the problem been produced, disseminated and defended? How could it be questioned, disrupted and replaced?

Adapted from: (Bacchi, 2009)

Figure 3.2 WPR approach to policy analysis

To apply this model to a clinical issue I modified the first question as follows;

Question 1: What’s the problem of young children’s CFDs represented to be in the clinical practices of the PFAT?

The six questions can be applied systematically but are more commonly applied as part of an integrated analysis that reflects the embedded nature of PRs (Bacchi, 2009). A WPR analysis involves working backwards from concrete proposals within policy documents to examine what the problem is represented to be within those proposals (Bacchi, 2009). Clinical decisions and practices are evidence of these concrete proposals (Lawless et al., 2014) and so, in this analysis, clinical practices outlined in documents, field notes, and transcripts (collectively referred to as sources) were used to examine the PRs.

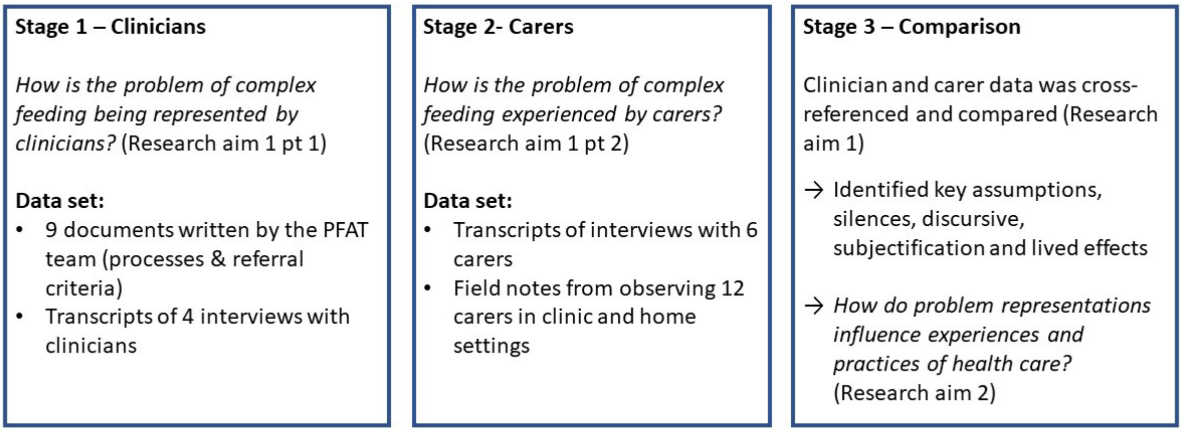
I interrogated both the clinician and carer data applying the WPR approach. This required immersion in the raw data and a process that involved examining the data, reflecting, triangulating, questioning simple meanings and first impressions and looking for correspondence and evidence to support any assertions (Stake, 1995). In this study, observation data provided a mechanism to triangulate, support or challenge the findings from the interview data. I followed the advice of Stake that "it is important to spend the best analytic time on the best data. Full coverage is impossible, equal attention to all data is not a civil right" (Stake, 1995, p. 84). Thus, documents and transcripts of interviews were read multiple times and closely examined, initial thematic codes were identified and then WPR question codes were assigned and discussed, justified, and agreed with my supervision team. I managed the data manually as this provided me with greatest flexibility to read, compare and analyse. Once the WPR question responses were determined, the observation data were examined in light of these to seek verification or alternate explanations. Appendix 9 provides an example of the coding process. As this was an integrated analysis, each individual question was not addressed separately for each source. Overlapping areas were indicated by notations eg Q1, Q2, etc., inserted to signal when a particular question was being applied (Bacchi, 2009).

Data analysis occurred in three stages (summarised in Figure 3.3.) In the first stage, I analysed the document and clinician interview data sets. The document data set was comprised of nine documents written by the PFAT to provide information about the PFAS to other staff and clients. The transcripts of semi-structured interviews with four clinicians formed the clinician interview data set. I analysed the data from the documents and the interviews separately and then compared them to answer the question What's the problem of CFDs represented to be by the clinical practices of the PFAT? As a form of preliminary analysis to familiarise myself with the data, I undertook an additional content analysis to determine the frequency of terms related to family composition, feed/feeding, eat/eating and trauma. This information is presented in Table 3.7. The results of the WPR analysis are presented in Chapter 4.

In the second stage, I analysed the carer data which was comprised of transcripts of semi-structured interviews with six carers (six initial interviews and five follow up interviews after the mealtime observation) and observational data field notes from 12 carers (six carers who had been interviewed and an additional six carers who had been observed). These interviews captured the experiences of carers across their many encounters with the tertiary health service. The observation data set comprised field notes from observations of all 12 carer participants across home and clinic settings. Carer interview information is summarised in Table 3.8. The results are presented in Chapter 5.

In the third stage of analysis, I compared how the clinicians represented the problem of young children's feeding difficulties with how this PR was experienced by the carers. This offered insight into the impacts of this PR by considering the carers experiences as a comparison and critique of the clinicians' PRs. This highlighted key assumptions, silences and the discursive, subjectification and lived effects of the PRs and how these impacted on service responses. In this way I was able to address my second research aim.

Figure 3.3 Analytic Process



Stage 1 – Clinicians

How is the problem of complex feeding being represented by clinicians? (Research aim 1 pt 1)

Data set:
- 9 documents written by the PFAT team (processes & referral criteria)
- Transcripts of 4 interviews with clinicians

Stage 2- Carers

How is the problem of complex feeding experienced by carers? (Research aim 1 pt 2)

Data set:
- Transcripts of interviews with 6 carers
- Field notes from observing 12 carers in clinic and home settings

Stage 3 – Comparison

Clinician and carer data was cross-referenced and compared (Research aim 1)

→ Identified key assumptions, silences, discursive, subjectification and lived effects

→ *How do problem representations influence experiences and practices of health care?* (Research aim 2)

Table 3.6 Summary of clinician interview data analysis

		Number of times the following terms were used in the interview:							
Clinician	**Interview time**	eat/ eating	feed/ feeding	trauma	Mum/ Mother	Dad/ Father	Family	Carer; Parent	Grandmother/Grandfather/ Grandparent; Siblings/brother/sister; Aunt/uncle
Clinician 1 (C1)	96 mins	153	124	0	28	3	114	0;21	0/0/0; 4/0/0; 0/0
Clinician 2 (C2)	62 mins	*	*	*	*	*	*	*	*
Clinician 3 (C3)	51 mins	27	72	0	31	0	39	0; 9	7/0/1; 0/0/0; 0/0
Clinician 4 (C4)	82 mins	10	79	0	22	8	21	0; 20	2/0/0; 1/0/0; 0/0
Total	291 mins Average= 73 mins	190	275	0	81	11	174	0; 50	9/0/1; 5/0/0; 0/0
* transcript not available for analysis									

Table 3.7 Carer interview data summary

Carer, role	**Child, age**	**Interview details: Length, location, child present**
Carer 1 Rachel, Mother	Ellie, 17 months	131 mins, home, child present
Carer 2 Kate, Mother	Noah, 2.5 years	66 mins, home, child not present
Carer 3 Karen, Mother	James, 4 years	100 mins, home, child not present
Carer 4 Jane, Mother	Jack, 2 years	67 mins, In hospital, child present
Carer 5 Fardin, Father	Nazir, 3 years	68 mins, home, child not present
Carer 6 Emily, Mother	Summer, 16 months	92 mins, home, child present

3.11 Ethical considerations

Formal ethics approval was granted by the Southern Adelaide Human Research Ethics Committee (SA HREC EC00188) on 27 April 2016, project number 525.15 (Appendix 2). An amendment to change mothers to carers as participants was approved on 29 November 2016.

Throughout the research process the participants' anonymity was maintained through the use of a single confidential project spreadsheet that contained the name of each participant, their participant number, and their assigned pseudonym. All names in reports, summaries, presentations, and papers were pseudonyms. Transcriptions and audio-recorded material were treated in the strictest confidence, stored on a password protected university computer and seen only by me and my supervisors. Clear boundaries were established with the members of the PFAT to maximise confidentiality of the carers' information. Any carer information shared with the PFAT was of a general or collated nature to reduce the likelihood of identification of the individual carers. Given the small numbers of families involved in the service and the specific nature of their experiences there was however a risk that carers could still be identified. This was clearly explained to the carers. Clinician information was identified by number only as referring to gender or profession would identify the participants.

3.12 Trustworthiness

To ensure the trustworthiness of this research, I undertook prolonged engagement with the participants and service over the seven months of data collection. Data collection and analysis occurred iteratively and involved multiple check back points with participants for clarification ensuring I gained a deep understanding of the service (Yin, 2018). Additionally, data triangulation is a core aspect of this study. I used data from a range of sources including interviews with clinicians and carers, observations in a range of clinical settings and home, and document analysis. In this way data and methodological triangulation occurred. Data triangulation occurred by me comparing and cross-checking the consistency of information gathered at different times and by different means (Hesse-Biber, 2017). This involved comparing the perspectives of carers and clinicians and ensuring that the range of carer participants reflected the attendees at the PFA service to gain a wide range of perspectives. These triangulation strategies enabled depth and breadth of understanding to be gained. Each research strategy I used provided a particular perspective and contributed a different piece to the puzzle ultimately leading to a deeper and more nuanced understanding of the workings of the team and the effects of clinical practices

(Curtin & Fossey, 2007; Stake, 2009). Triangulation offered me the opportunity to consider the overall patterns of data from the different sources, to look for consistency but to also consider differences and to develop reasonable explanations for these thereby contributing to the overall credibility of the findings (Curtin & Fossey, 2007). This part of the process was undertaken with my supervision team and involved discussion and agreement to minimise the risk of researcher bias.

A thick description of the research process and findings involved providing a detailed description of the context and participants, and a thorough rationale for the research processes so that the meaning and importance of data could be fully understood (Curtin & Fossey, 2007). This required a detailed and reflexive account of the epistemological position and its congruence with the methodology and methods employed, enabling the reader to link the process to the outcome and judge the validity of the steps undertaken (Roberts, Dowell, & Nie, 2019). Consistent with recommendations by Houghton, Casey, Shaw, and Murphy (2013), this thesis contains detailed descriptions so that readers can make informed decisions about the applicability of the findings to other contexts. The necessary details include accounts of the context, site, participants, methodology and analytic structure and examples of raw data so that alternative interpretations could be considered. Direct quotes from the participants have been used to illustrate findings.

Rigour was enhanced by outlining the decisions and processes undertaken throughout the study to provide a rationale for my methodological and interpretative judgements (Houghton et al., 2013). I provided a clear and transparent process and maintained a reflexive stance throughout the research process in recognition of the role the researcher plays in qualitative research (Houghton et al., 2013). I used a reflective journal through this study and kept detailed notes of the ways I was affected by and may have influenced the research process. I discussed these notes and debriefed regularly with my supervision team. Additionally, a detailed section on my position as researcher is included in this thesis. Self-awareness and reflexivity and the communication of these are important in increasing the credibility of a study (Houghton et al., 2013).

3.13 Conclusion

This chapter described and provided a detailed justification for the methodological approach underpinning this research and outlined the research methods and processes that were undertaken. By employing a critical epistemological approach, I was able to examine health care practices in a new way. A poststructural approach based on WPR methodology offered the mechanism to question the taken for granted nature of the clinical problem of CFDs. As will be shown in the following results Chapters, I was able to deconstruct the clinical ‘problem’ from the perspectives of both carers and clinicians and see how that influenced health care practices. Applying Mol’s work in considering a logic of care, provided the mechanism for discussing the results of the WPR analysis in Chapter 6 and applying this to health care practices. This combination offered me a way to contribute to theoretical considerations of good health care practice.

Chapter 4 WHAT'S THE PROBLEM OF COMPLEX FEEDING DIFFICULTIES REPRESENTED TO BE IN THE CLINICAL PRACTICES OF THE PAEDIATRIC FEEDING ASSESSMENT TEAM?

4.1 Introduction

In this chapter I apply the WPR approach to analyse clinician data to determine how the problem of CFDs was represented through clinical practices. I present the results of the analysis of document data and interview data and then present a comparison of both that highlights inconsistencies between the intention and pragmatics of the practices of the team. This addresses the first part of research aim 1; to critically examine how the problem of CFDs is being represented by clinicians.

4.2 Document analysis

The document data set for analysis included:

1. Appointment letter (1a), Information sheet for parents (1b), and Medical, Developmental and Feeding Questionnaire (1c)
2. Information sheet for staff (2)
3. Inpatient tube wean process checklist (3)
4. Inpatient tube wean pre-admission information (4)
5. Inpatient tube wean discharge information sheet (5)
6. Referral form (6)

These documents were provided by the team when asked for any supporting documentation that explained the role of the service. They reflect different purposes; documents 1a, 1b and 1c represent the first contact the team have with families who have been referred to the service. Documents 2 and 6 are written for staff within the hospital to help promote and streamline referrals to the service. Documents 3 and 4 are designed to help plan an inpatient tube wean amongst the relevant staff at the hospital and document 5 is for parents who have completed the tube wean process.

4.3 Results of document data analysis: What's the problem represented to be?

4.3.1 Question 1: What's the problem of young children's complex feeding difficulties represented to be in the clinical practices of the Paediatric Feeding Assessment Service through the documents they have developed?

The overwhelming impression from the document analysis was that the problem was represented as a physical one (1,2,6) that affected a child and their ability to feed and required medical and allied health intervention (3) and medical processes (3,4,6); "The Feeding Assessment Team (FAT) is for children with complex feeding disorders requiring input from multiple health professionals". (1b). When presenting information to other hospital clinicians the defining feature was the severity of the conditions: "this service is reserved for those with highly complex feeding disorders and tube dependent children… Simple feeding disorders should go through usual practice" (2). Document 2 contains the only occurrence when the service explained itself by linking families and children:

it should be noted that this is a consultative service and as such this clinic is not for initial assessment but rather a planning of therapy and also an opportunity to set goals with the families of children who have not responded to standard care.

The problem was also represented as one that the team were responsible for solving; "requiring input from multiple health professionals." (1b). Power dynamics between the team and the clients (defined by me as child and carer) were communicated through the language of these documents. As an example, in document 5, the use of "we" and "you" reflected the power balance and ensured that the control was kept within the team (the we).

> We know from experience that changing feeding preferences, practices and aversions can take a long time and the changes we have made this week are just the beginning of what we hope to see in the coming weeks and months.
>
> As a reminder, here are some suggestions for things you can be doing at home:…

On first read the 'we' could be seen as a collaborative client and clinicians working together, but the ownership of the 'we' is clearly established in the 'we know from experience' and the subsequent use of 'you' in "for things you can be doing at home", set a clear delineation between 'we' as experts ie the team and 'you' as other, that is, the recipient of the expertise. This use of 'we' conveyed a proprietorial rather than collaborative tone to the document.

Document 5 also represented the issue as predominantly physical affecting the child but made the connection between this also having emotional implications for the family. This document was provided to families after they had been through a tube wean process and offered congratulations and recommendations for discharge. The experience of supporting a child with a CFDs was referred to as "you and your child's feeding journey" and made explicit reference to the emotional impacts; "This week has likely been a roller-coaster of emotions and you may be feeling worried about going home, and confused about where to from here". There was also specific reference to the impact of stress and advice to parents to look after themselves. This is further unpacked under Q2.

Document 1 represented the first contact between the team and the client and therefore set the foundations for how the relationship would unfold, what was expected, what was valued, what was held to be true by the service. These documents represented the problem as, again, a physical one assigned to the child and their ability to feed. All the questions asked in the questionnaire (1c) focussed on physical aspects of the child, there were no questions that asked how difficulties with eating were affecting the child emotionally or socially.

4.3.2 Question 2: What presuppositions or assumptions underlie this problem representation?

This representation was underpinned by a biomedical model of health which has as its foundation a separation of mind and body and so ignores the connection between mental and physical health (Baum, 2008). Evidence of this was reflected through examples of a body/mind binary where the body was privileged. As already mentioned, document 1c provided the first mechanism for gathering knowledge (information) from the client and provided insight into the types of knowledges that were valued by the clinicians. The predominance of questions about the physical child, and the corresponding lack of questions about the child's emotional or social experiences was evidence of this biomedical context. There was a clear privileging of medical and physical knowledge-gathering over knowledge about social, emotional, and psychological factors of the child and their family (Q4) based on the assumption that this knowledge is more important and valuable in helping understand and addressing a child's CFDs. These questions also assumed that a child's health and wellbeing occurred in isolation from their environment including the key people in their lives and the community they lived within (1c). This is discussed further under question 3.

Document 5 offered the most holistic representation which included a focus on the parents and their role in supporting their child:

> And lastly, look after yourself! We know this time is stressful and it is easy for parents to neglect themselves and dismiss the impact feeding is having on you and your family. Make sure you get time out, have someone to talk to and get the support you need. Please chat to the team if you want to discuss this further.

While this document attempted to set a positive and encouraging tone, there were problematic assumptions within this. These included, firstly, that parents would be able to get help, have someone they could talk to or have the capacity (social, financial and/or pragmatic) to be able to have “time out”. That is, there was an assumption that these parents have the physical, mental, financial, social and emotional resources to “look after” themselves. Thirdly, there was an assumption that the right help would be available if they were to seek it. Fourthly, there was an assumption that looking after yourself as a parent equated to getting time out, talking to someone and getting support and that these terms or concepts were commonly understood. These are all terms that may hold different meanings for different parents and families based on gender, cultural and social norms.

Where information was sought from and about someone other than the child, it was sought from and about an individual parent (1c) see more about this in Q3. This assumed that only one individual parent had responsibility for and was impacted by a child with CFDs.

4.3.3 Question 3: How has this representation of the problem come about?

The team, services and clinical responses were firmly situated within and influenced by the biomedical model (Q2). The service operated from a large tertiary hospital and the language within these documents reflected a technical and medical construction of the problem. For example, document 4 referred to “the current feeding regime” when gathering information about the child’s eating patterns.

Document 1 formed the first point of contact between the team and the family. The framing of these questions offered insight into how the problem of CFDs was represented by the clinicians (Q1) and the types of knowledge that was valued by the clinicians. This document also set the foundation for how the relationship would work between the team and the client. This was conveyed through the focus of the questions, as already discussed, but also through the types of questions asked. All of the questions in 1c) were defined by a biomedical model of health and asked about specific problems. Most of the questions asked for ratings, yes/no, or short responses. They did not ask open ended questions that sought information about experiences. As an example, there were no questions that invited comments or specifically asked the respondent about how the physical issue being explored (for example, frequency of vomiting) impacted on them or their family or what it was like for them or their family.

Further evidence of the influence of the biomedical model is that under the section named Pregnancy and Birth History, there were no questions about the pregnancy, they all focused on the physical aspects of the birth (1c). Additionally, in the section named Feeding History and Current Eating/Drinking Skills, there was a question that appeared to be asking about mental health but asks the respondent to;

> Please indicate if anyone in the household is currently receiving medication for depression or has done so in the past

This representation of depression is a biomedical one that emphasises the taking of medication. This then served to limit the ways of conceptualising mental health and silence the parents who may have responded to a question that asked them if they had ever or were currently experiencing depression or feelings of being overwhelmed, exhausted or worried. The next question in this section similarly asked about “receiving care for anorexia or any other type of eating disorder”. There was no opportunity to explain this, and the framing of this issue again limited the conceptualisation to a biomedically focussed one. People may have responded quite differently to this question, and it would have reflected different assumptions and values, if it had been worded to ask about people who had experienced difficulties with eating and/or their relationship to food, as an example.

There were some indications of a biopsychosocial approach that conceptualised health more broadly, however these took the form of statements not followed through with actions or resources. As an example, in document 1c, the preamble to the questionnaire that gathered information before the first team assessment stated:

> Please fill out the following questionnaire as completely as you can. This information gives the Feeding Assessment Team (F.A.T.) a very detailed picture of your child’s medical history, general development and feeding skills**. It also asks about how your child’s feeding or medical problems may be affecting you, your child and your family**. (emphasis added)

While this is stated in the preamble, there were no questions that asked about the impact on the family. Section 10 in the questionnaire contained four questions which seemed to be attempting to address these broader impacts. The first of these examined stress levels and asked the person filling in the form to rate as follows:

> 10. My levels of stress when trying to feeding (sic) my child and at mealtimes:
> In general, the level of stress surrounding mealtimes in our house is….(Please circle the appropriate number)
> 1 = Not at all stressful: the experience did not cause you to feel upset, tense, or anxious.
> 2 = A little stressful
> 3 = Moderately stressful
> 4 = Very stressful
> 5 = Extremely stressful: the experience upsets you and causes you a lot of anxiety or tension.

This question attempted to gain a sense of the level of stress associated with feeding but asked the respondent to rate their individual level of stress not that within the household. Similarly, the second question asked the respondent to rate how often they were worried that their child was not getting enough calories to grow. These questions gathered information about an individual's level of concern but missed the opportunity to examine any broader concerns within the family. By asking these questions an individual focus is privileged over the focus of the whole family (Q4). This appeared to assume that only an individual parent/carer had responsibility for the child and was therefore impacted by the child's eating difficulties (Q2). This meant that the voices of the broader family members were silenced (Q4). The experiences and perspectives of the mothers, fathers, co-parents, carers, grandparents, siblings, friends and so on remained unheard and unexamined.

A further factor in this representation was that the team worked within a system of medical dominance. Medical dominance occurs when a medical practitioner holds a more dominant position based on their role and are afforded greater power, influence, authority and autonomy (Sidani et al., 2018). Glimpses of this are reflected through these documents. As an example, despite the speech pathologist and dietitian being very experienced clinicians, core members of the team who developed this service, and responsible for most of the administrative tasks associated with the team, the team is led by a paediatrician. The information sheet about the service that accompanied the appointment letter and questionnaire stated;

> At your initial FAT appointment, you can expect to be seen by Paediatrician, Dr. (name specified but omitted for confidentiality), a Dietitian, and a Speech Pathologist. Other professionals who may be involved in your child's care as a part of the FAT include Occupational Therapists and Physiotherapists.

This statement implicitly outlined the hierarchy within this system; the doctor was named, the next most important allied health practitioners were referred to singly eg a speech pathologist, and then the less involved allied health clinicians were referred to plurally.

4.3.4 Question 4: What is left unproblematic in this problem representation? Where are the silences? Can the problem be thought about differently?

The silences in this PR have, in part, already been shown above. These included the experiences of the broader family and community members and their potential roles in supporting a child with CFDs (1c). By privileging the physical health of the child, the mental and emotional health status is overlooked and minimised for both the child, their carer and their family. This then diminishes other constructions of the issue, for example, as an environmental, social, family or community issue.

The biomedical framing of depression and eating disorders (1) discussed in Q3, together with these being the only issues asked about, created an impression that these are the only considerations that impact on caring for a child with CFDs. This then had the potential to silence a range of carers who, through feelings of shame or through lack of resonance with the specific language used, may not have responded to those questions. They may have felt that it was unsafe or inappropriate to have raised other issues or considerations. Additionally, this PR may have silenced and limited the range of situations and conditions that could influence a carers' perception of their capacity to support their child including such things as tiredness, financial pressures, living conditions, their own physical or mental health, their work commitments, their relationships, and support systems.

Another aspect left unproblematic in this representation is the make-up of the team who provide services to these children. There is no mention of psychology or social work being part of the broader team to be notified regarding an inpatient tube wean, but nursing, occupational therapy, physiotherapy, and play therapy are listed (3). Emotional and social aspects of health are again silenced through the team composition. Additionally, a tailored approach to each family is not evident. Document 5 outlined recommendations for families to undertake on discharge from an inpatient tube wean process. The family's specific and unique experiences and needs appeared unexamined in this process. It was not clear how individual families' situations, hopes, goals and dreams were reflected in this set of general recommendations and advice.

Finally, the diversity of families is silenced in this representation of CFDs. Document 1a refers to parents only and the only options for demographic information were "Mother" and "Father". Document 1c asked about Primary Caregivers for this child and listed the possibilities as: "(i.e. parent, foster parent, relative, babysitter etc)", but other than occasional references to carer or parent/carer, most of the documents only referred to parents and the implication was very clear that this equated to a mother and a father. There was also little evidence that people from diverse cultural or linguistic backgrounds were considered. The appointment letter mentioned the option of an interpreter in tiny font with no details about how to arrange this service.

4.3.5 Question 5: What effects (discursive, subjectification, lived) are produced by this representation of the problem?

Discursive effects are the limits that are imposed on what can be said or thought about an issue based on its PR (Bacchi, 2009). Subjectification effects are the effects on people and how they are seen, see and can operate within the PR (Bacchi, 2009). Lived effects are the material impacts of the PR on people's bodies and lives (Bacchi, 2009). These effects overlap and are strongly influenced by the silences created through the PR.

The terms feeding and eating offered insight into the discursive effects of the representation. All of the documents, with the exception of document 5, consistently used the term feeding. The team is called the Feeding Assessment Team, with the unfortunate, ironic or possibly insensitive acronym, FAT; "This information gives the Feeding Assessment Team (F.A.T.)…"(1c). The service they provided was referred to as multi-disciplinary feeding assessment (1a). The term feeding in these documents appeared to reinforce a more biomedical construction of the PR (Q3). As children were graduating from the tube wean process, the language changed to eating, this was reflected in document 5. Feeding, in common parlance, has connotations with the very young needing assistance; babies and very young children are fed or feed; young children and adults eat. It is also strongly associated with breast or bottle feeding and implies a passive relationship: being fed. The term feeding carries with it an implication that someone (a carer and most commonly a mother) needs to take responsibility for the feeding of the passive recipient of this process (the baby or child). Eating, in common parlance, is a much more active process that maintains the agency of the person eating. By using the term feeding an implied sense of responsibility may be conveyed to carers/mothers. This may have the unintended effect of increasing the sense of blame and guilt associated with caring for a child with CFDs. This is discussed more in Chapter 6.

Within document 2, the referral criteria for the team are outlined. Two of the five criteria relate to parental capacity; “Patient-carer dyad has capacity to manage tensions/change in feeding tasks” and “Parent able to allow some autonomy on part of the child”. The implication is that to be able to support a child with CFDs a carer must be able to meet these criteria. These criteria, however, require further examination and clarification. There are underlying assumptions that these terms and actions have a shared meaning and are understood by carers, clinicians and referring agents. In considering the subjectification effects of this representation on the carers, it is important to reflect on who holds the power in this representation. The medical or allied health clinicians acting as referring agents to the team are assumed to be able to judge the ‘suitability’ of the parent/carer and act as gateways to the service. If carers do not meet this referral criteria, as determined by the referring agents, they are not able to access services for their children. In this way, parents are held responsible for their children’s access to services.

This PR also holds parents responsible for the physical wellbeing of their child but without opportunities to gain support and knowledge or acknowledgement of their own support needs. The carers’ voices are absent from these documents and thus, there is no space facilitated for them to be able to say and influence what matters to them and their child. This PR places the power and control of addressing CFDs within the sphere of the medical system, hospital, and team. The hospital is represented as a precious and privileged place with requirements that must be accommodated. The clinicians who work within the hospital are the ones who determine and request the information to make decisions about service eligibility and service type. Clinicians thereby hold the power, they set the requirements for what knowledge is valued. This PR sustains a busy, self-important, power-holding medical system (Q6). In doing so, the children with CFDs, their parents and families are relegated to a less powerful and less central role. The effects of this have potential to influence the agency and self-determination of carers, difficulties in being heard and believed, effective exchange of information and the consequent development of relationships and service responses that are limited and less effective.

4.3.6 Question 6: How/where has this representation of the problem been produced, disseminated, and defended? How could it be questioned, disrupted and replaced?

Documents 1a,b,c convey the expectations, culture and values of the service and as such produce, disseminate and defend this PR. Documents 1 and 5 are provided directly to clients of the service and therefore disseminate and perpetuate this PR to families. Documents 2 and 6 promote the service to other members of the hospital and potential referring agents and Documents 3 and 4 exchange information within the broader hospital environment thereby disseminating and perpetuating this PR to hospital staff.

This PR could be disrupted by a different framing and construction of the issue. In the current PR, there is a silencing of holistic and mental wellbeing and a privileging of physical health, accompanied by a silencing of the family and carers' experiences and a privileging of the individual child's experiences. If CFDs were considered as highly complex experiences that impacted the whole family's emotional and physical health, then different information and service responses would be required, and these documents would be worded very differently.

4.4 Results of clinician interview data set analysis: What's the problem represented to be?

In presenting these results, I referred to the clinicians by number and used the gender-neutral pronoun 'they' to preserve anonymity.

4.4.1 Question 1: What's the problem of young children's complex feeding difficulties represented to be in the clinical practices of the Paediatric Feeding Assessment Service through their interviews?

The problem of young children's CFDs was represented by the clinicians as one that was challenging, compounding and multifactorial. It influenced a child's ability to feed or eat an adequate range of foods to gain sufficient nutrition to grow and thrive. There was a strong sense that the priority for service needed to be the nutritional status of the child as this impacted on their growth, development and immune capacities;

> So, you - you can't go six months without nutrition and go, well, we'll fix it in six months... It doesn't - doesn't work that way. You're having cognitive deficits with that level and we know immune deficits as well, so, particularly in - in the main age group that we see, the zero to two year olds and the zero to five, nutrition has a major impact on developmental outcomes, but also immune outcomes as well, so immune function. So, yep, that would be the basis that I'm thinking of is all of the time I'm thinking is this child nutritionally meeting their requirements and are they growing and developing properly? C3

A team approach was considered very important to this work. Clinician 2 captured the feeling of the clinicians when they said that the different perspectives of the team enabled them to understand the complexity of issues for the family and child and be more focussed on the family. Dietitian and paediatrician services appeared to be considered more central to addressing the nutritional and growth aspects and speech pathology and occupational therapy appeared to play a more supporting role in providing therapy aimed at addressing eating/feeding skills and capacities. Clinicians 3 and 4 emphasised these priorities; “what are the nutritional requirements of this child and how are we going to meet them in the current situation and factor in what the therapists are saying into what my recommendations are?”C3; “so I'm relying on my dietitian to help me from a nutritional point of view to be seeing where this child is from a growth point of view, because that's obviously, you know, first things first.” C4

The reasons for CFDs were often considered to be difficult to determine, but there were consistencies across the clinicians’ perspectives. Clinician 2 considered that for children with CFDs there was always a physiological basis first and then associated family, socio-cultural and emotional aspects compounded the layers. Physiological reasons identified included allergies, tonsils, reflux (C2). Clinician 1 agreed that CFDs were often triggered by allergies or an acute event, pain, or stress. They also brought in the element of enjoyment of eating and feeding for both child and parent; “Or they had something happen when they were really tiny that then made feeding very stressful and then feeding … eating was never an enjoyable experience and then it sort of became worse and worse.”C1. Clinician 3 also identified organic and non-organic causes. Organic included chromosomal issues, gut malfunctioning, syndromes, prematurity, allergies, intolerances, reflux, dysphagia. Non-organic causes included neglect, missed opportunities to gain skills and experiences in eating, and parent behaviours such as force feeding. The concept of a trigger and additional compounding factors was also supported by clinician 3;

> usually to get to point of a complex feeding disorder, usually requires, you know, two or more of those various reasons to come together …, so it may be that a child had severe reflux as a baby and was also force fed, so they've developed an aversion, because they've associated it with pain, and they've continued to force feed, so you've just developed a child who is massively aversive to the bottle. C3.

Throughout the interviews there were indications of holding carers responsible for their child’s CFDs. This is evident in the statement above; “so you’ve just developed…”. It was also evident in Clinician 4’s statements linking physiological and sociocultural factors contributing to a CFDs;

> so the children with multiple allergies and the children who are failing to thrive are sort of our core group, but you know looking outside those things. I mean I think - I don't know whether it's just got to do with the time that parents invest in feeding their children and building up those skills. C4.

Clinicians raised the social and time pressures that parents were under, with so many commitments and lack of family support and that this impacted on the parents’ ability to tune into their child’s cues around eating; “I'm sure that there are lots of parents, you know, with one hand on the phone, one hand, you know trying to feed a toddler and maybe not picking up on those cues."C4. While a sense of understanding of the stress and impacts of caring for a child with CFDs was conveyed in discussions and the team's practices, the language used, and therapy approaches could be interpreted as conveying blame through holding the carers responsible. All the clinicians indicated that for families living with a child with a CFDs, feeding their child became an all-consuming and highly stressful task. The impact of this, particularly on the mothers, was raised by all the clinicians; "then that directly impacts the mother's coping strategies and her level of exhaustion"C4. This then had impacts on the child and the feeding process; "But sometimes it feels like the mother might be so focused on feeding and - or very stressed about feeding, that it becomes very stressful for the child as well."C1. In this statement another hint of mother blaming is raised.

Families' routines, behaviours and priorities were raised as factors that influenced the development of CFDs. Examples of these included screen time, eating together as a family, types and patterns of eating. It was considered important to be able to understand and work with these to be able to achieve positive outcomes for the child;

> So getting a really good understanding of what the family structure looks like and what feeding means to the family as well and how that looks, … getting an understanding of what their goals are I think is really important. C3.

Clinician 1 summed up the complexity when they said:

> Initially … it seemed to be that there was some kind of acute issue that happened and then that sparked off other things. But I've now seen many families where they can't pinpoint something and I don't, sometimes I'm not sure why the issue has become so big as it has… some families I see and I think you've tried everything and nothing's working. Or they have multiple children in the family and some of them have feeding issues and some of them don't and they feel like they've parented them the same way. So, yeah, I think that it's really wide ranging. C1

The problem was represented as something that impacted on the child primarily physically but also had psychological impacts for the child and the parents. "So, there's a lot of emotional processing that needs to happen with going there" C3. All of the clinicians conveyed that caring for a child with CFDs evoked high levels of stress, guilt, and shame, primarily for the mother, but also within the family more broadly. Clinician 2 talked about needing to spend a lot of time with families reassuring them that "no-one was to blame" C2. Clinician 1 raised that this impacted on families seeking help; "…the stigma as well. We've got families who we've had trouble accessing because they don't want to admit that they have - that their child has a problem" C1

> Mother guilt is there all of the time and I think one of the biggest things I see all of the time and as a mum have experienced myself is your very drive is to nourish and protect a child and if you can't nourish your child, whether it be that you don't have adequate breast milk supply, whether they refuse solids, whether they don't take bottles, whether they go to the extreme of faltering growth and needing naso-gastric feeding, there is a lot of guilt and shame…C3

These examples offer insight into a mismatch between the understandings of the team, and their practices and ways of representing a CFD that actually conveyed a sense of blame. There was clear recognition from all members of the team that social work, psychology and especially an infant mental health focus were missing components of the current team approach. Team members all reported that they did not feel that they had the expertise to respond to the emotional and psychological needs of these families. “We don’t have an infant mental health worker which we feel is a big gap in our service and often families need that and we haven't got that level of expertise within our team.” C1. “I mean ideally it would be nice to have a social worker and a psychologist” C4.

All the clinicians had a strong awareness of the broader social aspects that influenced caring for a child with CFDs. In addition to the social expectations of feeding a child and the time pressures families are under, the impact of poverty or financial pressures was also discussed. As an example, the cost and access to car parking being a significant barrier to accessing their services. Clinician 4 captured the clinician’s awareness of the impact of broader social factors on service responses; “you know our intention was to get them to a weekly feeding group here, but they haven't been able to leave the house really or they haven't got transport and that sort of stuff.” C4. Another example raised was that part of the therapy approach with these children is encouraging them to play with, explore and become comfortable with food without the pressure to eat. Clinicians were mindful of how difficult this could be for families with limited incomes:

> Because the idea that we offer children food that then doesn’t get eaten is very stressful for some families. And so mum might just eat whatever's leftover or doesn’t eat because the food is going to the kids or what's available for them to eat is restricted in itself because of how much it costs C1.

The problem of CFDs was represented as one that was strongly influenced by culture and that cultural differences impacted on the complexity and severity of the feeding difficulty; “Our most complex families also have ethnic backgrounds” C2; “a large portion of our cohort are from different cultural backgrounds” C4; “culture has definitely got a big, big part to play in feeding”C3. All the clinicians identified particular challenges with families from, in particular, Asian and Indian backgrounds; “I generalise but Indians, Sri Lankans – force feed, so much pressure just to get fed, to get food in” C2; “So we've had, yeah, families from, yeah, Asian and Indian and Sri Lankan backgrounds all with those issues.” C1. The clinicians consistently expressed the tension between being culturally responsive and addressing the needs of a severely underweight child with CFDs. This is captured by clinicians 4 and 3 in the following quotes;

> …we're trying to understand and obviously respect and aware of where people are coming, you know, from various cultural backgrounds, but we do find that a lot of our patients are coming having been force fed from grandparents and mothers have, you know, have obviously picked up that as - this is the way to feed your child. C4
>
> We have definitely in our team noticed that there is, um, some cultural differences around how we feed and definitely, I guess, the two - like, sort of the Asian and Indian cultures that have come through, we have noticed there's a lot more force feeding, a lot more feeding left up to grandparents or grandmothers in particular. And that has…caused some issues in trying to communicate what we're trying to achieve therapeutically with a - with a child because they're very - different ideas and there's some - some culture clashes there, I think, about how - how feeding is best to operate. C3

As well as different feeding practices, all the clinicians also commented that shame had a particularly strong influence in families from different cultural backgrounds; “there was a lot of shame in telling the extended family that there was something wrong with the child.”C3. In reflecting on one particular family with an Asian background, clinician 4 talked about the role of shame and how that impacted on family functioning and levels of support; “there certainly is - there's a lot of shame around her … genetic diagnosis, around her feeding difficulties, around the feeding tube and that's really not sort of talked about very much amongst the extended family, which affects the family support.” C4

The problem of complex feeding was represented as one that impacted most strongly on mothers within families. The content analysis indicated that while clinicians frequently referred to families, mothers were considered to be primarily responsible for feeding within the family. Of the three interviews with transcripts, there were a total of 174 references to families; 81 references to mothers, 11 references to fathers, 50 references to parents; nine references to grandmothers, five references to siblings and no references to carers, aunts, uncles, brothers, sisters or grandfathers. The nine references to grandmothers were all related to families of diverse cultural backgrounds.

> So we're probably finding that a lot of the patients, the mother is the one, you know, trying to hold everything together, but keeping it all, you know, inside …and the dad may be aware to an extent. Certainly the dad last night… he's not very involved and his parents who they live with are not very involved.C4

All the clinicians indicated that the complexity of the condition made it an interesting, challenging, frustrating but rewarding space in which to work; “the psychosocial complexities make them quite - yeah, quite challenging.” C4. But “when we make a difference, lives are changed” C2. There was a sense of this work being well recognised within speech pathology and nutrition/dietetics but relatively new and not recognised or valued as much within occupational therapy and paediatrics. Quotes were not used here as they would identify the discipline members.

4.4.2 Question 2: What presuppositions or assumptions underlie this problem representation?

As reported in Q1, there is a strong assumption that nutrition needs to be addressed first; “because nutrition is not something you can wait for”C3. This representation privileges the physical and silences the mental aspects of health (Q3). Of course, a child will die without adequate nutrition and this needs to be addressed as a priority, but this could be undertaken whilst also addressing the levels of stress experienced by children and families (Q6). This prioritisation fits with a biomedical construction of health that considers physical and mental aspects separately and not interconnected.

The concepts of feeding and eating offer insights into the assumptions around the purpose of this service. In the three transcripts available for analysis, the terms feed/feeding were used a total of 275 times and the terms eat/eating were used 190. These terms or their differences were not described. This was similar to the literature review findings as discussed in section 2.3.5. In common parlance, however, as already discussed in section 4.4.5, the terms eating and feeding convey messages about agency and age.

The prevalence of the use of the term mother in the interviews reflected an assumption from clinicians that mothers should and do bear the responsibility for their child’s weight status and eating. This reflected the gendered nature of health care systems. Additionally, assumptions underpinning this PR are based on neoliberal influences on health care policy and service delivery that hold individuals to account for their health problems rather than addressing family and social issues and responsibilities (Q3). There was also an underlying assumption within this PR that health issues would fit within an acute- sub-acute- community continuum and therefore could be addressed in specific sites. The location of the service within an acute hospital site restricted the types of services that may have been required for the children and families (Q3). An acute hospital setting is vital for children who require admissions but not for the ongoing treatment of a core everyday occupation such as eating. These points will be addresses in Chapter 6.

4.4.3 Question 3: How has this representation of the problem come about?

This PR is strongly influenced by funding and management structures and the location of the service within an acute hospital. This impacted on the types of services that could be offered. For example, home visiting was difficult to prioritise; “it’s very much seen here that we're an acute hospital and we're an acute service.” C1. All the clinicians discussed the challenges they experienced because of these structures and the impacts this had on their work. “But because we're just borrowing funds from everyone, we're kind of scraped together on nothing and we just try to do a lot with very little time.”C1

> But there's been no formal funding, so I guess we all do it from a point of interest of: is this the best thing for the child and are we going to have better success rates doing it this way? And therefore having time savings longer term C3

> And none of us got specific funding for it, so it meant pulling from resources that we currently had in place for managing these children. So, the idea was to take time from the - the kids that I was seeing anyway and to put it into PFAT, but PFAT is more intensive and PFAT requires report writing and then we've done intensive admissions, which we didn't do in the way that we used to … So, it's definitely been more time than what we’ve taken from, I guess. So, at the moment it's - my allocation when I breakdown the workload is a day a month but once you add in admission there, the report writing and the fact that the clinic pretty much takes up most of the day, it ends up being more than that. C3

Clinician 2 reported that they felt that the multi-disciplinary team worked well to address the needs of families with children with CFDs despite not having enough funding or time. This was supported by clinician 3 who particularly commented on the service being more time efficient;

> It certainly is effective in, I guess, it's almost like a sorting service too though. Like, we can see the kids that do have the potential to tube wean and that we can get working on there and then there are kids that come through that we're just like, look, this child is going to need a PEG. It doesn't mean they can't eat and we can't keep giving them therapy, but it's not in the near future that a tube wean. Whereas before, we might have nasogastrically fed on and off for, you know, two, three years, so I do think that we're more time efficient in getting the things done now. C3.

Clinician 4 reported on the impact of working within a public health system; “I mean I think it's part of the public system is our clinic - as you probably have seen - is under so much pressure” C4. They went on to discuss the impact this had on innovation and the need for more funding;

> I’ve got all these good ideas, but things happen very slowly and especially in the public system [Laughs]… So I think it would take more sort of dedicated funding and that's - in this environment it's nigh on impossible really. C4

Clinician 1 reported that discipline management affected their clinical reasoning in this specialised area of practice. They discussed the importance of building a relationship with the family as part of gaining accurate information for thorough assessment and the importance of doing this face to face to help address the stigma and blame associated with this area of practice. However, “there is a push from my [discipline] supervisor to do a lot of that over the phone” C1. This clinician also talked about the challenge of having a discipline specific supervisor who was not familiar with the area of practice and therefore had some assumptions about the risk of this work (Q2);

> the supervisor who I work with now hasn’t worked in feeding before. So is supportive of the work that I do but doesn’t really have many practical suggestions for my role. My manager of [discipline] has no experience in paediatrics and probably feels a little hesitant about [discipline] being involved in feeding because [they don’t] understand the role very well … I think that my supervisor feels the same way that um, that it is risky work working in feeding. C1

Clinician 4 expressed similar concerns about the lack of understanding of feeding as a speciality area of practice within their discipline and that this meant that clinical issues were overlooked, early indicators were missed and feeding problems for children and families became more entrenched; “I don't know if there's a big awareness of feeding difficulties … in the general [discipline] field at the moment.”C4.

4.4.4 Question 4: What is left unproblematic in this problem representation? Where are the silences? Can the problem be thought about differently?

Cultural and family diversity was silenced in this PR. While all of the clinicians talked about the role culture played in CFDs, they also identified a lack of understanding about the specifics of the ways in which this having an impact. There appeared to be a tendency to treat different practices as concerning and to make assumptions about the role culture was actually playing without the knowledge to confirm this. This indicated that there was a lack of inclusive practice and culturally responsive care. As already discussed, (Q1), family diversity was also missing in this PR. There were assumptions (Q2) that the key carers were primarily mothers, and this silenced the role and consideration of impacts on the broader family including siblings, fathers, and grandparents. Additionally, understanding the real everyday experiences of eating and feeding occurring in their natural environments for the families was missed in this representation. Assessments and therapies took place in clinic settings and clinicians tried their best to gain as much information as they could;

> Then I'll get them to the table and we will eat something. I usually ask them to bring along, if it's at lunchtime bring their lunch or bring a snack. And mums, I will encourage them to

> bring the foods that they like and maybe some of them that they'd like them to eat that they don't eat. And then I get a chance to see what the child does at a mealtime. So that's one of the most valuable aspects of the assessment because you see straightaway that um they don't sit at the table or that they over stuff their mouth or that they only eat one particular thing. Or that mum is feeding them or whatever it is. So that's a really useful part of the assessment. C1

Clinician 2 reported that families missed out on home-based services and more intensive services and that impacted on the team really understanding what it was like for families and being able to respond most effectively. Clinician 1 agreed with this;

> I'd like to be able to do services more intensely. So maybe see people in their own homes or be out in the community so that we could be doing work in a less stressful way. Lots of the children that we see think hospital is a very bad place and they're coming in here for their appointments where they've had nasogastric tubes shoved down while they've been strapped to a bed and they are just stressed the moment they walk in here.C1

The was a strong recognition from all the clinicians that they were missing information about the range of social and psychological factors that influenced families caring for children with CFDs. They had attempted to address this within their limited resources by allocating time and effort to collecting data on parental stress and psychosocial information;

> …being able to sort of analyse, you know, the psychosocial background and the parental stress index out of that we're using is an important tool too. It's not the most ideal tool, but it's a tool and I try and wear a bit of a social worker hat too in terms I really try and get a bit of an idea of the background and the day to day stresses and time pressures on these families. C4

This brought additional pressures to the team as the time to collect, score and collate this data was not funded or allocated. Clinician 2 reported that they picked up this responsibility because; "personally it is my style to just get in and do it" C2. This clinician reported feeling an overwhelming sense of responsibility for the work and the functioning of the team which they attributed to being passionate about the area of practice, a senior clinician, naturally more organised than the other team members and an instigator of this team approach. This team member reported feeling frustrated with the lack of resources and the impact this had on timely service responses for families and that, at times, this spilled over to frustrations with their team members. All of the other clinicians referenced this clinician as holding this default team organiser role and they expressed appreciation for the role they played and guilt about the impact of their behaviour (as examples; lateness of reports, failure to follow through on recommendations, failure to prioritise and commit to team meetings) on their colleague and the service responses for families.

> we're just spread too thin I think. So yeah, you know reports don't get out in time and, um, just time to just sort of sit down and think C4

> On PFAT day, that's not my only responsibility. I still have to take pages from the ward; I still have home feeders coming in at the end of the day; and on that particular day, I also have a team leader meeting in the morning before I go to clinic. C3.

This lack of resources meant that these clinicians were pulled in multiple directions, which not only affected their own mental health and wellbeing but also impacted on team functioning and on carer and child experiences. The pressure that these clinicians were under was a significant silence. They all reported experiencing demanding workloads and yet could see that their service was working. They raised the lack of time for reflecting on practice and meeting together as a team to work through clinical, administrative and system issues. The short-term push to see clients was privileged over opportunities to reflect, think, and plan for better, more coordinated and resourced services that would achieve better outcomes more efficiently.

> So, yeah, we don't get that time to reflect as a team and I think that we could do so much better if we had more time and we had more time to work together and we had more time to reflect and we had more time to do training and things together as well C3.

Clinician 4 reported the frustration of “being part of the team but with one hand behind your back a bit because of all your other commitments.”C4

Additionally, trauma was silenced in the clinicians’ PR of CFDs. There were no overt references made to trauma in any of the interviews undertaken. There was discussion about stress and the emotional and psychological impacts on children and families but the naming and framing of the experience of CFDs as traumatic did not happen.

4.4.5 Question 5: What effects (discursive, subjectification, lived) are produced by this representation of the problem?

There are a range of effects produced by this PR for clients and for clinicians. For clients there is a risk of compromised care because the systems do not allow the clinicians to gain a comprehensive real-life picture of what is going on for families. This means services are potentially less targeted and less effective. In this representation the burden for change is placed primarily on the mother within the family without the appropriate supports available to enable her to manage this. The primary role of mothers appeared to be that of supporting the needs of their child (Q4). Their own needs, wellbeing and mental health were compromised in the process of caring for their child. The silencing of the impact of stress and trauma in this PR has ongoing implications for the child, their family, and the relationships within the family. It was recognised that this was not currently being addressed; “So I'd like for families to be able to receive like counselling around their feelings and their thoughts and emotions around feeding. Because I don’t think we do that very well” C1.

As discussed in Q2, the clinicians all reported experiencing significant over work with not enough time or resources allocated to the team to do the required work. “So, you're sort of still wearing multiple hats” C3; “I'm being pulled in different directions, … yeah, I think we're doing on the run at the moment” C4. The effects of this were impacts on work satisfaction, enthusiasm, and innovation. Clinician 4 talked about their interest and ability to see opportunities for innovation and change to improves service responses but felt constrained by limited resources;

> I think sort of leading innovation … in this environment's hard and, you know, from a resource point of view again, like it comes back to, you know, resources of dietitians, … of speech pathologists and the fact that we'd love to have a social worker and infant mental health team member C4

They then talked about the effect of this on them personally; “Yeah, I'm finding it hard. I'm trying to do new things all the time and I think I'm just going to get bored. I'm going to be sort of bitter and, um…jaded very soon.” C4. All of these clinicians are experienced seniors within their disciplines, and they all felt like their skills were not being used to greatest effect. Clinician 2 discussed the lack of suitable allied health assistant support for their discipline resulting in them spending three hours shopping and cooking to prepare for a feeding therapy group. They all talked about having to cover for other staff on leave on top of their current duties and this created additional pressure. As well as stress for the staff, this also impacted on their ability to complete reports and follow through on their clients. They all reported that frequently these clients were being seen by other specialists without having the required information finalised and available to support this process.

4.4.6 Question 6: How/where has this representation of the problem been produced, disseminated, and defended? How could it be questioned, disrupted and replaced?

The documentation about the service analysed in section 4.5, plays a key role in producing and disseminating this PR to both carers and other hospital staff. The siloed discipline structures enable this representation to be defended. This could be disrupted and displaced through different funding structures. Currently the managers of the different disciplines make the decisions separately about discipline and funding priorities which results in the team not having appropriate autonomy, leadership, and resource allocation to enable their work to progress. All four clinicians raised the need for increased funding that was allocated to the team rather than through individual disciplines. This would allow an expansion of the team to include infant mental health and counselling services to address the emotional wellbeing of the children and families (C1, C4). They recognised that this would also enable them to set the priorities for their service model and develop more client-centred assessment and intervention approaches based on the emerging evidence. They all also indicated that they would like to be able to offer more home-based services to reduce the stress that coming to hospital places on children (C1, C4) as well as offer a more accurate and realistic understanding of the needs of the families (C1,C2,C4) and support the translation of therapy outcomes to home (C3).

> I'd like for the team to be funded. Because then I feel like we would be protected a little bit and that we could be a bit more flexible with how we used our funding. And we could decide that we wanted to focus on something like a trial or try something or focus in a particular area. C1

All four clinicians identified that the lack of funding translates to lack of time to reflect as a team and to appropriately plan the feeding assessment service and this means that systems are not examined, and improvements are not enacted. All of the clinicians had a clear idea of what they would prioritise if they had adequate funding. All of them would like to be able to offer a more intensive service for families. For C3 this was in the form of a two-week inpatient admission where the children and families had access to hydrotherapy, play activities and play space, separate dining rooms where families could eat and the clinicians could join them and support them. For C1 this would be an intensive home-based service, where the clinician stays with the family and is available to support overnight and across all mealtimes, daily routines including, bedtime, playtimes, dressing and bath time, as well as support with shopping and meal preparation. For C2 this looked like a day assessment service with a focus on one family per day and for C4 a community-based assessment and intervention service was envisioned which included GPs, family support workers and stronger links to the other major hospital as well as gastroenterologists.

> more scope to support them in their home environment, because that's ultimately where they're going to end up C3

> I'd like to be doing more observations and be with families for mealtimes in their own homes. C1

> case conferences with more extended family members and maybe GPs and other family support people - definitely. Um, could we have a more direct link to a gastroenterologist or could we be better integrated with the service [other hospital] - maybe. C4

4.5 Integrated analysis results: Clinician responses - What's the problem represented to be?

This section contains an integrated analysis and summary of how the clinicians represented the problem by considering both their documents and their interviews. The problem of CFDs was represented by the clinicians through the documents as a serious physical problem that affected a child and their ability to feed and required medical and allied health intervention and medical processes. Parents played a limited role in supporting these children that is, one of being able to manage the inevitable tensions and changes in feeding and the ability to allow their child some autonomy. The problem was assigned to the child. Power relationships between clinicians and clients were communicated through the language of the documents and indicated that the responsibility for solving the problem sat with the clinicians. There was a clear delineation between the team as experts and the parents and children as recipients of expertise. Information was only sought about the physical child. The functioning of the family, the mental health of the child and family, and family and cultural diversity was silenced.

The overall results from the interviews with the clinicians was that the problem of young children's CFDs was represented as one that reduced a child's ability to feed or eat a sufficient range of foods to gain enough nutrition to grow and thrive. It was complex, compounding, and multifactorial and most often had a physiological basis with additional social and psychological contributors and effects, but it was often difficult to determine a cause. The problem was represented as one that was strongly influenced by culture, but cultural knowledge and responsivity was lacking. It was something that impacted primarily on the physical child but there were psychological and social impacts as well. The impacts were felt most strongly by mothers within families evoking high levels of stress, guilt, and shame. Family's routines, behaviours and priorities influenced the development of a CFD and so it was considered important to be able to understand and work with these to be able to achieve positive outcomes for the child but there was limited evidence that this was able to happen in practice. There was a strong sense that the priority for service needed to be the nutritional status of the child as this impacted on their growth, development, and immune capacities. A team approach was considered very important to this work, with dietitian and paediatrician services considered central and speech pathology and occupational therapy playing a more supporting role. It was recognised that social work and psychology and especially an infant mental health focus were missing components of the current team approach. Working with the carer of the child, who was most commonly considered to be the mother was valued.

In comparing these two sources, it was apparent that the documents did not accurately reflect the practice, values, and beliefs of the clinicians. Through their interviews, the clinicians demonstrated a strong understanding of the social influences and impacts of caring for a child with CFDs but the information they gathered and the way they explained their service privileged the physical impacts on the child. The role of the family was limited in both representations with a clear emphasis on the mother's responsibility for caregiving in isolation. A clear assumption was conveyed that mothers should and do bear the responsibility for their child's weight status and eating (Q2). Clinicians discussed the importance of working with the family to understand the problems and how they were impacting on the child. This was in contrast to the way the documents were worded and framed. Despite their obvious understanding of the broader social impacts on and influences of the family on a child with CFDs, the clinicians tended to work with an individual carer and child, and this was most often the mother, in isolation from their home, family and community (Q4).

The documents conveyed power dynamics constructed as a team who held the expertise and were responsible for solving the problem of CFDs. The clinicians, however, used language that reflected a more collaborative approach and a valuing of working with a family to understand what was going on. The language throughout the interviews and during the observations reflected empathy and understanding of the pressures that families were experiencing but often indicated holding carers accountable for the development of the CFD. There were indications of practices that lacked cultural responsivity.

4.6 Conclusion

This chapter presented the results of the WPR analysis of clinician data. This occurred in three stages, firstly documents were analysed, then interview data, and finally these were compared to present an integrated analysis that enable me to critically examine how the problem of CFDs was represented in the clinical practices of the team. This comparison highlighted contradictions between the intentions and philosophies of the team and the way things played out pragmatically. Chapter 5 will then apply the WPR methodology to analyse and report on the carers' experiences of this PR. The comparison of both carer and clinician experiences will be presented in Chapter 6 and this will form the basis of a discussion regarding health care practices more broadly.

Chapter 5 HOW IS THIS PROBLEM REPRESENTATION EXPERIENCED BY THE CARERS?

5.1 Introduction

This chapter presents the results of the WPR analysis applied to carer observation and interview data to answer the question, how is the PR described in the previous chapter experienced by carers of young children with CFDs? This analysis highlighted key silences and effects of this PR on carers. This addresses the second part of research aim 1; to critically examine how the problem of CFDs is being experienced by carers.

During my analysis, I wrote vignettes that reflected the lived experiences of the carers in this study and provided a narrative summary based on in-depth interview and observational data across a range of settings. These vignettes served as analytic tools to capture and clarify my perspectives. Three of these have been included as Appendix 8.

5.2 Results of carer data set analysis: What's the problem represented to be?

It is important to note that this analysis does not only reflect the carers' experiences related to the PFAT. Carers also reported on their experiences with the health system more broadly and particularly their experiences prior to encountering the team.

5.2.1 Question 1: How is this problem representation experienced by the carers attending the Paediatric Feeding Assessment Service?

The carers experienced CFDs as a rare, complex, multifactorial, compounding, physical problem that affected a child's ability to feed, eat and gain weight. They also reported significant challenges to the mental health and emotional wellbeing of themselves, their child, siblings, other family members and friends. A CFD was something that invaded and changed every aspect of everyday life. It was a visible problem that invited advice, blame and shame but that needed to be proved. Carers considered that it required specialised medical knowledge and expertise, access to dietetic advice and nutritional supports, medications, specialised equipment, speech pathology and sometimes occupational therapy. It was highly specialised, individualised, and traumatic. Fear, pain, and struggle were ever present in caring for a child with CFDs. Carers' sense of their own wellbeing became interdependent upon their child's weight and hope and desperation were constant companions battling for supremacy throughout the experience of caring for their child.

The process of determining and ‘diagnosing’ a CFD was lengthy and frustrating for all the carers. For two of the six, Jane and Karen, a condition (Russell Silver syndrome and eosinophilic oesophagitis respectively) was eventually diagnosed that helped explain the feeding difficulties. For the other four carers, no specific cause was identified and for all six carers trying to make sense of why their child would not eat and did not gain weight was frustrating, time and energy consuming. All of the carers believed their children’s CFDs developed from multiple, compounding factors rather than a specific disease. As Rachel described it; “She's had so much bad experience that she doesn’t trust [the feeding process]”. When asked what he thought had contributed to his son’s difficulties with eating, Fardin replied “To be honest with you I don't have an answer for that, … I mean it could be his behaviour, it could be heredity, or the other thing could be actually, we're introducing the milk when he is not taking at all.” For Emily and Rachel, their children experienced difficulties with vomiting and reflux. For Rachel and Kate, their children’s pain, one related to oral thrush and one related to tonsillitis, lead to severe oral aversion. Jane and Karen both believed the nasogastric tube was a contributing factor in their children’s difficulties. For Jane the length of time the tube was in place affected her son’s ability to eat and for Karen her son couldn’t tolerate the nasogastric tube and so this contributed to his lack of weight gain and associated low energy. What was clear for each family was that a series of factors built upon each other and contributed to their child’s inability to eat.

Carers were very aware of both the physical and mental effects of the CFD and the interrelationship between the two. They consistently reported how concerned they were about the mental and emotional impacts on themselves and the whole family. “I think as time has gone on, I think it's perhaps turned into more a mental thing with him now as well” (Kate); “ in the first beginning as the food allergies grew I was always so worried about the mental - like, what it would do mentally to him” (Karen). “… the mental health aspect of this for me, her Dad as well, and our son […] just yeah, the impact that it's had, it's been like a bomb basically.” (Emily).

All the carers talked about the very visible nature of the problem. The child is small and very thin, or they have a nasogastric tube taped to their face with or without a pump attached. Kate talked about the impact on her and the activities they undertake; “He does swimming lessons every Saturday and we keep him in his full little zip sunsuit … because I just can't bear to sort of show his skin and bones to people.” She went on to say, “He looks like a child with anorexia.... It's quite disturbing to see.” Emily described her severely underweight baby as “just so flat and just listless. Just that dead sort of look to her, she was so tiny.” For Jane the visibility of the problem was also painful and associated with the core role of being a carer; “It's just a basic - you know, you're supposed to be able to feed your child and your child's supposed to put on weight and grow... It's just a, you know, a basic thing with raising a child...”. This sense of what is normal, of what is supposed to happen was also echoed by Kate, “So often I think why can't he just be like a normal child that eats, why can't he look like a normal child with weight that, you know, I'd love him to have a few chubby rolls like a normal toddler”. Emily also talked about the expectations of a ‘normal’ happy family; “We were expecting this happy beautiful family, this gorgeous little pink bundle, and we got a gorgeous pink bundle but we got all of this other stuff too that's just decimated our lifestyle.”

The impact on everyday life was enormous. Emily’s 16-month-old daughter could only tolerate very slow feeds and was connected to a pump for 23 hours a day; “you're just constantly connected by a tether to this thing; this life-saving thing. So it's, yeah, it's so necessary, but it's a love-hate relationship.” This has a huge impact on their everyday life; “You'll work something out and then something will change and the system has to change. So she went from crawling to walking and then it was just like, oh God, what do we do now?” (Emily). Kate and Jane talked about the judgement and embarrassment they felt in family and social situations and how frustrated and exhausted this made them; “it’s constantly thinking somebody's judging you for what you're feeding your child.” (Jane).

> It's embarrassing when you go out. We go out for meals a lot with family and friends and every other child eats and there's this one that won't touch anything… And everyone's giving you their advice …oh, just do this, or don't let him have anything else, or don't rah-rah-rah, and you know it's so much more than that so you're just trying to politely say to people look, no, we can't do that, and you know, you're trying to bite your tongue. (Kate)

The carers experienced a CFD as a problem that needs to be proven. Many of the carers talked about not being believed by the health services. Emily showed me photographs of her and Summer covered in vomit that she needed to use as evidence to be believed: “So taking photos of the vomit so that they would believe how large-scale her reflux was and what we were dealing with on a multiple time a day basis. It's a lot of vomit.” Similarly, Rachel used videos and photographs as evidence of the distress her child was in; “which is why I started - I took videos of how she was screaming to the point of vomiting, and I took photos…just because the doctors seemed to – ‘she's been fine. We don’t know what you're talking about’.” Jane also talked about not being believed. She was constantly asked about her milk supply even though she was breastfeeding her twins, one of whom was putting on weight and growing well, the other of whom was not growing.

CFDs are experienced as rare and unusual. Carers talked about their child's unique experiences and not finding universal services helpful. This contributed to caring for a child with CFDs being an isolating experience; I don't have any friends going through this sort of thing. So, yeah, it's quite isolating. It's hard to sort of convey the daily difficulties just verbally, unless you're living it." Emily. "…no one that I speak to has got a child like this" Kate. Rachel and Fardin also talked about how frustrating and isolating it was when no one else understood what was going on for their child. Carers reported that universal services like help lines and GPs immediately directed them to the acute hospital once they realised their child had a naso-gastric tube. Jane and Karen reported the relief of having a diagnosis that explained their child's CFDs as this led them to discovering online support groups related to that condition where they finally felt heard and understood and accessed specific support and advice.

For those carers whose children with CFDs required naso-gastric tube feeding there were additional aspects to be considered. These included the specialised skills and knowledge to be able to manage the day-to-day care of the tubes, tapes and pumps as well as the calculations of formula and speed of flow; the unacknowledged trauma, pain and fear associated with the tube and the impact on the carers of dealing with. This is covered more in Q4.

5.2.2 Question 2: What presuppositions or assumptions underlie carers' experience of this problem representation?

Fardin is from Bangladesh and his experiences offered insight into the cultural assumptions and expectations that underlie food and eating and impact on carers' experiences. Fardin reflected on the differences between types of food and schedules for eating as well as the role of the extended family in supporting feeding and all aspects of child rearing:

> Back in my home country we don't eat regularly, but we are having [grapes] and things like - on a regular basis.
>
> … from every prospect - from feeding, for other development, for learning, playing - [extended family] is good
>
> There are huge differences in terms of culture and food and everything. For example, here the babies even used to sit on a highchair and start to feed by themselves, but in my country it's more like mummy's doing that so they are sitting on mum's lap. I mean the difference is actually they don't start that early. So here babies start very early. In my country it's a bit later.

Cultural expectations about food and eating underpinned how all carers experienced CFDs. This included acceptable weight, types of foods, amounts, whose responsibility it was to feed and to eat. The sense of responsibility these carers felt to be able to feed their child 'properly' and for their child to put on weight and thrive was evident throughout all the interviews.

This representation was also firmly grounded in a biomedical model of health and the consequent assumption that physical and mental aspects of health could be considered and treated separately. Within this medical system there were assumptions about the clinician/client relationship, what this meant and how it would operate. Carers talked about the struggle to negotiate this new relationship and how this impacted in their children's care and their own emotional state. As an example of this, Rachel talked about not being sure how to clarify or follow up on issues for her daughter; "…do I mention her? Has she forgotten? Is it written there? Or is she ready to move on? Because she seems okay."

Power dynamics based on medical dominance also influenced this relationship. There were assumptions that carers would be advocates for their children, but this was not made explicit and there was no training for this new role. The carers were from a range of backgrounds, with varying educational levels and socio-economic status. Yet, they all appeared to have difficulty holding their own in this highly medical environment. Rachel reported finding it difficult to know how to talk to the doctors who treated Ella prior to being referred to the PFAT and she didn't feel heard or valued by them:

> And you get into a position where you don't feel comfortable with it, so why push it? Do they look at me like I'm thinking of making stuff up, or am I pushing it because I want something to be wrong? Or - and it's just more knowledge and, you know, I think a lot of mums get themselves all worked up.

Jane also expressed difficulties with negotiating this relationship and her language echoes that of Rachel and offers further evidence of the power positions at play in the socially constructed role of care seeker, that is, good, compliant patient versus neurotic patient who makes things up;

> ... I guess, you know, they, they will listen to me. They know that I'm not, you know, I'm not a neurotic mother... I'm just trying to make sure that they bear in mind some of the specifics of it when they are making some of the decisions...(Jane)

Kate also struggled to hold her own in the relationship with her son's first paediatrician. She felt strongly that her son was misdiagnosed with severe food allergies and that this contributed to his fear of food. When I asked her if she had raised this with the doctor her response was "Not her directly, and I don't know that I would say it directly to her" and when I asked why;

> Um, I don't know, fear of conflict maybe on my part. I don't like conflict, I'm not that sort of person and I won't push people, um. [Name removed for confidentiality] is lovely but quite headstrong on that too and I just don't think that would go down well, me more or less pointing the finger at her going look, I feel that this is your, your - you know, um, you know, because of your advice, yeah, I just don't think I would go there.

This very clearly captures the power dynamic at play in the patient-doctor relationship. Kate did go on to say that she had raised her concerns with the dietitian she was also working with at the time indicating a more comfortable and equal relationship.

Despite her background as a nurse, Emily also found it difficult to advocate for herself and her new baby:

> As a nurse you know what to look for, you can see these glaringly obvious signs, but nobody would listen in the hospital. Nobody - they just kept saying that I was trying to latch her incorrectly. So I kept saying, well, fine, you watch me her and tell me what I'm doing wrong so that I can fix this. But no help arrived and they just put it down to her - she's a lazy sucker, she's just too tired. There was always some excuse which was basically, we're too busy to deal with this, get out, was how I felt. So I went home as soon as I could, yeah, with this completely unhappy child.

Karen's experiences reflected the way that the medical system prioritises cases and responses based on medical diagnoses and severity of physical symptoms rather than any other psychosocial factors. She talked about her ongoing battle with waiting lists, especially for gastroenterology services but reflected that the severity of James' condition meant that once she was finally able to see specialists they tended to respond well and listen to her:

> but, um, I do feel that [James's] case is quite severe and that's probably assisted it. Um, you know, whenever you go to see a new doctor and they have three - three folders in front of them for [James'] history, they're like, oh.

Fardin was the only carer who did not report difficulties with communicating and being heard within the hospital system. His attitude to health care was very different to the other carers and this may have been influenced by both his cultural background and gender. He appeared to be very comfortable interacting with clinicians, persisting with asking questions until he was satisfied. This may have been a manifestation of the gendered nature of health care systems. His attitude and approach may also have influenced this as he did not expect doctors or clinicians to have all the answers:

> I don't have any frustration with them, but some of the advice they are giving definitely didn't work. But I would say because every kid is different so I shouldn’t expect okay whatever they are saying this is like a bible.

5.2.3 Question 3: How has this representation of the problem come about?

This PR has come about through the broader health system and its funding models which drove the practice of health care and set the expectations of acceptable practice. This included the paradigm of evidence-based practice. There are very different treatment approaches to young children with CFDs across the world especially when it came to tube feeding. As Emily raised, America had very different expectation regarding naso-gastric tube feeding timeframes:

> But yeah, in the States they would have - she would have had a gastrostomy by now. But then of course everything's private over there, so they have insurance companies that are happy to pay for these things. Whereas here it's a different system.

Additionally, the practice and processes of health care within an acute hospital occur within a medical system based on medical dominance. As discussed in Q2 and Q4 these have particular effects on service responses and the experiences of the carers and children which will be discussed further in Chapter 6.

5.2.4 Question 4: What is left unproblematic in this problem representation? Where are the silences? Can the problem be thought about differently?

Carers’ own knowledge and expertise were often silenced. As discussed in Q1, medical knowledge and expertise was privileged over all other forms and carers reported feeling overlooked and ignored, not listened to, or believed. Clinic and hospital experiences were privileged over the daily experiences of the carers and children. So, if a child was presenting happily at the clinic, the reports of screaming, pain and distress were minimised or dismissed. This meant that the everyday impacts on the routines, roles and occupations of the whole family were often ignored. Physical symptoms were privileged, the focus was on the magic number – the weight of the child and anything that impacted on this was prioritised. This led to a process by which carers became technicians needing to develop highly specialised knowledge and skills in calculating pump flows, formula supplements as well as managing daily tape changes and tube changes at a minimum every six weeks but often much more frequently. A process of enculturation to the medical world as part of becoming an expert and advocate for their child appeared to occur and this was reflected in their language and skills.

Tube changes needed to occur every six weeks but were often accidently dislodged requiring an emergency trip to hospital. Carers reported feeling powerless as they watched and often had to hold down their screaming child while the tube was reinserted. The level of pain and physical trauma experienced by these children and their carers was significant:

> Because it was, you know, blood from the nose and the mouth and he would choke, and I was like ……it's just too horrible an experience. Um, but then we had issues with the taping to keep the tube in that was burning his face, even after just like 12 hours on. I'd take it off and it would just be pus-y and red raw. (Karen)

Emily reported similar difficulties resulting in a traumatic reaction to every tape change; “She just screams the house down” and every tube change; “re-tubing her is getting more difficult because she's had a tube in for 14 months. So now we get a lot of pain, a lot of bleeding. A lot of bleeding. It's just very traumatic for her.” As a consequence of this, the children often developed a fear of the hospital and especially anyone in uniform:

> sometimes my son was very afraid going to hospital at the early stages because he knows - I mean even if he sees someone with a uniform he starts - I mean he probably understands what does that mean for him because he had the probably trauma or something like that with the tube. (Fardin)

To be able to cope, carers reported needing to remove or distance themselves from emotions to deal with practicalities and pain of everyday care. Even though her son did not have a nasogastric tube, Kate also reflected on the stress of caring for a child in ongoing pain: “So he's constantly obviously living with some sort of pain and discomfort.” Karen summed it up by saying; “Just have to get on with it – it is just what you do”.

> It can be really easy to get bogged down in the chore aspect of all of it without getting emotionally involved. Which is - it sounds awful, but if I dwell every day on how much pain she's in I'd never get out of bed in the morning. (Emily)

Despite these frequent experiences of living with pain and trauma, responses that addressed or acknowledged the emotional wellbeing, mental health or impacts of trauma were not evident for the child, their carers or family members. Carers reported that their whole family was effected but that service responses prioritised the child’s physical wellbeing and so the experiences of the carers and their family was also silenced. Emily captured it eloquently when asked was her own wellbeing considered:

> Not really, no. I know people ask you, how are you, and I can say that things are shit [laughs], but beyond that it's all about trying to fix [Summer] because she's the end goal. Anything I have issues with I have to take to my GP and sort of tend to separately, like I have the time… quite honestly I am skating on thin ice. It's really hard to maintain a positive mental sort of state when you're dealing with all of this, and you are so sleep

> deprived. I don't eat properly, I don't drink properly, I don't sleep properly. I don't shower when I want to.

An additional silence was the influence of uncertainty on these families. The idiosyncratic nature of CFDs, the lack of a clear diagnosis, the long-time it often took to determine what was going on for the child and develop a treatment plan, and the many health professionals involved all contributed to carers feeling very unsure as to what was happening for their child. This was not acknowledged by the clinicians and processes to communicate and respond to the stress that was evoked by the uncertainty were not evident.

5.2.5 Question 5: What effects (discursive, subjectification, lived) are produced by this representation of the problem?

The lived effects of this representation are the unaddressed impacts on the carers' physical and mental health and wellbeing as a result of living with such very high levels of stress. Fardin reported on the time that his son needed his first naso-gastric tube as; "… very stressful. It was absolutely a very stressful event. We were crying and things like that." Kate described the ongoing experience of caring for a child when "eating is such a battle … it has been very, very stressful, always worrying that you're not giving them enough, they're not getting enough." For Karen it was a heart-breaking experience; "But it's tough. It's - it - yeah, there's so many times where your heart gets broken." Emily reported needing to be in survival mode to cope:

> Basically we're in survival mode 24/7, it's just get through the day bit by bit … On a bad day we just get through second by second and handle the various meltdowns as they occur, and they certainly do occur - from her end and from mine [laughs]. It takes its toll".

All of the carers described a process of relentless worry, constantly monitoring pumps, tubes, calories, and weight. They also talked about the juggling required to balance the needs of their child with CFDs as well as the rest of the family's needs.

> there's a lot of things to juggle... So we are having to balance the calorie intake to get his weight up. We're having to balance how often he eats that to keep the hypos at bay and work on behaviour around the overstuffing of mouth and you know, messing around. (Jane)

Rachel talked about the demands she experienced and the sense of everyone wanting attention and how hard this was to respond to. Most carers reported a similar sense of desperation; "We're really just hanging on and hoping and praying that that will be, you know, the light at the end of the tunnel to get him eating." Kate. Fardin and Jane also reported on the ongoing strain of caring for a child with CFDs. Emily reflected on her utter determination to fight for her child to have a PEG insertion rather than continue with the continuous pump feeding by nasogastric tube; "I can't anymore, I just can't. Sorry, it's just too hard and it's too much pain.” Karen summed it up when she said, “this just can’t be as good as it gets”. In this PR, it was apparent that carers’ wellbeing, stress levels, and mental health including their feelings of anxiety, fear, and happiness became inextricably linked to their child’s weight status; “He's gaining quite good. So that's the moment I feel like okay - probably the days are getting better for us so that's the moment actually I feel like okay, I feel better.” (Fardin).

This PR has significant impact on the children, their carers and their ongoing relationships with each other. The focus on the physical problem of an underweight child ignores the broader impacts on the child and their family’s mental health and emotional wellbeing. In this representation, the child reaches their weight status but at what cost? As discussed in Chapter 6, service responses need to consider the ongoing trauma effects on the family. There was no evidence that these issues were being considered or addressed in current service responses. The effects of this include current and ongoing harm to these children and their families.

5.2.6 Question 6: How/where has this representation of the problem been produced, disseminated and defended? How could it be questioned, disrupted and replaced?

As discussed in Q3, the processes and practices of the medical system produced and reinforced this PR. This PR is disseminated and defended through hospital systems that do not allow time for critical reflection and questioning of processes and their effects.   Additional social and cultural perspectives of healthy eating and appropriate weight and whose responsibility it is to achieve this for a child, further reinforced this representation. Idealisations of parenthood and childhood also supported the silencing of emotional distress and the focus on physical and medical problems and solutions. All of the carers reported the frustration and pain that came with not being able to feed their child and having a child who does not fit with the normative assumptions of development and weight. These will be discussed more in Chapter 6.

It is important to note that this PR was often well developed before these carers encountered the PFAT. The system responses to children with CFDs occurred across two major hospitals, and included contact with neonatologists, pediatricians, gastroenterologists, allergists, nurses, OTs, physiotherapists, speech pathologists, dietitians and occasionally social workers and psychologists, before they encountered the PFAT. Even though the PFAT operated within and was part of this broader system which influenced the development of this PR, there appeared to be ways that the team disrupted this through their responses to and interactions with the carers. These carers unanimously reported that this team was unique in a system where the norm was not to be listened to, believed or valued. They talked about the contact with the team being a relief and described them as a “one-stop shop for all your feeding needs” (Emily) that offered knowledge and expertise. Emily and Fardin’s comments are representative of the responses made by all the carers;

> Awesome [laughs]. They're all parents, which really helps with the empathy I think. Unless you're living it, it's hard to, like I said, convey. They just seem to get it, you don’t have to bring in evidence, you don’t have to show them photos or videos. You just tell them and they're just on board, and then it's - they're there to back up your problem solving and add their specialty knowledge into the mix, which makes overcoming the obstacles a lot easier. (Emily)
>
> I mean they didn't give any magic or anything that actually helped. But the things actually worked better because - because they are working as a team and when they are talking on a particular issue, everyone is putting their own input. So it gives us a better understanding actually how to deal with that. (Fardin)

Aspects of the team’s functioning that worked for the carers included the attention they paid to the carers and children. This translated to the carers feeling that the team members were genuinely invested in getting to know them and their child. Additionally, the carers all reported that the team worked with them, valued their opinions, and involved them in decision making. They explained things well without using medical jargon. They were also flexible and responsive to working around the special needs of the families. Examples of these included scheduling appointments at the end of the day for Jane who worked fulltime, working around Rachel’s caring responsibilities for her five children and fitting Karen in to an already fully booked clinic when she said she really needed to see them. The practical benefits of a team approach were very clear to the carers; “to have that such a cohesive sort of therapy session that encompasses everything, instead of having to see four people individually, which is time consuming” (Emily). But it was more than practicalities, their language and approach validated the carers’ experiences of both struggles and successes and the team were proactive in advocating for the carers with other specialists. This all contributed to the carers feeling seen and heard in a health system where they often felt invisible and powerless.

> They definitely put all of their focus and attention on me and her, and they were paying attention. And if they missed it, they'd go back and - what was that you said? They were writing down notes and making sure that they got everything. (Rachel)
>
> But yeah, that's certainly a unique experience. I don’t think I've had that with any other specialist, and we've seen a lot. They just - the parent's role is minimised, it's, yeah, quashed. (Emily)

> They give me enough information medically to understand what the benefits or side effects could be of each area we can go towards. But they really do allow me to - to bring… our personal situation into it and what I think (my son) can and can't tolerate to make the final call on the situation. (Karen)

This occurred because of the team members' expertise, approach, and communication skills and despite rather than because of the structure and processes of the PFAT clinic. All of the carers reported finding their appointments overwhelming. The clinic room was small, with no obvious child focus. Toys, if available, were tucked away and often not brought out. It was crowded with each of the four team members plus there were often students involved and this left limited room for a child to play. The children were often distressed, and this manifested itself in clinging to their carers or becoming busy and disruptive and so the carers' focus was pulled between responding to their child's needs and listening to the team, answering questions and contributing to the discussion. When assessment of the child's eating needed to happen there was often limited space or the required food or equipment (adapted cups, thickened formula etc) were not on hand. Karen reported finding it "chaotic" trying to manage her screaming son while participating in the session and Jane found balancing the needs of her twins "disruptive". Jane also raised the point that there is risk of people feeling judged:

> it can feel a bit like you're being interviewed and … I'm sure there's no judgement, but it feels a bit kind of oh okay, I've got all of these people looking at me and listening and it's yeah...a bit overwhelming… I mean I, I didn't feel it but I can - I wonder whether other parents might feel a bit like okay, I'm here and it's a, you know, it's - this is a judgement situation.
>
> Well, it was quite overwhelming walking in, because I think there was six or eight people in the room… and it was just like all eyes on me…I'm, like, oh, I don't know how to do this [laughs]. (Rachel)

Carers were asked what an ideal service for their children would look like and their responses to this question provide insight into the ways this representation could be disrupted and replaced. The carers talked about the initial processes of coming to terms with having a child with CFDs and how isolated and scared they were. They suggested that a 24-hour point of contact for advice and reassurance with a clinician who was experienced in feeding difficulties and who had access to their child's medical notes would have been very valuable. Universal services, GPs and helplines were of no use and everyone referred them back to the emergency department. Karen talked about the challenges of taking your child to the emergency department as the first step when you weren't sure what to do. It places a burden on other family members, as well as the need to take time off work, find care for other children and put your child through the trauma of yet another hospital visit and then there was the wait times; “When you go to emergency, the - the transfer from emergency to a room, um, can sometimes be like anywhere from two hours to 18 hours”.

> But a point of contact, no matter what time of the day it was, even a call to say, look, my baby - I can't calm her down. This is what she's doing. Can you - what can I do? I don’t know what to do. I can't pick her up, because I'm worried she's going to vomit. She's at full pelt. She's waking the house up. I'm crying my eyes out and I don’t know what to do. (Rachel)

All the carers talked about needing additional support and advice that focused on the everyday realities of caring for a child with CFDs and felt that this translation from hospital to home was lacking in current service models. They needed the clinicians to understand their unique circumstances and tailor their services responses to these. They felt this could have been addressed better if assessment and intervention services were offered in their homes. For Fardin this was about reducing the trauma for his child in attending hospital-based services and ensuring the team understood what his home environment and routine was like. Jane agreed that intervention suggestions would have worked better if the team understood her home life better. For Kate this was about the pressure she felt and placed on Noah to eat. In hospital-based sessions this pressure did not exist, was not acknowledged and feeding was fun. But that did not translate to feeding at home, but because no one worked with her to understand or address the impact of the pressure she placed on herself and him; “I go to those sessions and I feel very relaxed, yep, there's no pressure, he doesn't have to eat, whereas at home I'm like he does have to eat, he has to eat something.” (Kate). Rachel needed help with translating strict feeding routines designed to increase Ellie’s calorie intake into the reality of responding to a baby and her four siblings; “Can I take her off [the pump] and pick her up a certain way? If she vomits, can I extra-feed her?” Emily agreed with all these points and raised the specific issue of family mealtimes and the gap between what she was asked to do as part of her therapy for Summer and the reality of her everyday experience of mealtimes.

> It's supposed to be this totally functional time when we help her with therapy and stuff, but it's not [laughs], it's this totally dysfunctional… (my son) hates listening to her scream. So yeah, he usually eats in his room...I describe our mealtimes as fraught with peril [laughs].

Another way that this PR could have been disrupted and replaced was through carer support groups. All of the carers reported feeling isolated and overwhelmed and that the focus of therapy was their child which meant that their needs for practical and emotional advice and support were overlooked. The unique nature of their child’s condition and the challenges this presented in terms of timing, juggling equipment, avoiding vomiting, and the very visual nature of the problem meant that these carers could not easily access and did not feel like they belonged to universal support services. They suggested that an informal support group with other families of children with CFDs would have been beneficial to counter the sense of being so alone and help build their own knowledge and capacity and support each other.

> These are the other people that do it like I do, every day. They live and breathe it. (Rachel)
>
> Where there might be that opportunity to perhaps mingle with, um, you know, some other parents with children in similar situations where you could maybe try and bounce ideas off of or, um, whether the kids could, you know, have a bit of playtime together… (Kate)

Greater client centred care and streamlining and coordination of services across the health care system would also help disrupt this PR. Fardin highlighted the lack of knowledge about the presentations and impacts of CFDs in general practice which resulted in delays with his son's condition being identified and referred to speciality services. Emily, Karen, and Jane raised the issue of very limited paediatric gastroenterology services and that these services spanned two hospitals. This often resulted in very long wait times and the carer bearing the additional burden of keeping both sites up to date. All of the carers reflected on their power within the health service encounters and expressed frustration that they were so often peripheral rather than central to the decision-making process regarding the care of their child. Examples of these included; provision of certain equipment (Emily), the processes for feeding times during an inpatient tube wean (Jane), guiding meal and bed time routines (Fardin), timing overnight tube feeds (Rachel) or access to a suitable outdoor play space during a lengthy hospitalisation (Karen). All the carers expressed the need to have greater coordination of services and more control and autonomy in the care of their child.

> …to have the ability to say, well - I guess in the States they can kind of say, well, I'm paying for this so I get what I want sort of thing. But to have that autonomy would be amazing. Make it work for me, that would - yes, I would like to be the extreme dictator. (Emily)
>
> I would love for everything to be based in the one hospital, that would be so amazing for us. Just to have the team be able to have access to all that information all the time, instead of having to get things second-hand through me. Or trying to connect to different computer systems so they can get this report or that report from the different hospitals…Not everything's available in real time, so it can be really tough for them to get an accurate picture of what's going on with a kid when all of that's going on. (Emily)

5.3 Conclusion

This chapter has presented the results of a post-structural analysis of interview and observational data to determine how carers experienced the PR determined in Chapter 4. This provided insight into the effects of this PR. A comparison of the clinician results presented in Chapter 4 and the carer results presented here will be reported in Chapter 6 and this summary will form the basis of the discussion of these results.

Chapter 6 DISCUSSION: HEALTH AS CARE - CLINICIANS' REPRESENTATIONS AND CARERS' EXPERIENCES OF COMPLEX FEEDING DIFFICULTIES

6.1 Introduction

In this chapter I bring together the analysis of clinician and carer data and discuss the connections and contradictions between the carer and clinicians' perspectives based on a poststructural analysis using the WPR approach. This addresses the second part of my first research aim, to critically examine and compare how the problem of CFDs is represented in clinical practices and experienced by carers. Key themes that emerged from the analysis are discussed through a Foucault-influenced post structural theoretical lens to identify and discuss the discursive effects of this PR and how they effected clinical practices within the PFAT. Mol's work on the logic of care provided an additional layer to this analysis and brought a focus to the practices of health care and its effects to address the second research aim. This chapter applies a theoretical lens to discuss the results outlined in Chapters 4 and 5 and summarised in the introductory section of this chapter.

6.2 Problematising and discourse analysis

As introduced in Chapter 3, problematising is a poststructural approach based on the work of Michel Foucault that aims "to question taken-for-granted assumptions, to shake up habits, ways of doing and thinking." (Foucault, 1984, p. 389). Problematising health care responses offers a mechanism for examining complex health care situations. By questioning clinical problems rather than attempting to solve them in better, leaner, more productive ways, opportunities are opened up and new possibilities and options emerge. This process of questioning may result in "discomfort, disorientation and unsettlement" (Terwiel, 2018, p. 72) but it is in experiencing and tolerating this unease and uncertainty, that clinical practice change may emerge.

Foucauldian discourse analysis, refers to an analysis of discursive practices or discourses, which gives access to the rules that explain how it becomes possible to say or know certain things; 'the rules governing a knowledge" (Cousins & Hussain, 1984, p. 94). Discursive practices are "historically and culturally located systems of power/knowledge [that] construct subjects and their worlds "(Holstein & Gubrium, 2011, p. 344). Discourses are "not merely bodies of ideas, ideologies, or other symbolic formulations, but are also working attitudes, modes of address, terms of reference, and courses of action suffused into social practices" (Holstein & Gubrium, 2011, p. 344). An analysis of discursive practices from this perspective, therefore, provides a mechanism to examine the “interconnected practices that give [certain] knowledge formations authority” (Bacchi & Bonham, 2014, p. 183), to show “how knowledges form their truths” (Bacchi & Bonham, 2014, p. 187) within institutional systems, sites and practices.

6.3 Comparison of clinician problem representations and carers’ experiences and the implications of this for service responses

Both carers and clinicians conceptualised feeding difficulties as a complex, multifactorial, compounding, physical problem that affected a child’s ability to feed and eat. Clinicians framed this around the effects on the nutritional status on the child and their ability to thrive and grow. Carers experienced this as a focus on their child’s weight status. The PR was a serious physical problem that affects a child’s ability to put on weight. The implied ‘problem’ was weight of the child. Carers’ experience of this PR resulted in them feeling isolated and often unsupported. The real everyday challenges of their role were often unseen and interactions with clinicians and health care systems often unhelpful and undermined their agency. These findings were consistent with current understandings of CFDs as being highly heterogeneous (Sharp & Stubbs, 2019) and difficult to treat because of their complexity and the range of causes and presentations (Norris et al., 2016; Sharp et al., 2017). While there are a number of studies that identify feeling isolated and alone as a carer of a child with CFDs these mostly focus on this as an aspect of stress (Garro et al., 2005; Greer et al., 2007). As established in Chapter 2, there is a body of literature that recommends CFDs are treated by an interdisciplinary team but there is very little information about what this looks like or the impacts of clinician, team and health care system functioning on carers’ experiences. There is little current evidence to suggest that carers’ experiences of isolation and lack of support can be directly linked to the way the problem is represented and the corresponding service responses. This study adds to the current body of knowledge by making an explicit link between how the condition is represented and its effects on carers.

6.3.1 Biomedical discourse

Carers made strong connections between the physical and emotional impacts on their child, themselves, and their broader family. Clinicians focused more strongly on the physical aspects. While clinicians understood broader social and emotional factors, they did not offer corresponding service responses to address them. Carers’ experience of this contributed to them feeling that they could not talk about their own mental health or the emotional consequences for their child.

Their experience was that the focus and purpose of the service was their child's physical health and most importantly their child's weight gain. This PR was possible through a biomedical conception of health and the consequent assumption that physical and mental or psychological aspects of health could be considered and treated separately (Baum, 2008; Ferreira, Prado, Carvalho, & Kraemer, 2015). Foucault in one of his seminal works, The Birth of a Clinic, provides an analysis of the history of medical practices to challenge assumptions about how disease, pathology and medical practice is thought about. He provides an explanation of the ways that these practices have come to be known and accepted as 'true' and describes the processes by which "disease, emerging beneath our gaze, becomes embodied in a living organism." (Foucault, 1973, p. 6). This provides a context for practices occurring within the PFA service and for how this PR of complex feeding has come to be possible.

The PR as one that effects the physical child is firmly grounded in the biomedical discourse. The relentless focus on the physical body of the child in considering CFDs and its concurring system responses are a function of the biomedical system dominance and an example of how it is afforded "hegemonic control in understanding and responding to human distress" (Fennig & Denov, 2019, p. 305). As Fennig and Denov (2019) describe in their paper examining the mental health responses to refugee youth seeking asylum, the biomedical system can be considered as a 'regime of truth' and is afforded power to define problems and consequently shape policies and responses. Within this discourse hospitals are constructed as curative spaces (Davis et al., 2019) whose role is to diagnose and treat medical problems. This allows little space for responses that focus on the impacts of a condition more broadly; on carers, families, everyday lives and the society that surround and influence this condition. This then creates certain ways services, teams and clinicians can respond.

6.3.2 Governmentality

From a Foucauldian perspective, the Western biomedical model can be considered a discourse that has evolved from specific cultural, temporal, economic and political environments and serves a purpose of social regulation. This discourse is a product and expression of power relations that ensures priority of knowledge in particular disciplinary areas and also establishes who has a claim to that knowledge. The discourse becomes the means through which power relations are developed and maintained. Governmentality, derives from the work of Foucault (1978) and as introduced in Chapter 3, is a mechanism for regulating behaviour into acceptable practices and forms of conduct that are deemed desirable for governing practices (Bacchi & Goodwin, 2016). This involves a process whereby individuals are not merely subjects of power but also active actors in its operations (Rose & Miller, 1992). Power in this context refers to the complex working out of heterogeneous relations in which ’subjects‘ and ‘objects’ are produced, and power is seen as relational and productive (Bacchi & Goodwin, 2016). Power therefore is not about constraining people, it is about creating certain kinds of people who regulate themselves (Van Rensburg, Rau, Fourie, & Bracke, 2016).

Hospitals and health care services are intricately linked to mechanisms of governing. They are both influenced by and influencers of the governing system. They are influenced through legislation, funding models and policy directives. They are influencers of through their role as experts and knowledge generators in developing and informing clinical practice, policy, research and clinical initiatives. The delivery of health care services within a hospital requires and privileges certain knowledges and creates experts and expertise, it creates ‘subjects’ of patients, clients, carers, doctors, clinicians, who behave in particular ways that help establish and maintain social control. The delivery of health care contributes to the creation and reinforcement of acceptable standards of health, and healthy behaviour, and sets the rules for how to act to respond to and maintain this. The role of experts and expertise has come to play an important role in governmentality, “in establishing the possibility and legitimacy of government” (Rose & Miller, 1992, p. 188). A key characteristic of modern government is “action at a distance” (Rose & Miller, 1992, p. 180) whereby the regulation of conduct does not rely solely on politics, interpreted as the laws and actions of political parties and state bureaucracies. Governing also occurs outside of 'politics' through the activities of independent authority agents including experts; managers, planners, health professionals, and parents. In this way hospitals and health care services become mechanisms of governing. Rose and Miller (1992) conceptualise an expert as “embodying neutrality, authority and skill in a wise figure, operating according to an ethical code 'beyond good and evil'” p187. Expertise supports processes of governing at a distance and is conceptualised as a complexity of “actors, powers, institutions and bodies of knowledge” (Rose & Miller, 1992, p. 188).

In the health sector, clinicians take on the role of experts who call on their expertise and support the processes of governing at a distance by acting as authority agents focusing on and shaping the problematisations of the political authorities. They translate political concerns about health and wellness into the language of the various disciplines that they represent. The relationships formed between clinicians and their clients also serve to govern by translating their clients’ daily health and wellness concerns into “a language claiming the power of the truth” (Rose & Miller, 1992, p. 188) and offering them the techniques and interventions to address these concerns and become more ‘appropriate’ citizens (that is healthier, fatter, thinner, less contagious etc). Policy directives such as ‘patient choice’ (Mol, 2008) and ‘patient- centred care’ (Gardner, 2017) become governing techniques that constrain rather than liberate (Mol, 2008).

Foucault defines a discipline as “a domain of objects, a set of methods, a corpus of propositions considered to be true, a play of rules and definitions, of techniques and instruments”(Foucault, 1981, p. 59) . The PFAT can be seen as a sub-discipline operating within the broader discipline of medical and allied health clinicians. The discipline sets the limits for discourse, for what is considered acceptable actions, thoughts, and beliefs. Something or someone accepted by the discipline, “must fulfil complex and heavy requirements to be able to belong to the grouping of a discipline” (Foucault, 1981, p. 60). These requirements include qualifications, but they also include practices, gestures, behaviours, language that translate into and reinforce the acceptable discourse.

A clinical team working from a hospital becomes a ‘system of action’ through which governing occurs (Rose & Miller, 1992, p. 177). This perspective offers a way of examining the PFAT and their operations as a product of government through analysing the technologies at play in their interactions. A range of mechanisms exist through which connections are established between the aspirations of authorities (the ‘expert’ clinicians) and the activities of individuals (the clients - carers and children with CFDs) (Rose & Miller, 1992). Examples of these in the PFAT setting include their clinical practices; the ways they gather information, the types of information that is gathered, how and where they meet their clients, the language they use, documentation, referral criteria and processes, appointment systems, waiting list processes, as well as the techniques of measurement, medication and tube weaning processes, assessment, and intervention strategies.

6.3.3 Clinical practices as problematisations

Clinical practices are themselves problematisations, they create particular understandings of what the problem is (Bacchi, 2009). The practices of this multidisciplinary team constructed CFDs as a serious problem that affects a child’s ability to put on weight, whereby the implied problem is the weight of the physical child. This was created and reinforced through technologies of government and enacted by the clinicians as ‘experts’ who relied on certain forms of ‘expertise’. Similarly, Gardner’s (2017) Foucauldian analysis offered insights into the ways a multidisciplinary paediatric neurology team made sense of their patients, their illnesses, and the impacts by privileging consideration of certain characteristics. This was enacted through similar technologies of assessment and conveyed through a weekly team meeting process whereby each discipline, relying on their specific knowledge and expertise, reported on their perspective of the ‘problem’. Through this a collective picture of the patient emerged based on certain biomedical, social and psychological dimensions. Gardner named this the ‘broad clinical gaze’, building on from Foucault’s characterisation of the medical gaze which was a way of interpreting empirically observable, biological phenomena within the patient’s body to render disease understandable (Gardner, 2017). The medical gaze is at its most obvious in modern health care through medical rounds and case presentations where doctors and medical students learn and convey information about patients in hospitals and an individual’s interpretation of a patient’s subjective and private experience of illness is publicly conveyed as a concise, objective, scientific account (Tierney, 2004). The broad clinical gaze calls upon the various perspectives of the multidisciplinary team to make sense of the patient. In this process, each team member takes on an authority to speak about and delineate some aspect of the disease and its impact which then runs the risk of reducing the patient’s agency to act and speak for themselves. Gardner’s analysis highlights the power imbalances at play in the multidisciplinary team decision making processes. Gardner makes the point that the broad clinical gaze renders a patient as an object of certain knowledges and in doing so obscures “ ‘messy’ and cumbersome personal detail” (Gardner, 2017, p. 253).

The simple practice of requiring children to be weighed prior to each clinical consultation assumed a governing role and had the effect of forcing carers to “calibrate themselves in relation to 'where they should be'” (Rose & Miller, 1992, p. 187). The weight of the child was problematised through the broad clinical gaze and specific clinical practices. This resulted in carers feeling held accountable for and driven to achieve a certain precarious and precious weight status for their child and to realise this they needed to become enculturated into the medical world and to take on the role of technician. This role enabled them to cope with the technicalities and specialist knowledge and skills of managing their child’s physical needs which included tube, tape and pump management, nutritional supplement calculations, adjustments to feeding flow and timing. But this required them to distance themselves emotionally from the daily pain and suffering of their child and to ignore their own mental health needs and those of their family. Through this process, carers’ sense of their own wellbeing became enmeshed with their child’s weight.

This focus on the physical child’s weight additionally obscured the impact on everyday life. Carers talked about the CFD impacting on every aspect of everyday life and clinicians talked about everyday routines and practices contributing to the problem and the solution. Carers did not feel like their everyday life experiences were valued and clinicians did not feel like they had the capacity to understand or explore their clients’ everyday life experiences. Carers frequently reported that their everyday life experiences were minimised, ignored, or not believed in preference to the presentation of the child on the day. Clinicians sought opportunities to see the child eat or interact with food in the clinic to gain ‘credible’ information to help with clinical decision making but felt constrained in their ability to offer homebased services that would give them a truer sense of the real everyday challenges families face. Both groups raised the highly stressful nature of CFDs but again there were no corresponding service responses to address this. This contributed to carers feeling desperate and often unseen.

My study had many parallels with Gardner (2017) and also identified the risks and unintended consequences of certain clinical practices. Within the biomedical discourse there were assumptions about what the clinician/client relationship was and how it would operate. Carers reported how difficult it was to learn and negotiate this new relationship and how powerless and frustrated they often felt. They reported that this influenced their children’s care and their own emotional state. Clinicians appeared oblivious to the challenge this presented to carers. The socially constructed nature of the clinician/client relationship and its inherent power imbalances were silenced in this PR. The ‘broad clinical gaze’ of the PFAT obscured the carers’ everyday life experiences and roles as experts in the children’s care. Carers were relegated to a less powerful role in the health care exchange which then influenced; the agency and self-determination of carers, difficulties in being heard and believed, effective exchange of information and the consequent development of effective relationships and service responses.

6.3.4 Cultural factors

Cultural expectations about food and eating underpinned this representation of CFDs. This included socially constructed gender and cultural norms regarding acceptable weight, types of foods, amounts, whose responsibility it was to feed and to eat. Clinicians believed that culture played an important role in the representation of CFDs but limited the conception of culture to people from ‘other’ cultures, specifically people of Indian and Asian backgrounds. There was a sense of othering when the clinicians described people from Indian and Asian cultures as being different and that their different practices were impacting negatively on their children's feeding outcomes. Othering is a process that "identifies those that are thought to be different from oneself or the mainstream, and it can reinforce and reproduce positions of domination and subordination." (Johnson et al., 2004 p. 253). People who are othered often experience marginalisation and this this can be conveyed through "seemingly innocuous and everyday" practices (Johnson et al., 2004 p. 254). Examples of this came through in both interview and observational data regarding the practice of force feeding. Carers embodied a broader view of culture and felt that their individual and unique circumstances, values and everyday practices around food and eating influenced their child's CFD. There were indications that the team responses and practices did not reflect inclusive practice or cultural responsivity and did reflect a deficit discourse that represented certain cultural groups in terms of their deficiencies and did not pay attention to the broader structural factors that were at play (Fogarty, Lovell, Langenberg, & Heron, 2018). Culturally responsive care can be defined as an extension of client centred care that involves paying particular attention to social and cultural factors in managing therapeutic encounters with people from different cultural and social backgrounds (Indigenous Allied Health Australia, 2015). It is "a process of actively developing a synergistic relationship grounded in mutuality and an intentional respect for a person's cultures" (Muñoz, 2007 p. 256). Inclusive practice is based on clinicians capacity to move beyond identifying difference to be able to build effective and respectful relationships with clients that enable genuine engagement (Richardson, 2015). The deficit discourse did not allow for exploring and considering the diverse cultural practices and the possibilities and advantages they may present. The lack of culturally responsive and inclusive practices has potential to miss opportunities for full and inclusive clinical information gathering, service planning and service delivery options to support more relevant, nurturing and sustainable responses for young children with CFDs and their families

6.3.5 Regulatory discourse of shame

The sense of responsibility these carers felt to be able to feed their child 'properly' and for their child to put on weight and thrive was evident throughout all the interviews and observations. Both carers and clinicians framed CFDs around a discourse of blame and shame. Clinicians and carers identified that carers and especially mothers experienced high levels of shame around societal expectations that they should be able to feed their child. Carers added that the highly visible nature of the problem presented an additional invitation to feel shame, be blamed and be the recipient of unsolicited and unwanted advice. Feeling judged was a common experience of all the carers. As discussed in Chapter 4, there were indications, conveyed through language and clinical practices, that the clinicians held the carers (most often mothers) accountable for both the cause and the solution to their child's CFD.

Clinicians valued working with carers, but most frequently considered the carer to be the mother and prioritised working with an individual carer (mother) and child rather than the broader family. The predominance of the discourse of shame in this PR reflects the broader gendered societal expectations that women play an instrumental role in producing 'normal' citizens (Rose, 1990). In this way motherhood is governed by expectations to be and do the 'right' thing in regards to producing acceptable children (Craig & Scambler, 2006). The public nature of CFDs and the very real and frequent battles over feeding an underweight child add another layer of regulatory discourse. A mother must feed her child, but she must do this with sensitivity in accordance with current dominant expert discourses regarding parent-child attachment and child autonomy (Craig & Scambler, 2006). For example, Stern's motherhood constellation concept posits that four developmental themes must be addressed in order for a woman to develop a maternal identity. Two of these are central to being able to effectively feed your baby; maintaining the life and growth of the baby and forming an emotional attachment to the baby (Stern, 1995). This theory connects a woman's capacity to feed and nurture a child to her identity as a mother. The fear of not living up to the idealised attuned mother becomes a form of governmentality (Craig & Scambler, 2006).

6.3.6 The silence of trauma

Carers described CFDs as a traumatic experience. They talked about living with fear and suffering, watching their child in pain, and often having to cause pain in the process of caring for their child. In stark contrast, the clinicians' representation of CFDs did not include a conceptualisation of trauma. This silencing of trauma meant that the appropriate services to help address this for both child and carers were not available. Additionally, many of the intervention services occurred in the same spaces that traumatic processes such as tube insertions were undertaken. The lack of trauma informed care practices around regularly occurring processes such as tube changes and weighing perpetuated the trauma. In this way the health system continued to retraumatise children and carers. For many of these children and their carers the impact of this trauma on their ongoing relationships, their relationships to their own bodies, their relationships to food, their ability to feel safe and to trust was not addressed and the potential harmful longer-term impacts of this warrant attention.

Potentially toxic stressors for hospitalised unwell young children include long periods of separation from their parents, inconsistent nursing care, repeated painful procedures without environmental supports and an overwhelming sensory environment (Sanders & Hall, 2018). All of these stressors can contribute to experiences of trauma and are indicators that a trauma- informed care response is warranted. Trauma-informed principles aim to understand clients' behaviours and experiences by considering previous traumatic experiences, acknowledging the impact of this, enhancing the client's feelings of safety and reducing the potential for ongoing re-traumatisation (Sanders & Hall, 2018). There are some unique aspects of medical trauma for children that include discomfort/pain due to injury, illness, or medical treatment, interaction with medical treatment providers, and medical interventions; all of which can contribute to the child's emotional reactions to their condition (Marsac, Kassam-Adams, Delahanty, Widaman, & Barakat, 2014). Understanding the indicators and actions of children during the child's experience of trauma can be important for the prevention of longer term posttraumatic stress disorder symptoms (Marsac et al., 2014). Sanders and Hall (2018) outline a trauma informed care approach adapted to a neonatal intensive care setting that would be highly applicable in the PFAT setting.

Trauma as an aspect of CFDs was also absent in the literature. Mol's work offers a possible way of making sense of this silence (Mol, 2008). She proposes that health care practices operating within a discourse of patient choice tend to avoid situations that evoke a sense of failure. Struhkamp (2005) further suggest that the current language practices of a western culture that focuses on self-determination and conveys patients as active and empowered citizens, risk silencing bodily experiences, pain, and suffering. This in turn then further isolates those people who experience the pain and suffering and reduces their access to supports (Struhkamp, 2005). A child's suffering goes against shared cultural beliefs about the role of health care as that of alleviating suffering (Davis et al., 2019) and evokes strong feelings on the part of the clinician which include feelings of powerlessness (Struhkamp, 2005). It may be that the discomfort that arises from acknowledging certain practices as traumatic drives clinicians to avoid this conceptualisation and instead focus on what they can do to fix the problems.

6.3.7 Feeding and eating

The terms eating and feeding require further examination as they have the potential to convey messages about age, agency, power, and purpose. These terms were predominantly used without clarification by clinicians and carers and within the literature. Examining these terms and how they are used may help clarify intention and set a solid framework for the service. As described in section 4.3.5, feeding, in common parlance, has connotations with the very young needing assistance; babies and very young children are fed or feed; young children and adults eat. Within the literature, as discussed in section 2.4.1, where it is outlined, feeding is considered to be an interaction between the child and their caregiver, while eating comprises actions relating to nutritional oral intake that are performed autonomously by the child (Keren, 2016; Yang, 2017). These two different framings; everyday understanding versus expert understanding as reflected in the clinical setting and the literature, may reflect assumptions in knowledge and understanding that require further attention.

In everyday understanding, the term feeding may carry with it an implication that someone (a carer and most commonly a mother) needs to take responsibility for the feeding of the passive recipient of this process (the baby or child). Whereas eating may be perceived as a much more active process that maintains the agency of the child. The implications of calling this service a feeding assessment service and referring to feeding so frequently may be an implied sense of responsibility conveyed to carers/mothers. The relational and reciprocal process that is meant by feeding in 'expert' understanding may be lost. This may have the unintended effect of increasing the sense of blame and guilt associated with caring for a child with CFDs and overlooking the role of the child as an active participant in the feeding process. A service that responds to young children with CFDs and their families, needs to pay attention to these terms. They need to consider their meanings and examine the assumptions and differences that may be at play between carers and clinicians and what the implications of this may be. This then needs to be explicitly discussed with the clinicians and carers.

6.4 Effects on service responses

As discussed in Chapters 4 and 5, this PR was able to come about through the broader health system and its funding models which underpin health care practices. This also includes evidence-based practice and its often-unexamined impacts and effects (Greenhalgh, Howick, & Maskrey, 2014; Upshur, Vandenkerkhof, & Goel, 2001). Evidence based practice requires close examination regarding who was studied, how and in what contexts (Greenhalgh et al., 2014; Mol, 2008). There are very different treatment approaches to young children with CFDs across the world especially when it comes to tube feeding. Different countries preference different types of tube feeding and have different expectations regarding the length of time a child would be tube fed and tube weaning processes and criteria. As an example European countries preference gastrostomy feeding for longer term solutions and consider nasogastric tube feeding should be limited to less than six weeks (Dahlseng et al., 2012).

This PR was also strongly influenced by funding and management structures and the location of the service within an acute hospital. This impacted on the types and ways services could be offered. Funding models for hospital services were allocated per individual 'patient' with a focus on individual outputs. This drove reductionistic rather than holistic service responses. The system within which the clinicians worked was structured to facilitate work with an individual in the hospital setting. It did not facilitate working with that individual and their family within their home or community. This was also driven by neoliberal influences on health care policy and service delivery that frame individuals as the 'problem' and hold them responsible for their own health problems rather than addressing broader social issues and constraints and the ways that they contribute to these problems (Bacchi, 2015; Dean & Hindess, 1998; Ferreira et al., 2015). Neoliberal political rationality promotes an "individualized, autonomous and responsibilized self" (Bay et al., 2019, p. 948). This influences both clinician and client actions and responses. Clients are likely to feel the pressure to behave and make good choices (increase their child's weight) and clinicians are likely to feel a sense of failure and that inadequacies in the system are their fault and "a problem of their own making" (Bay et al., 2019, p. 949), (we take on too much, we need to work smarter, not harder, we should manage our time better). Political rationalities drive funding models and these drive service delivery and clinical practice (Braithwaite, 2018), they also shape and reflect PRs (Bacchi, 2016).

The system was driven by siloed, discipline specific funding and management models and this contributed to a lack of designated funding for this team. This impacted on workload, autonomy of clinical decision making, innovation and planning and drove inefficiencies in clinical responses and consequently child and carer outcomes were potentially compromised. The clinical experts in this complex area of practice were distanced from decision making in a system response model that has been shown to perpetuate inefficiencies and impact on clinical care options (Braithwaite & Goulston, 2004). This then had direct impacts of the carers experiences of service delivery including waiting times, options and locations for services. For clinicians, their experience of overwork as a result of underfunding was silenced. The effects of this were reduced work satisfaction, stress, and innovation. It also impacted on their ability to complete their work in a timely manner. For clients, this represented a risk of compromised care because the systems constrained the clinicians' ability to work to their full capacity.

Another example of this was that both clinicians and carers reported valuing a team approach to addressing the needs of children with CFDs. A team approach was consistently affirmed as best practice for working with CFDs (Begotka et al., 2018; Edwards et al., 2015; Marshall et al., 2018; Mazze et al., 2019; Sharp et al., 2017; Williams et al., 2017). The funding models and structures, however, constrained the ways that the clinicians could work as a team. Both carers and clinicians would have preferred home- based assessment and therapy options, access to mental health support services for children and carers, and carers additionally wanted access to group support for themselves. The lack of resources in the team also resulted in a corresponding lack of time for reflective practices such as team-based planning and review. In this way systems, processes and practices continue to operate in unexamined ways, and possibilities for change are minimised.

The physical environments in which services took place also influenced health care responses. Physical spaces act as a vehicle for transmitting and reinforcing dominant discourses and hospital buildings are places where power relations are evident through architecture and the use of text and images (Carter, 2019). Foucault and Miskowiec (1986) refer to hospital spaces as heterotopias, they are unusual cultural spaces of transience where people gather to seek help for medical/ health problems. As receivers of services in hospitals we are not in control of what happens or when it happens (Carter, 2019). Architecture as well as procedures, practices and resource allocations direct the conduct of both clients and clinicians (Carrasco, 2018) The physical and relational aspects of the spaces inhabited by the carers and children contributed to their feelings of stress and powerlessness. Health and safety messages were privileged over messages of welcome, inclusivity and reassurance and served to project the priorities of the hospital (Carter, 2019). The lack of trauma informed care was evident in the ways that many of the therapy and assessment services occurred in the same spaces that traumatic processes such as tube insertions were undertaken. Private and challenging experiences of breast, bottle, gavage or tube feeding needed to be conducted in the public space of the waiting room as did negotiations with distressed and fractious children. Mol (2008) asserts that it is important to pay attention to the ways health encounters occur and the places in which they occur as these are opportunities to convey or counter messages of health care. These practices reflect a lack of care. More detail on this is available in Appendix 5 a briefing document regarding the Paediatric Clinic space based on my observations. The spaces in which clients must wait and be seen should reflect consideration of "the inhabitants, their experience, their preoccupations and dispositions" p.6 and should be open to critique by patients, visitors and clinicians (Carter, 2019).

6.5 Challenges for change and improvement

The conceptual framework of paediatric feeding disorders proposed by Goday et al 2019 offers a potential opportunity to challenge the "hegemonic control" exercised by the biomedical model (Fennig & Denov, 2019, p. 305) and reframe CFDs much more holistically. Strongly informed by the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) (World Health Organization, 2001), this framework considers the functional impacts of CFDs from the perspective of body functions, activities and participation as well as the impacts of contextual factors (Goday et al., 2019). The ICF considers functioning as an umbrella term encompassing all body functions, activities and participation and disability as an umbrella term for impairments, activity limitations or participation restrictions (World Health Organization, 2001). Further, the ICF considers both functioning and disability in light of contextual factors which make up person and environmental factors incorporating the physical, social and attitudinal environments in which people live (World Health Organization, 2001). This framework provides a basis for interdisciplinary assessment and intervention across four related domains of medical, nutritional, feeding skills, and psychosocial aspects (Goday et al., 2019). Consideration of CFDs from this biopsychosocial lens has the potential to disrupt the current PR and support the more holistic considerations consistent with the findings of clinician and carer preferences and may offer an alternative basis from which to reconceptualise and structure the clinic and services offered.

However, as acknowledged by both Fennig and Denov (2019) and Mol (2008), the biomedical model plays an important role in health care responses. It offers a framework through which to understand medical problems, diagnoses, epidemiological data and a common language through which clinicians communicate (Fennig & Denov, 2019). It provides mechanisms and technologies for examination, monitoring and access to specialised care that are essential for many people living with complex diseases and conditions (Mol, 2008). Clinical practices for young children with CFDs are inextricably connected to the biomedical model as these children are at risk and often seriously ill from their inability to consume enough nutrients to grow and thrive. They require specialised medical and allied health help, they need to be examined, monitored, and fed. They rely on hospitals, technologies and equipment and so discarding the medical system is not an option (Mol, 2008).

Caution also needs to be applied as even within well- intentioned health care responses carried out by caring and committed health professionals embracing a biopsychosocial consideration of a clinical issues, there are risks and compromises. It is not enough to simply say a biopsychosocial approach to health care practices is better than a biomedical one. Gardner's (2017) analysis offers insight into the ways that specific clinical practices, described by him as sociotechnical arrangements such as multidisciplinary team structures, architectural forms, technologies, and protocols, exhibit a form of disciplinary power. The interdisciplinary team that he studied was committed to enacting principles of patient-centred care and provided services based on a biopsychosocial consideration of children with movement disorders. Through their specific clinical practices patients were described, assessed, and graded according to specific biopsychosocial criteria. They were thereby created as certain kinds of subjects and normative effects applied. To be acceptable they needed to meet certain criteria. While these were more holistic than a biomedical conception of the condition, they still served a purpose of constituting the "'biopsychosocial individual' as a legitimate way of being human " (Gardner, 2017, p. 254). Similarly, the PFAT was a committed team of experienced clinicians passionate about supporting families and young children and although they worked within a system strongly influenced by the biomedical model, they embraced a biopsychosocial understanding of health and CFDs. Yet, as has been discussed, many of their practices and processes inadvertently compromised care outcomes.

6.6 Health as care

To this point my purpose has been to interrogate and examine clinical practices through a poststructural lens. This section moves on from this and specifically aims to explore and build ideals around good health care practices based on the work of Annemarie Mol. The logic of care proposed by Mol embraces the "fleshiness and fragility of life" (Mol, 2008, p. 13) and keeps 'disease' central to considerations of health care and health care practices. Mol's work examines the dominant discourse of patient choice. Her findings indicate that a focus on patient choice does not result in improvements in health care or address issues of power and influence. In fact strengthening policies and practices associated with patient choice appear to risk interfering with clinician-client interactions and the practices that are vital for providing care to people who live with diseases and conditions (Mol, 2008). She suggests that reconstructing health as care rather than health as choice provides a mechanism for claiming back the care, the people and the relationships in health care practice (Mol, 2008) and in doing so improving the quality and outcomes. This approach forms the basis for my consideration of good health care practices and provides a framework for addressing the final challenge in the WPR model; how could things be questioned, disrupted, and replaced? Health as care will be discussed in relation to what best practice looks like at the level of a clinician, a client, and a team.

Mol suggests that 'best practice' involves the client and clinician discussing "the intricacies of daily practices in their emotional as well as their technical detail. How to go about them? How to include treatment in your daily life without messing too much with other things that are important to you?" (Mol, 2008, p. 60). This is similar to the Fundamentals of Care theoretical framework proposed by Kitson and colleagues which describes the essential elements of a caring encounter as a focus on the routine, every day, physical, psychosocial, and relational needs of clients (Kitson, 2018). This framework is rooted in nursing but has applicability to other health care professions. Mol proposes that best practice is a process of working collaboratively to consider and adjust technologies, interventions, daily habits, and people's skills, preferences and needs in an ongoing way throughout the process of providing care. In this approach the real and everyday impacts of living with or supporting someone to live with a disease or condition are foregrounded and considered of equal importance as the symptoms and physical impacts. This construction of care also considers the physical, practical, and emotional impacts and implications of clinical practices.

6.6.1 Role of clinician

The role of the clinician goes beyond providing evidence-informed options in a clear and logical manner and then allowing the client to choose. This construction of care is based on the paradigm of patient choice (the logic of choice) which dictates that the clinician must be knowledgeable, accurate, skilful, able to handle and process large quantities of information and act competently in delivering this information to the client (Mol, 2008). The logic of choice also requires the client to competently determine the direction of the intervention. This approach suggests that decision making is a logical process of properly balancing the advantages and the disadvantages of various courses of action and that this decision making is a bounded, fixed process (Mol, 2008). But as was demonstrated in my study health care interactions are much more complex and fluid than this simple exchange would indicate. Without paying attention to the assumptions and broader structural and political influences at play in the construction of a health care condition we miss the nuances of what makes health care work by relying on such overly simplistic approaches.

Health care is not an exchange, it is a relational and reciprocal process whereby both the clinician and the client work together. The role of the clinician then becomes a facilitator who works with the client to elicit information, establish facts and create a true sense of what is going on for the client and then jointly determine the way to proceed that meets the unique factors of that person's condition or disease, life, hopes, dreams and environment. To achieve, this both the client and the clinician may have to be flexible and adapt their approaches and expectations (Mol, 2008). "The logic of care wants us to experiment carefully. Try to be attentive to what happens, adapt this, that or the other, and try again." (Mol, 2008, p. 61). Spence (2005) suggest that all health care encounters are encounters of difference and clinicians need to be able establish authentic relationships with their clients to move beyond surface assumptions and truly understand their needs and challenges.

In the construction of health as care, the role of clinician as expert is challenged. Expertise becomes reframed to be more than specialist knowledge attained through formally sanctioned processes. Expertise becomes the ability to use that knowledge with and in the service of the client. Carers repeatedly highlighted examples of good care they had experienced. They commented on the expertise of the PFAT clinicians and identified the following as what made a difference; the attention they paid to the carers and children, a sense that they were working with them, that they valued their opinions and involved them in decision making, that they explained things well without using medical jargon and that they were flexible and responsive to working around the special needs of the families. The clinician's language and approach validated the carers' experiences of both struggles and successes and they were proactive in advocating for the carers with other specialists. These aspects of clinician behaviour contributed to the carers feeling seen and heard in a health system where they often felt invisible and powerless.

6.6.2 Role of the team

Teamwork is considered essential in managing CFDs (Begotka et al., 2018; Edwards et al., 2015; Marshall et al., 2018; Mazze et al., 2019; Sharp et al., 2017; Williams et al., 2017) and yet there is little research into what this looks like. Mol's work offers a contribution that is consistent with the experiences of the carers in my study. A well-functioning team is one that works together and includes the whole care team including the client in what Mol describes as “an interesting model for the democratization of expertise” (Mol, 2008, p. 64). She challenges us to go beyond considering who leads the team to think about the quality of the team’s functioning, to consider whether the team and their activities are well attuned to one another and whether there is a sense of cooperation or tension. Carers in my study spoke of this quality of team functioning and valued the ways solutions developed as part of inclusive discussions and processes that were relational, cooperative, and respectful. These practices were empowering and helpful even if the solutions did not work. The carers’ lived experiences told them that were no easy solutions, that things were messy, contextual, and challenging and far from being disappointed when suggestions did not result in changes, they valued a team approach that honoured the complexity of their everyday lives.

To be able to work from this relational team practice approach requires clinicians to let go of previous notions of themselves as experts and embrace expertise as something that is collaborative, relational, messy, and focused on everyday life. They need to challenge the role of expert as one who knows best and thus needs to be right and instead be prepared to embrace a practice of wondering and wandering with. Carers in my study appreciated clinicians who went on a journey with them, remained invested and committed to trying to puzzle together what may be going on. Mol describes this as experimenting, experiencing and tinkering together (Mol, 2008). Maynard (2020) outlines the process of stepping away from his biomedically informed role as expert relying on evidence-based medicine to enter into a mother’s space and spend time as a team really listening to her concerns as transformational both for him in his training as a paediatrician and for the mother whose expertise was validated. These examples highlight that relational team practice requires clinicians to pay attention to so much more than their own disciplines’ knowledge and perspective. They need to listen to and respect each other’s contributions and viewpoints but also be mindful of the client’s whole experience that takes into consideration their body, mind, medicines, technologies, needs, wants and everyday life experiences. They need to understand and work with all team members’ strengths and limitations. They need to be prepared to trial strategies and fail and try again. They need to be prepared to really examine their practices and the effects of these.

> They must change whatever it takes, including themselves. Shared [teamwork] requires us to take nothing for granted or as given, but to seek what can be done to improve the way

> in which we live with our diseases. And remember that failure is inevitable… (Mol, 2008, p. 65).

Relational team practice has some parallels with principles of interprofessional collaborative practice which espouse values and competencies related to values and ethics, roles and responsibilities, communication, teams and teamwork of interprofessional practice (Interprofessional Education Collaborative, 2016). Interestingly, interprofessional teamwork is described as levels of cooperation, coordination and collaboration characterising the relationships between professions in the delivery of client-centred care (Interprofessional Education Collaborative, 2016). In this definition clients still sit outside the team and are presented as recipients of the practice. The World Health Organization make the place of the client more central when describing interprofessional collaborative practice as occurring when multiple health workers from different professional backgrounds work together with clients, families, carers and communities to deliver the highest quality of care and achieve local health goals (World Health Organization, 2010). These principles and competency documents offer high level guidance about collaborative practice but work that pays attention to how this is or isn't enacted and how this looks and feels in clinical practice provides a much-needed step towards achieving these goals and addresses a research gap. Key aspects missing from these current framings of interprofessional practice that emerged from my research and are complemented by Mol's work include the importance of; holding the client and their everyday experiences central, being able to reframe the role of expert, and critical reflection on one's practice as a clinician and a team member.

6.6.3 Reflective practice

An essential component of being able to provide health as care is a willingness to examine the unexamined and consider the unintended effects clinical practices may be having. To be able to do this requires processes and practices of critical reflection. Maynard (2020) describes an example where the same behaviours in two mothers were judged and interpreted differently based on different contexts. He also describes that, after a process of critical reflection, the team were able to reconceptualised one mother from a 'noncompliant', 'bad' mother to a mother who was advocating for her child (Maynard, 2020). This critical reflection was based on a poststructural foundation that supported clinicians to see the dominant discourses and how certain constructs of clinical practice were products of certain power/knowledge relationships (Maynard, 2020). Similarly, closely examining nurses' preconceptions and practices of addressing sexual health with cancer patients uncovered ways that services could be more inclusive and supportive (Annerstedt

& Glasdam, 2019). In another example, social work practices of field education and critical reflection were strengthened by a focus of examining the dominant political rationalities influencing practice (Bay et al., 2019). These examples of different health care professions highlight the vital role critical reflection plays in health as care to enable clinicians to look beyond the lens of their individual professional training and uncover the dominant discourses and potential biases and assumptions, many of which are unconscious. The role the WPR model can play in supporting such critical reflection will be discussed more in the next chapter.

When health is practiced as care, failures, and the messiness of everyday life with a disease or condition cannot be "taken out of the equation as mere noise, nor taken to be offensive transgressions to be avoided at all costs. They are not marginalised. Instead they are talked about and tinkered with, they are attended to" (Mol, 2008, p. 107) as part of health care. Clinicians need to embrace uncertainty and support their clients to do so as well. An experimental attitude is required in the process of working together. Carers in my study appreciated acknowledgment of uncertainty and valued the process of working with. They found "pseudo-certainty" (Mol, 2008, p. 107) frustrating and patronising, they wanted honest responses to questions about diagnosis, prognosis and interventions.

Health as care embraces failure as inevitable and requires clinicians to face rather than avoid death, dying, suffering, and the emotional, psychological, cognitive, sensory, physical and social aspects of a condition need to be explored (Mol, 2008). The burden this may place on clinicians is not to be underestimated. Providing health care is demanding and exhausting and risks of vicarious trauma, compassion fatigue and burnout are very real. Indirect exposure to trauma involves inherent risks of significant emotional, cognitive and behavioural changes in clinicians (Bride, Radey, & Figley, 2007). Consideration of the types of physical and attitudinal environments that support health as care practices are very important. Environments where time is pressured, there is less autonomy, less connection with patients and high expectations of output are known to contribute to compassion fatigue (Pfifferling & Gilley, 2000). Processes for critical reflection and reflective supervision are essential to counter burnout. Other protective factors include opportunities to engage in meaningful self-care (exercise, healthful food, sleep), undertaking activities that replenish and renew, and fostering meaningful relationships (Pfifferling & Gilley, 2000). Using a logic of care opens up the possibility for clinicians to not always be right, to not know everything. This may relieve some of the pressure experienced by clinicians and free them up to build authentic and nurturing relationships with their colleagues and clients that are also protective.

6.6.4 Role of client

Being a member of a health care team as a client is demanding, especially if they live with or care for someone who lives with a disease or condition and experience pain, cognitive challenges, fatigue, mental and physical limitations. Health as care invites clients to be central to their care processes but clients may find it difficult to achieve a balance between being actively involved in their own care and needing to be cared for or care for others (Mol, 2008). Clients are often experiencing other pressures related to their unique living, social and financial circumstances. The carers in this study indicated that while they wanted to be involved in decision making, they often felt burdened rather than empowered by processes that included them. This was especially so when they were asked to hold the clinical knowledge about dates, types of interventions and medications and asked to represent a condition when little was known about it. Carers wanted and expected the paid clinicians to do their jobs and manage the health systems and information. They expected the clinicians to call upon and share their knowledges and expertise. They expected clinicians to challenge them, ask probing questions, clarify, seek information. This fits with Mol's expectation that clients want caring clinicians who seek to cultivate their minds and encourage them to take good care of themselves (Mol, 2008).

Mol raises the concept of 'patientism', a term she agrees is not ideal but one that aims to consider what being a patient is. She proposes that to ignore the diseased and compromised body/mind of the health care recipient/ consumer/customer/citizen is to pander to the dominant ideology of the well and flawless body. 'Patientism' does not "seek equality between 'patients' and 'healthy people', but tries to establish living with a disease, rather than 'normality' as the standard" (Mol, 2008, p. 35). Health care practices that embrace 'patientism' pay attention to rather than try to control, nourish rather than tame, and see bodies as more than causal links (Mol, 2008). The role of the patient/client is to find a way of 'nursing, fostering and enjoying [their body] so as to lead a good life" (Mol, 2008, p. 47). Struhkamp (2005), a colleague of Mol, offers an excellent way to relate this to the concept of suffering. Her work reflects a similar approach to examining and understanding a client's approach to living with pain and suffering in a rehabilitation setting. Struhkamp describes the rehabilitation process as an active engagement between the client/patient and the team where suffering can be responded to in three ways. Firstly, it can be translated into actions that may transfer or transform the suffering. Secondly, it can be approached as something the team, including the patient, problem solve ways to manage. Thirdly, a space can be created within the health care service where the aim is not to stop the suffering but to acknowledge and allow it to exist (Struhkamp, 2005).

6.7 Conclusion

In this chapter I presented an analysis of clinician and carer data based on the WPR approach to address the second part of my first research aim, to critically examine and compare how the problem of CFDs is represented in clinical practices and experienced by carers. I discussed key themes that emerged from the analysis through a Foucault-influenced post structural theoretical lens. The discursive effects of this PR and the ways that it influenced clinical practices within the PFAT were discussed. I paid particular attention to the influences of biomedical discourse, governmentality, clinical practices as problematisations, cultural factors, the regulatory discourse of shame, the silence of trauma and the terms feeding and eating. I then discussed the constraints on service responses in light of broad structural factors that included evidence-based practice, funding and management structures, neoliberal political rationality and the physical environments in which services took place. This explained how service responses and practices had come to be. I presented the challenges for change and improvement and made the point that it is not enough to simply replace a biomedical approach with a biopsychosocial one. This led to the final section of the chapter which was informed by Mol’s work on the logic of care and unpacked the practices of health as care. Within this section I explored the roles of the clinician, client and team when health was reconceptualised as care. This chapter addressed my second research aim, to analyse how PRs influence experiences and practices of health care.

Chapter 7 CONCLUSIONS: IMPLICATIONS OF THE ADAPTED WHAT'S THE PROBLEM REPRESENTED TO BE MODEL AND A LOGIC OF CARE FOR CLINICAL RESEARCH, TEACHING AND PRACTICE

7.1 Introduction

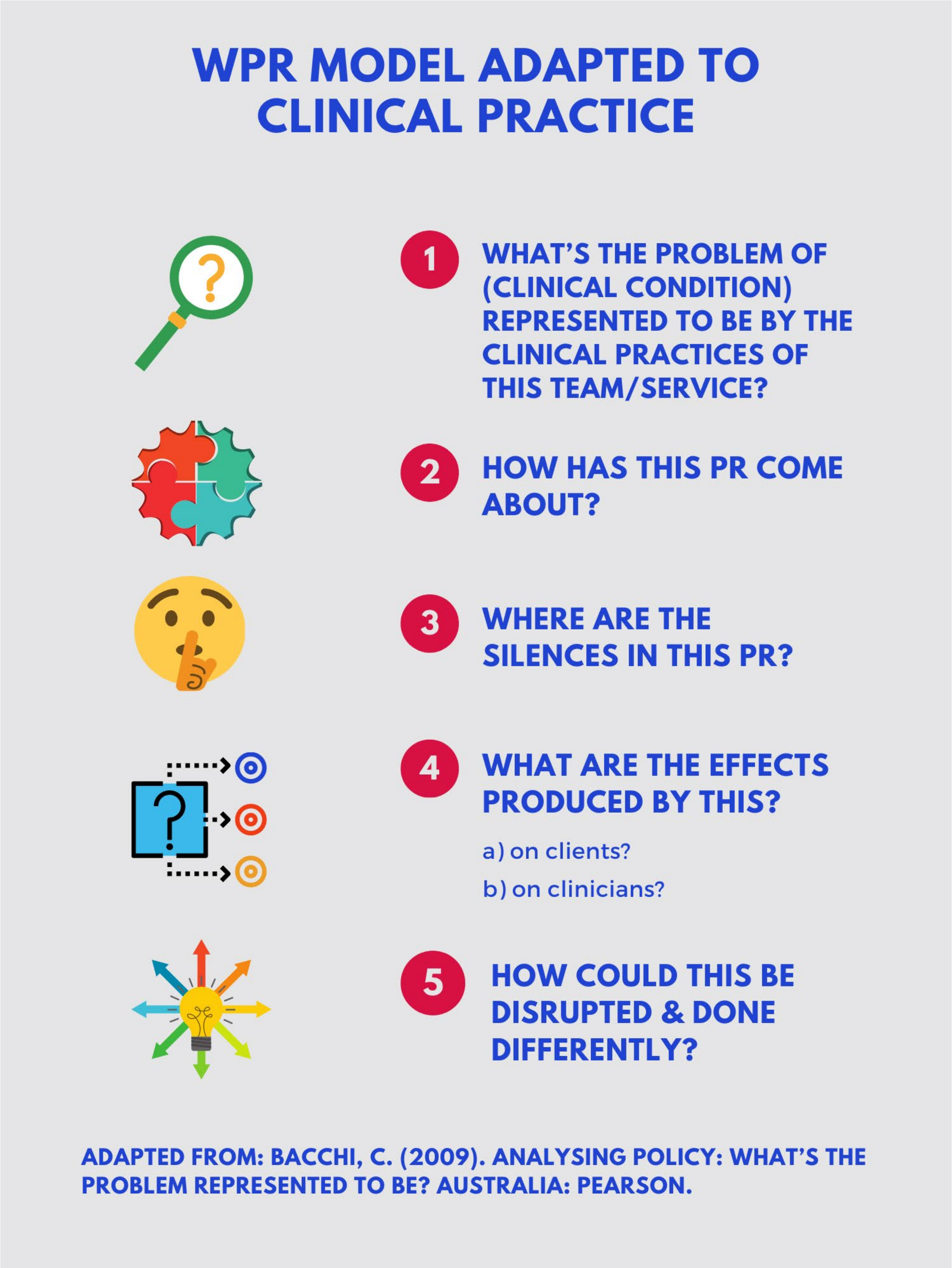
In this final chapter I discuss the contribution of the WPR approach to clinical practice and present an adaptation of the model that supports its application to a new field. I discuss the need for a sensitive and careful approach when applying this adapted model to health care practices. I present a snapshot of findings of the adapted WPR model applied to the PFAS as a way of demonstrating the benefits of this approach at a practical level. I also discuss the recommendations for its use and applicability in health care settings and pay particular attention to critical reflection and teaching. This addresses my third research aim; to reflect on the contribution and extension of the WPR approach (Bacchi, 2009) to clinical practices. The final section of this chapter serves to conclude my thesis and presents a discussion of the quality of my study and recommendations for future research.

7.2 A different approach

In considering the application of the WPR model to clinical practices, it is important to keep context and purpose in mind. The original model was developed by Carol Bacchi and designed to critically examine policy documents. Policies are distant and objective, practices are close and personal and so a different approach to the application of this model is essential. When this model is applied to practices and people it needs to be careful and kind. It needs to be framed in a warm, gentle, respectful, and curious questioning of what's this about. This does not diminish or undermine the effectiveness of a critical approach that sets out to question, challenge and disrupt and in doing so open up new possibilities for health care improvement. I propose that they can be undertaken simultaneously; that we can ask challenging questions with care and respect. This tool is designed to support clinicians to examine their practices through a new lens and provide access to a way of thinking that honours their work, expertise, and effort. Far from blaming clinicians or setting out to identify 'poor' practice, this tool aims to help clinicians identify and make sense of the broad structural constraints upon their practices and free them from the burden of blame that is invited by the predominant neo-liberal discourse (Bay et al., 2019). When this tool is applied in research, a relational approach is required that prioritises building relationships and works with clinicians to support them to examine their practices.

7.3 The adapted What's the problem represented to be? model

The WPR model (Bacchi, 2009) has not previously been directly applied to a clinical setting. As discussed in Chapter one, I could see the relevance and value in adapting this model to clinical practice. As outlined in the analytic process sections of Chapters 4 and 5, I set out to test the approach and applied the model by slightly adjusting question one. In November 2019 I was invited to attend a symposium that brought together academics and doctoral students working with the WPR model to explore its challenges, clarifications, and extensions. This provided me with an opportunity to discuss my application of the model directly to clinical practice with leaders in this field, including the originator of the approach Carol Bacchi. I then continued to analyse the data and write up my findings. In the process of my analysis, and following significant consideration and reflection, I identified the ways the model could be adapted that would better suit the requirements of clinicians and clinical health care environments. This section presents my adapted model. I adapted the six questions of the original WPR model to five simplified questions by combining questions 2 and 3. I adjusted the language to bridge the gap between a poststructural theoretical approach and clinical practice requirements. All five questions in the adapted model have both practical and theoretical value but question 2 is more theoretical and could be omitted or completed at the end of the process. As per Bacchi's (2009) approach, I propose that these questions can be undertaken systematically or in an integrated way depending on the relevance for the team and the clinical issue being examined. Figure 7.1 outlines the adapted model. To further support the application, I developed a document that explains the adapted version, clarifies each question and offers specific examples as to what to look for and how this applies in a clinical setting. (Appendix 10 Adapted WPR version for clinical practice)



WPR MODEL ADAPTED TO CLINICAL PRACTICE

1. WHAT'S THE PROBLEM OF (CLINICAL CONDITION) REPRESENTED TO BE BY THE CLINICAL PRACTICES OF THIS TEAM/SERVICE?
2. HOW HAS THIS PR COME ABOUT?
3. WHERE ARE THE SILENCES IN THIS PR?
4. WHAT ARE THE EFFECTS PRODUCED BY THIS?
    - a) on clients?
    - b) on clinicians?
5. HOW COULD THIS BE DISRUPTED & DONE DIFFERENTLY?

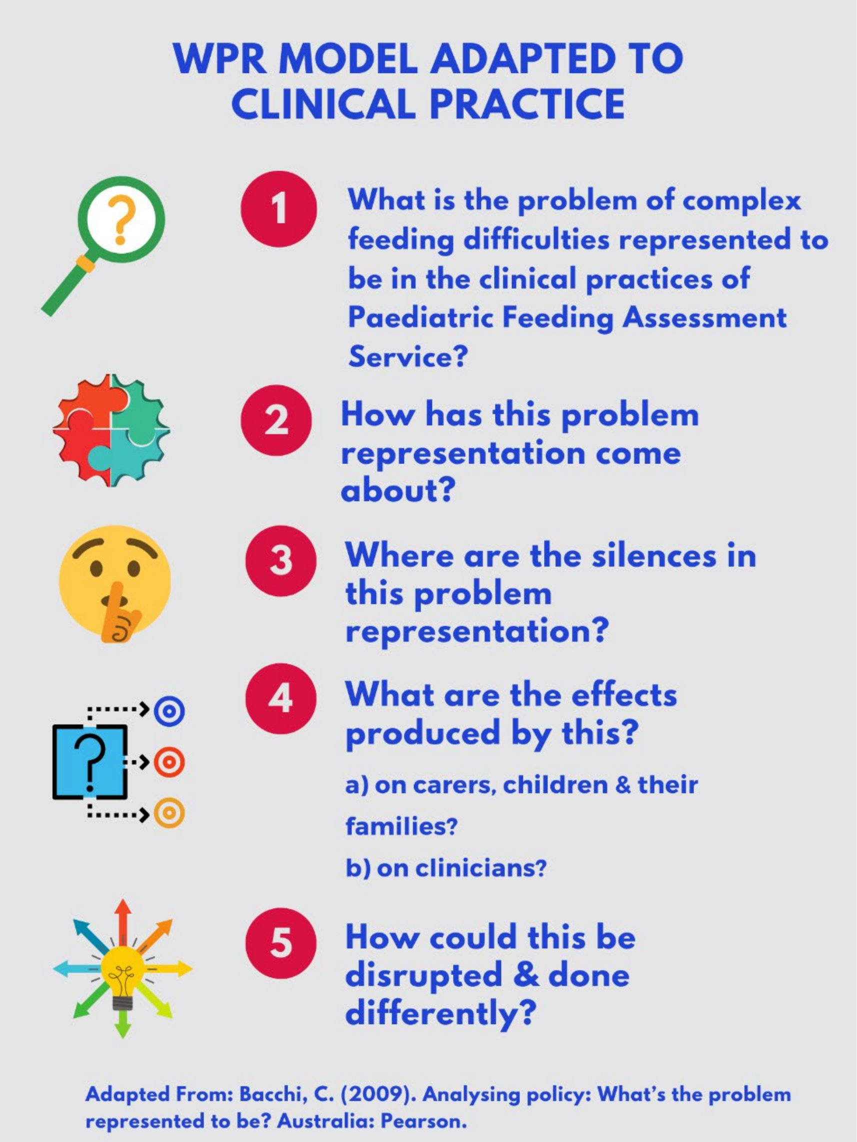
ADAPTED FROM: BACCHI, C. (2009). ANALYSING POLICY: WHAT'S THE PROBLEM REPRESENTED TO BE? AUSTRALIA: PEARSON.

Figure 7.1 WPR model adapted to clinical practices

7.4 The adapted model applied to the Paediatric Feeding Assessment Service

Rather than repeating the detailed results and discussion already covered in previous chapters, I will summarise some of the key findings from the adapted WPR analysis of the practices of the PFAS in the following figures. These figures present a snapshot of the results and provide an example of how to apply the model to clinical practices.

Figure 7.2 and the following images show the questions applied to the PFAS.



WPR MODEL ADAPTED TO CLINICAL PRACTICE

1 What is the problem of complex feeding difficulties represented to be in the clinical practices of Paediatric Feeding Assessment Service?

2 How has this problem representation come about?

3 Where are the silences in this problem representation?

4 What are the effects produced by this?

a) on carers, children & their families?

b) on clinicians?

5 How could this be disrupted & done differently?

Adapted From: Bacchi, C. (2009). Analysing policy: What's the problem represented to be? Australia: Pearson.

Figure 7.2 Adapted WPR model applied to PFAS

1 WHAT'S THE PROBLEM OF YOUNG CHILDREN'S COMPLEX FEEDING DIFFICULTIES REPRESENTED TO BE WITHIN THE PAEDIATRIC FEEDING ASSESSMENT SERVICE?

CLINICIANS

- Affects a child's ability to feed/eat to gain enough nutrition to grow and thrive
- Serious, complex, multifactorial, compounding
- Requires medical and allied health intervention
- Priority for service is the nutritional status of the child so that the child can grow and thrive
- Family's routines, behaviours and priorities influence the development of a complex feeding difficulty and need consideration
- Strongly influenced by 'culture'
- Evokes high levels of stress, guilt and shame particularly for the mothers

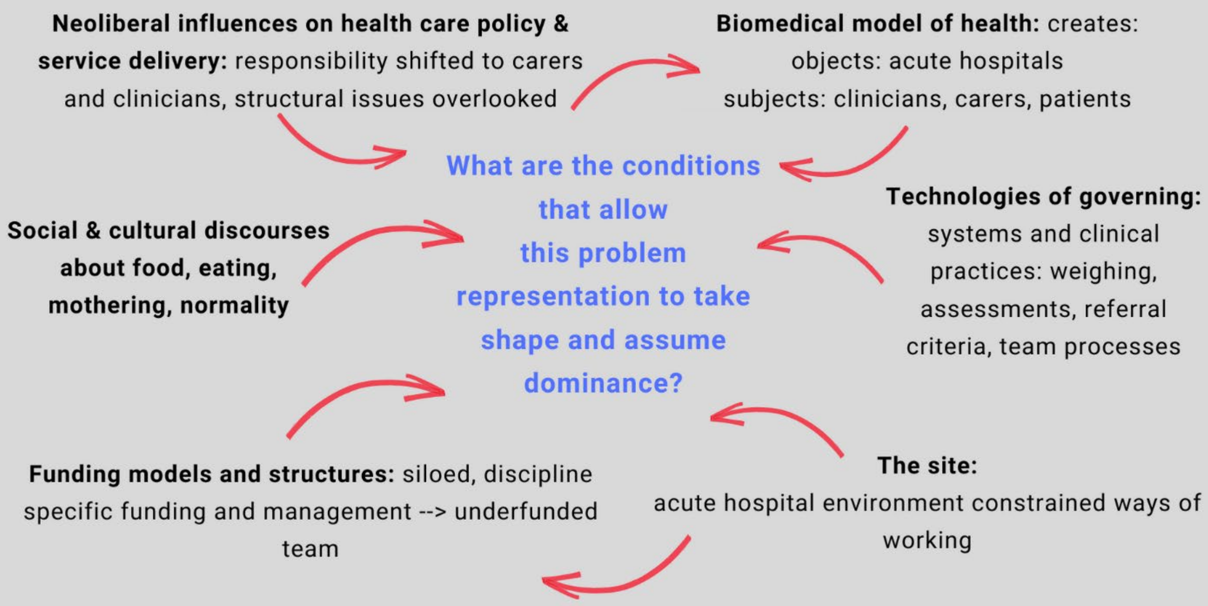
CARERS

- Affects a child's ability to eat/feed and gain weight
- Affects mental & emotional health and wellbeing of the child, carers, siblings, other family members and friends
- Complex, multifactorial, compounding
- Requires specialised medical knowledge & expertise
- Rare, highly specialised, individualised
- Highly traumatic
- Invades and changes every aspect of everyday life
- Visible problem that invites advice, blame and shame but that needs to be proved
- Fear, pain and struggle were ever present

Problem representation: a serious physical problem that affects a child's ability to put to weight

IMPLIED 'PROBLEM': THE WEIGHT OF THE PHYSICAL CHILD

2 HOW HAS THIS PROBLEM REPRESENTATION COME ABOUT?



Neoliberal influences on health care policy & service delivery: responsibility shifted to carers and clinicians, structural issues overlooked

Biomedical model of health: creates: objects: acute hospitals subjects: clinicians, carers, patients

What are the conditions that allow this problem representation to take shape and assume dominance?

Social & cultural discourses about food, eating, mothering, normality

Technologies of governing: systems and clinical practices: weighing, assessments, referral criteria, team processes

Funding models and structures: siloed, discipline specific funding and management --> underfunded team

The site: acute hospital environment constrained ways of working

3 SILENCES: CARER'S EXPERIENCE OF THE PROBLEM REPRESENTATION

- **Carer’s voices, knowledges, expertise were often silenced**
- **Medical knowledge and expertise was privileged over all other forms**
- **Daily experiences of the carers and children were silenced**
- **Clinic experiences were privileged**
- **Emotional, mental health and trauma was silenced**
- **Physical symptoms were privileged**
- **Child was privileged over carer and family**
- **Cultural implications were silenced**
- **Feeding was experienced as a process to instil calories and weight and privileged over eating**

“which is why I started - I took videos of how she was screaming to the point of vomiting, and I took photos and all that, just because the doctors seemed to – ‘she's been fine. We don’t know what you're talking about’.” Rachel

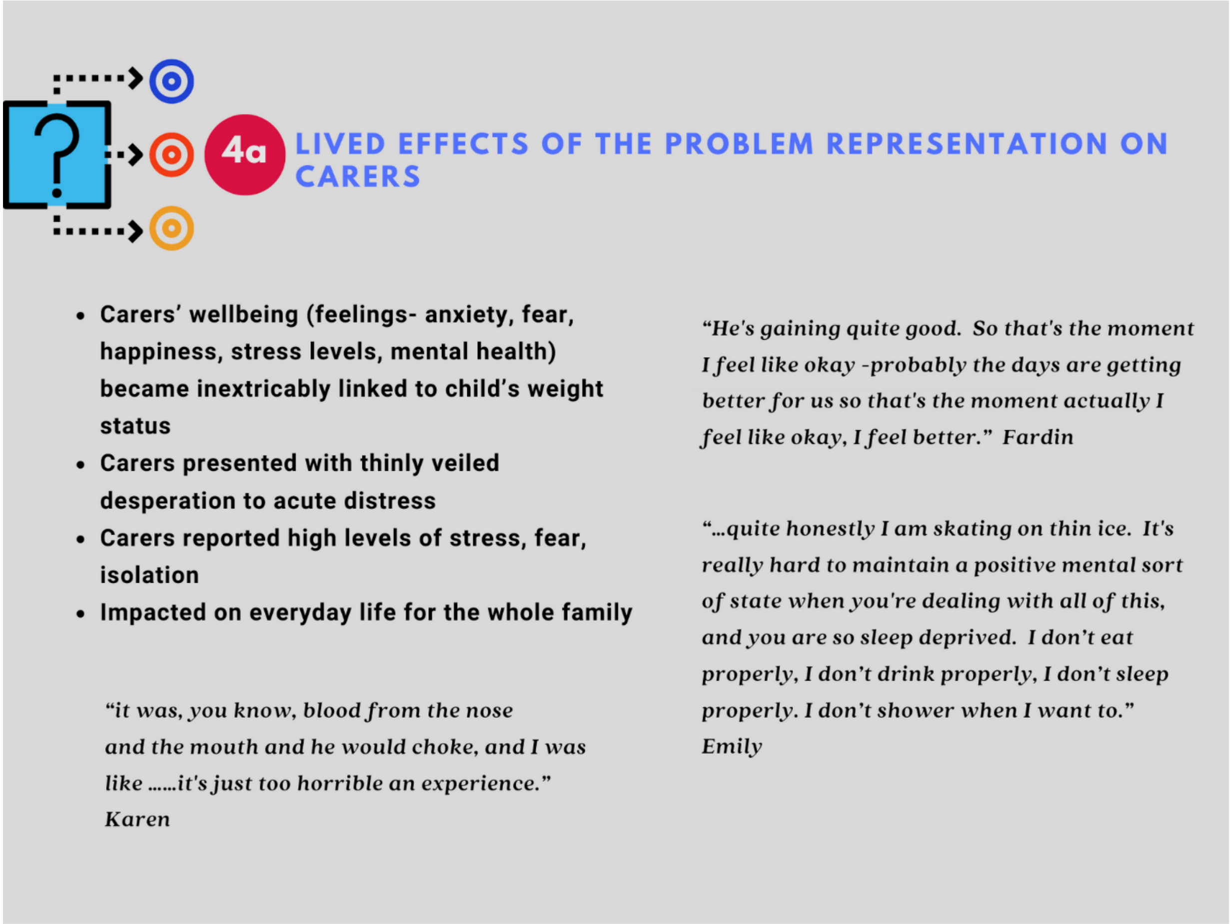
“people ask you, how are you, and I can say that things are shit [laughs], but beyond that it's all about trying to fix [Summer] because she's the end goal.” Emily

4a SUBJECTIFICATION EFFECTS OF THE PROBLEM REPRESENTATION ON CARERS

- **Drives an all consuming pressure to achieve a precarious and precious calorie intake and weight status which requires the carer to assume the role of technician:**
  - **Needing highly technical, specialised knowledge & skills in managing tube changes, pumps, tapes, calculating calorie input and timing of feeds**
  - **Balancing calories in vs vomiting risk**
  - **Enculturation to medical world as part of becoming an expert and advocate– reflected in their language and skills**
  - **Emotions removed/distanced to deal with practicalities, fear and pain**

“It can be really easy to get bogged down in the chore aspect of all of it without getting emotionally involved. Which is - it sounds awful, but if I dwell every day on how much pain she's in I'd never get out of bed in the morning.” Emily

“First time I did it, I - gagged, and I went, oh, no. I couldn’t believe I did it. But saving a hospital trip, I'm - I've got a lot more comfortable.” Rachel



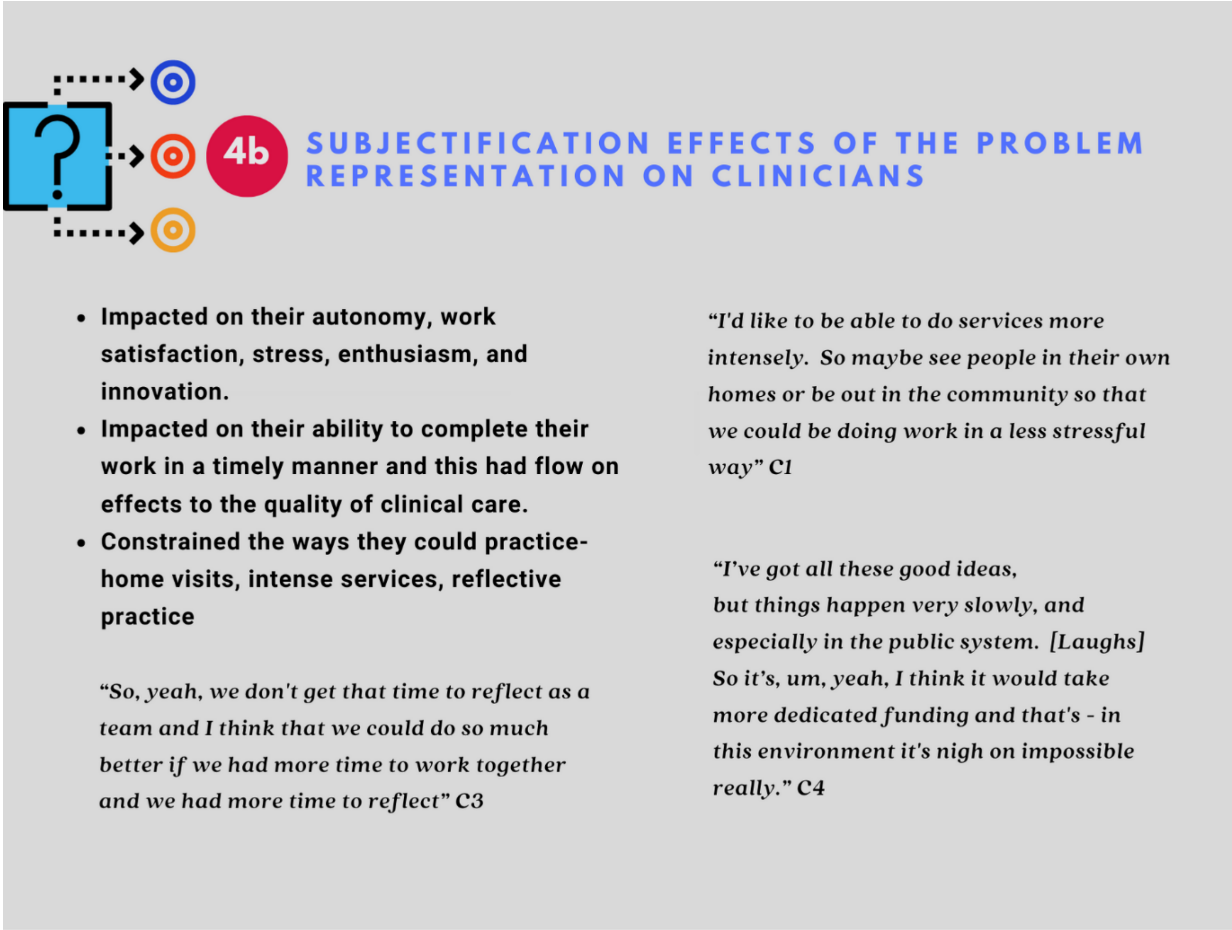
4a LIVED EFFECTS OF THE PROBLEM REPRESENTATION ON CARERS

- **Carers' wellbeing (feelings- anxiety, fear, happiness, stress levels, mental health) became inextricably linked to child's weight status**
- **Carers presented with thinly veiled desperation to acute distress**
- **Carers reported high levels of stress, fear, isolation**
- **Impacted on everyday life for the whole family**

"it was, you know, blood from the nose and the mouth and he would choke, and I was like ......it's just too horrible an experience." Karen

"He's gaining quite good. So that's the moment I feel like okay -probably the days are getting better for us so that's the moment actually I feel like okay, I feel better." Fardin

"...quite honestly I am skating on thin ice. It's really hard to maintain a positive mental sort of state when you're dealing with all of this, and you are so sleep deprived. I don't eat properly, I don't drink properly, I don't sleep properly. I don't shower when I want to." Emily



4b SUBJECTIFICATION EFFECTS OF THE PROBLEM REPRESENTATION ON CLINICIANS

- **Impacted on their autonomy, work satisfaction, stress, enthusiasm, and innovation.**
- **Impacted on their ability to complete their work in a timely manner and this had flow on effects to the quality of clinical care.**
- **Constrained the ways they could practice- home visits, intense services, reflective practice**

"So, yeah, we don't get that time to reflect as a team and I think that we could do so much better if we had more time to work together and we had more time to reflect" C3

"I'd like to be able to do services more intensely. So maybe see people in their own homes or be out in the community so that we could be doing work in a less stressful way" C1

"I've got all these good ideas, but things happen very slowly, and especially in the public system. [Laughs] So it's, um, yeah, I think it would take more dedicated funding and that's - in this environment it's nigh on impossible really." C4

5 HOW COULD THIS BE DISRUPTED AND DONE DIFFERENTLY?

Strengthening or developing system responses, environments and practices that;

- **conceptualise a complex feeding difficulty as one that impacted on the child and their family and affected their physical, mental and emotional health and wellbeing**
- **examine the use of the terms feeding and eating**
- **examine the physical environments in which practices occur**
- **support empowerment, relationships and trust between; carers and children; carers and**
- **clinicians; and between clinicians**
- **reconceptualise the client (child and their family) as central to the team**
- **reflect, understand and value the everyday experiences of the carers and children**
- **acknowledge, reduce, and address trauma**
- **ensure practices of critical reflection**

7.5 Benefits of the model

7.5.1 Critical reflection

As Kitson (2018) outlines, nurses are not supported to reflect on their practices in ways that generate new insights based on their practice wisdom produced through the complexity and richness of their interactions with their client. I propose that this applies to allied health and medical clinicians as well. Reflection requires a lifelong process of critical thinking that is applied to practices to support clinicians to move from processing information, to knowledge, to wisdom (Larkin & Pepin, 2013). Critical reflection in health care is a contested and often unexamined construct, but the key elements that appear to distinguish critical reflection from reflection appear to be those which involve some level of social and political analysis that enables transformational change (Fook, White, & Gardner, 2006). Bay et al. (2019), indicate that reflection for health professionals in Australia, usually requires a focus on feelings, assumptions, beliefs and values, and inner realties but rarely moves into critical reflection territory and supports clinicians to consider broader structural factors and how clinical practices occur within and are influenced by political rationalities that shape governmental and institutional policies and practices (Bay et al., 2019).

This is consistent with Larkin and Pepin (2013) who describe reflective practice as paying attention to what is done in clinical practice, being aware of the broad contexts in which work happens and considering how these both influence actions. In their small Australian qualitative study of social workers Bay et al. (2019) applied a post-structural theoretical lens to examine critical reflection processes. This study found that this form of Foucauldian theorising with its focus on examining political rationalities, subjectivities, and how these are shaped supported the process of critical reflection by answering the "rarely asked question; just what is it that is to be reflected on and why?" (Bay et al., 2019, p. 951). This then informed ways that critical refection could be enhanced to see beyond the individual factors and consider the often-unexamined factors at play in shaping health care delivery.

> As thinking about what we do is one of the hardest things to do, critical reflection processes could benefit from a range of conceptual resources when making sense of the ways we are governed, govern ourselves and govern others. (Bay et al., 2019, p. 951)

The adapted WPR model offers such a conceptual resource and provides a structured way to enhance clinical reflection that makes it more accessible to clinicians. Furthermore this tool can offer a way to bring to light the political role of health care clinicians as agents of change and provide a tangible way for them make this ideological stance more practical (Carrasco, 2018). Based on their comprehensive review Fook et al. (2006) define critical reflection as: (i) a process (cognitive, emotional, experiential) of examining assumptions (of many different types and levels) embedded in actions or experience; (ii) a linking of these assumptions with many different origins (personal, emotional, social, cultural, historical, political); (iii) a review and re-evaluation of these according to relevant context- and purpose- dependent criteria; and (iv) a reworking of concepts and practice based on this re-evaluation. The adapted WPR model can support all these components of critical reflection.

7.5.2 Teaching

The second major way that this model can contribute is in the teaching of future health professionals. Examining and challenging the truth status of discipline knowledges is an important function of teaching. As Foucault stated "any system of education is a political way of maintaining or modifying the appropriation of discourses, along with the knowledge and powers that they carry" (Foucault, 1981, p. 64). Universities play a key role in setting and reinforcing the thinking, practices and actions related to health care (Ferreira et al., 2015). Concepts related to health and illness, to discipline knowledge, to theories and evidence are not neutral or abstract, they are contested and deeply embedded within discursive frameworks (Maynard, 2020). As Freire describes, education can either reinforce the current ideologies and act as a mechanism to bring about conformity, or it can serve to support practices of creative, critical thinking that can transform behaviour and practice (Freire, 2018). To do this mechanism are needed that can support students to understand and uncover power and structural conflicts within clinical practices. This model can assist developing pedagogy that encourages such critical thinking. If students have access to frameworks and have developed skills to support questioning and critical reflection of clinical knowledge and practices, they are likely to become future health professionals who will apply this approach to their ongoing work.

This model also contributes to interprofessional education and practice by enabling a process of closely examining the functioning and practices of an interdisciplinary team. Interprofessional education is considered a necessary step in preparing a “collaborative practice-ready” health workforce that is better prepared to respond to local health needs (World Health Organization, 2010, p. 7). Analysing the practices of an interdisciplinary team using the adapted WPR model may provide both theoretical and practical information that can guide the teaching of students and the practice of clinicians. This model further facilitates analysis of the ways that teams interact with spaces, tools, and practices and the impacts of these on clients lives and their health outcomes. It provides a framework from which to teach a highly theoretical poststructural analysis and make it accessible and relatable to an audience of future clinicians.

The adapted WPR model specifically supports transformative learning. This is learning that “transforms problematic frames of reference—sets of fixed assumptions and expectations (habits of mind, meaning, perspectives, mindsets)—to make them more inclusive, discriminating, open, reflective, and emotionally able to change” (Mezirow, 2003, p. 58). To become a more effective clinician, university students need to develop adult learning capacities that include the capacity to be critically self-reflective and to employ reflective judgment and be able to assess assumptions and expectations regarding their own and others’ beliefs, values and feelings (Mezirow, 2003). Teaching approaches and strategies are needed to assist the process of transformative learning. One of the most powerful tools to do this is providing students with direct learning experiences that are personally engaging and stimulate reflection upon experience (Taylor, 2007). The adapted WPR model is a useful tool to support the structured analysis of case studies or real-world experiences. By working through the five steps of the model, students are encouraged to develop critical questioning skills, through examining assumptions and beliefs, silences and privileges and the effects of knowledges and practices on the everyday lives. It is important that this is done with an explicit, intentional, and supportive stance that sets the scene for critical questioning and examining the unexamined (Taylor, 2007). This intentional process would make it clear to students that this is likely to be uncomfortable and unsettling. Taylor (2007) identifies that specific support is needed for transformative learning to occur. Critical reflection is not enough, there also needs to be specific structured ways to enact the change that comes from these insights (Bay et al., 2019; Fook et al., 2006; Taylor, 2007). The fifth step of the model allows students to consider the ways that things could be disrupted and done differently and facilitates this action step.

Applying this tool, or any tool, is not enough to ensure transformational learning, relationships play an integral role in the process (Maynard, 2020; Taylor, 2007). Learning of this nature needs to occur within a context of trust where the educator and students work together to explore, question and make sense of this model. To teach and learn from a logic of care, educators and students need to embrace uncertainty and messiness in exploring the implications of health care practices on people's everyday lives. To teach health care as a relational and reciprocal process, requires modelling within the university and practice education environments. Mirroring the role of the clinician in the health care site, the role of the educator becomes one of facilitator, working with the students to elicit information, establish the most appropriate knowledge and evidence to call upon. The facilitator needs to also demonstrate a process of working with a client to determine the best course of action taking into account their unique circumstances that goes beyond their condition and also considers their hopes, needs, everyday life and the broader socio-political influences at play. This is a highly complex process, so much more than establishing and applying evidence to practice. It brings the how to the fore and keeps the clients' needs central to the process. The adapted WPR may be a practical tool to support teaching and learning from this perspective.

7.6 Quality of research

Popay, Rogers, and Williams (1998) identify three interrelated criteria as being foundational for good qualitative health research; interpretation of subjective meaning, description of social context, and attention to lay knowledge. They make the point that research aimed at improving health care and understanding client and clinician behaviour and practices must privilege subjective meaning if it is to provide good evidence to inform practice and policy (Popay et al., 1998). The key question they propose asking to evaluate this is, "Does this research, as reported, illuminate the subjective meaning, actions and context of those being researched?" (Popay et al., 1998, p. 345). In addition to this fundamental question, which I answer below, they propose eight other questions, my responses to which are summarised in Table 7.1. In addressing these questions, I demonstrate the quality of this research.

This work examined the practices of carers and clinicians of young children with CFDs. Multiple sources of data were gathered from both carers and clinicians separately and jointly by way of in-depth interviews, clinic and home observations. As detailed in Chapter 3, the research process was carefully designed to gather authentic, detailed and rich data. Data was gathered over a seven-month period where I was immersed in the practices of the PFAT. This enabled me to gain deep insights into the thoughts, actions and practices of both the carers and the clinicians to ensure that I was able to represent their meanings, action and context well as I applied the WPR methodology to my analysis. Chapter 4 addresses the clinicians' perspectives, Chapter 5 addresses the carers' perspectives and Chapter 6 brings these together to inform the final analysis and discussion. While a post-structural analysis such as this is designed to deconstruct practices, I was careful to keep both carer and clinician voices front and centre in my analysis. I demonstrate this through the extensive use of quotes throughout both Chapters 4 and 5. Chapter 6 was designed to bring the focus of this research back to health care practices through the use of Mol's work on health as care.

Table 7.1 Addressing the quality of this research through application of the criteria proposed by Popay et al. (1998)

1. Is there evidence of the adaptation and responsiveness of the research design to the circumstances and issues of real-life social settings met during the study?
Examples of this include the way I adapted my participants from mothers only to carers based on feedback from the team. I also adapted the planned use of photographs in data collection in response to the relationships I had built with the participants. I allowed participants to determine for themselves what 'a typical mealtime experience' was and adjusted my home observations around this. I also adjusted the timing of the post mealtime interviews to meet the needs of the participants and thereby increased family involvement and reduced participant burden. I reported back on the findings of the study rather than each carers' own summary based on feedback from the carers. I also adjusted the reporting back mechanisms to clinicians based on COVID 19 restrictions and their time pressures. These are described in detail in Chapter 3.
2. Does the sample produce the type of knowledge necessary to understand the structure and processes within which the individuals or situations are located?
All the clinicians agreed to participate in the study. The sampling strategy for carers was informed by the clinicians to ensure the best chance of recruiting carers who represented the broad range of attendees and patterns of involvement with the service. A flexible involvement strategy ensured a broader range of carers were able to participate. Of the potential pool of 18 carers, 12 participated. (Ch.3)
3. Is the description detailed enough to allow the researcher or reader to interpret the meaning and context of what is being researched?
Thick description is provided about the PFAT, the condition, the site, the participants, and their experiences. Context is described in chapters 1,3,4 and 5.
4. How are different sources of knowledge about the same issue compared and contrasted?
Data collection and analysis occurred iteratively and involved multiple check back points with participants for clarification. Document, interview, and clinic observation data were compared to inform the analysis of clinician data (Ch.4). Clinic, home, and interview data were compared to inform the carer data analysis (Ch.5). Carer and clinician data were then compared and contrasted to inform the final analysis and discussion (Ch.6).
5. Are subjective perceptions and experiences treated as knowledge in their own right?
Throughout this research there were many ways in which my own assumptions, biases, experiences and views impacted on this research process and its findings. I have provided detailed information on my position as researcher in section 3.7, that helps make these explicit. I also paid close attention to these when I was analysing data and applying the WPR model. To do this I followed Bacchi's (2006) recommendation to apply the six steps of the model to my own analysis of the problem representations. Additionally, as described in Chapter 3, section 3.13, I kept a detailed reflective journal throughout the study and discussed these finding with my supervisors.
6. How does the research move from a description of the data to analysis and interpretation of the meaning and significance of it?
The application of the WPR methodology as a consistent tool throughout the research process provided the mechanism to achieve this. Carer and clinician data sets were interrogated applying the WPR approach. This approach provided both the analytic and theoretical basis of this research and facilitated the smooth transition between data description, analysis and discussion. See Chapters 4,5,6.
7. What claims are being made for the generalisability of the findings?
The findings I present here are specific to the condition and site I studied and cannot be generalised to other conditions or sites. What these finding do offer is "points of contrast, comparison or reference for other sites and situations" (Mol, 2008, p. 11). For example, there may be similarities with other high complexity conditions and other interdisciplinary teams. The theoretical perspective of my approach can be generalised, and so the adapted WPR model offers a mechanism for analysing health care practices that may have relevance to other health care sites and conditions.
8. Are there clear implications for policy and practice?
I developed this research proposal from a knowledge exchange perspective and in partnership with the PFAT to ensure that it was addressing specific practice issues. The theoretical nature of my research has meant that I have been able to make a significant contribution to the future analysis of health care practices particularly regarding critical reflection and education as described in the previous section of this chapter.

7.7 Recommendations for further research

The focus of this research was examining the practices of the PFAT. This is a small team made up of a paediatrician, OT, speech pathologist and dietitian. I recognise that there are many other key clinicians involved in the care of young children with CFDs whose views were not represented in this study. These included nurses, allergists, gastroenterologists, neonatologists, and other neonatal clinicians. These clinicians should be engaged with in future research in this space. In particular, I noted the important role that nurses played in the clinical practices related to young children with CFDs. While not considered part of the team I studied, their work in weighing the children and changing the naso-gastric tubes made them key players in the overall response to these children and families' needs. This raised further research questions as to what constitutes a team in certain clinical areas and why. Nurses' perspectives would specifically inform further research regarding responses to trauma as they are managing the hands-on practices most associated with trauma in this space.

The carers in my study represented the pool of carers at the time of recruitment, however some notable omissions to the pool of carers included grandparents and foster carers. The voices of these participants may have added different and valuable perspectives and it is recommended that future research includes these voices. Another notable omission from this study was the perspectives of siblings and other family members. Carers in my study and in other research repeatedly discussed the importance and impact of the broader family and the need for this to be considered in health responses. They also consistently raised the need for services to be aware of and closely aligned to the everyday implications of this condition and especially the impact on family mealtimes. It is recommended that further research incorporates these views.

The adapted WPR model has not been applied to other settings and it is recommended that this occurs. The application of this approach to other areas of clinical practice, and the trialing of the adapted WPR model as a tool to support practice change in both clinical and tertiary education sectors are recommended areas for further research.

7.8 Knowledge translation

> Examining a practice is not a matter of collecting suitable examples, but of learning new lessons. Good case studies inspire theory, shape ideas and shift conceptions. They do not lead to conclusions that are universally valid, but neither do they claim to do so. (Mol, 2008, p. 10).

In line with this quote, the major contribution that my research makes is the application of a new approach to analysing clinical practices. The WPR model adapted to clinical practice makes a substantial theoretical contribution that has the potential to shape clinical and educational practices. Findings from this research have been disseminated in various ways. Consistent with the knowledge translation partnership approach that underpinned this research, there were points along the research pathway where I was able to provide direct and practical information back to my research partners. This aspect of knowledge transfer was enhanced through the role of my supervisor, Dr Brian Coppin, who was also the clinical director of the Department of Paediatrics and Child Health where this research was based. Through discussions with Dr Coppin throughout the data collection and analysis, I was able to test my ideas and findings in a way that was firmly grounded in the reality of the work. This enhanced my analysis and added credibility to the findings. He also provided me with practical ways in which my research could contribute back to the service. As an example, the hospital was considering a waiting room redesign for the paediatric clinic and based on my research I was asked to contribute to this by developing a briefing document based on my observations of the waiting rooms during my data collection phase (see Appendix 5). I was also asked to present my preliminary findings to the Paediatric Grand Round in September 2017 to bring attention to the research and the team. I built an excellent relationship with the team as I gathered data over seven months. Based on this my opinion was also sought as to ways to improve the experience of the clients during the PFAT clinics. I was able to provide simple recommendations about the venue, space, and access to toys and resources that resulted in a change of venue that carers and clinicians reported felt much more client centred.

Following my analysis, I presented my formal findings back to carers and clinicians by way of a written summary (Appendix 11) designed to communicate the process and findings in a clear and concise manner. I then met with the two clinicians who are still working with the service and have both also moved into senior leadership roles within the hospital, to discuss the implications of my research. These discussions have led to a number of key actions and ongoing collaborations. Together we are exploring the application of the adapted WPR model to support the review of the Paediatric allied health service models of care across the health service more broadly, and specifically to support critical reflection and review of other teams within the hospital including the diabetes, neonatal and child development teams. I have been asked to speak about my research findings to both the Paediatric Allied Health and Medical Grand Rounds, and to share the results of my literature review, and my research findings specifically related to interprofessional team practice. This ongoing partnership approach to knowledge translation is also contributing to the development of a collaboration between Flinders University and Flinders Medical Centre in developing an innovative interprofessional paediatric student-led clinic.

Findings from the study have also been disseminated more widely throughout the research process by way of national and international conference presentations. A list of these is provided on page viii. The presentations of preliminary results helped test the concept and value of a poststructural analysis of clinical practices within clinical audiences. Positive feedback from these presentations, provided me with reassurance that this model had potential value in a clinical setting. I have had papers of my final results and the application of the model to clinical practice accepted at the 2021 National Occupational Therapy Conference. Dissemination of results by way of conferences is a strategy that works well for clinicians and is consistent with a dissemination plan that focusses on the needs of the audiences who will use the knowledge (Gagnon, 2011). Similarly, in keeping with the needs of students and academics, I plan to present this work within the university sector. I will develop a set of teaching materials for occupational therapy students which can be easily adapted for other disciplines and interprofessional teaching. This approach will be shared more broadly within the university by way of the teaching specialist community of practice. I intend to use this research as a platform from which to apply for a teaching grant to help develop and apply this pedagogy more broadly.

7.9 Addressing research aims

This section addresses each research aim and summarises the theoretical and practice implications of this research.

1. **To critically examine and compare how the problem of CFDs is being represented in clinical practices and experienced by carers.**

Examining the clinical practices of the PFAT through a detailed WPR analysis offered deep insights into the experiences of caring for and working with children with CFDs. Having both perspectives analysed using the WPR framework and then compared provided new insight into the development, delivery, and experience of clinical practices in this area. This facilitated consideration of the broader structural factors at play, the silences and power imbalances as well as the discursive, subjectification and lived effects for both carers and clinicians. Considering how a clinical problem is represented through clinical practices by applying the WPR approach was a helpful way to view clinical practices and service delivery responses. Clinician perspectives were covered in Chapter 4, carer perspectives were covered on Chapter 5 and both were compared and discussed in Chapter 6.

2. To analyse how PRs influence experiences and practices of health care

This study offered a theoretical approach to undermine a clinical problem's taken for granted status and opened up ways of considering how a clinical problem is produced as a 'problem' and its effects. It provided a way to consider how this influenced and constrained service responses, and this then opened up possibilities for doing things differently. The application of the WPR questions offered a structure for critical analysis which was complemented by Mol's approach to considering health as care. Together these approaches provided the basis for discussion of good clinical care practices and the roles of the client, clinician, and team. This was covered in Chapter 6.

3. To reflect on the contribution and extension of the What's the problem represented to be? (WPR) approach (Bacchi, 2009) to clinical practices.

This research tested the methodological and analytic processes for applying this model to clinical practices and demonstrated the value of this approach. An adapted WPR model for clinical practices was developed which appears to have merit in application to clinical services at both a practice and theoretical level. This has been discussed in Chapter seven but in summary includes at a practice level benefits for clinicians to review their practices and promote greater critical reflection and for educators to support future clinicians to develop critical thinking. At a theoretical level, this offers a new way to conceptualise and analyse clinical practices & problems.

7.10 Conclusion

This chapter concludes my thesis by presenting the adapted WPR model and discussing its role and value in tertiary education and clinical practice. The quality of the research is discussed and directions for future research and knowledge translation are shared. This research was undertaken within a public health context of seeking to understand systems and support system change to improve health outcomes (Baum, 2008). It contributes to theoretical considerations of good health care directly informed by the messy everyday realities of living with a condition and the required interactions with health care settings and professionals. It honours the experiences of the carers who contributed to this research, who time and time again reported feeling that their everyday experiences and the impact of caring for a child with CFDs was minimised and somehow irrelevant to service responses to their child. It also celebrates the ways that the clinicians of the PFAT sought to subvert systems that bought into this and highlights examples of good care that made a difference to these families. This thesis contributes to the public health field of research through its development of a new model for critically examining health care practices. This adapted model is designed to support clinicians and health professional students to better understand interdisciplinary teams and develop critical reflection skills that are essential for improving health care practices and outcomes. In this way the logic of care can be applied to health care practices, and clients, carers and clinicians can be emboldened to work together in ways that go beyond current models and embrace the uncertainty and messiness of living and working with health conditions that impact on everyday lives.

REFERENCES

Aldridge, V. K., Dovey, T. M., El Hawi, N., Martiniuc, A., Martin, C. I., & Meyer, C. (2018). Observation and comparison of mealtime behaviors in a sample of children with avoidant/restrictive food intake disorders and a control sample of children with typical development. *Infant Mental Health Journal, 39*(4), 410-422.

Alvesson, M., & Sandberg, J. (2011). Generating research questions through problematization. *Academy of Management Review, 36*(2), 247-271.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*: American Psychiatric Publications.

Annerstedt, C. F., & Glasdam, S. (2019). Nurses' attitudes towards support for and communication about sexual health—A qualitative study from the perspectives of oncological nurses. *Journal of Clinical Nursing, 28*(19-20), 3556-3566. doi:10.1111/jocn.14949

Aponte, C. A., Brown, K. A., Turner, K., Smith, T., & Johnson, C. (2019). Parent training for feeding problems in children with autism spectrum disorder: A review of the literature. *Children's Health Care, 48*(2), 191-214.

Austin, Z. (2019). Competency and Its Many Meanings. *Pharmacy, 7*(2), 37. doi:10.3390/pharmacy7020037

Australian Government. (2014). *Reform of the federation white paper: roles and responsibilities in health. Issues Paper 3. Department of the Prime Minister and Cabinet.* Canberra: Australian Government

Australian Government. (2019). The Australian Health System Retrieved from https://www.health.gov.au/about-us/the-australian-health-system#health-system-challenges

Australian Institute of Health and Welfare. (2018). *Australia's health 2018. Australia's health series no. 16. AUS 221.* Canberra: AIHW

Australian Primary Health Care Research Institute. (2011). *Knowledge Exchange Report*. Canberra: Australian Primary Health Care Research Institute, The Australian National University

Aveyard, H. (2014). *Doing a literature review in health and social care: A practical guide*: McGraw-Hill Education (UK).

Bacchi, C. (2009). *Analysing policy: What's the problem represented to be?* Australia: Pearson.

Bacchi, C. (2015). The Turn to Problematization: Political Implications of Contrasting Interpretive and Poststructural Adaptations. *Open Journal of Political Science, 5*, 1-12. doi:10.4236/ojps.2015.51001

Bacchi, C. (2016). Problematizations in health policy: questioning how “problems” are constituted in policies. *SAGE Open, 6*(2), 2158244016653986.

Bacchi, C., & Bonham, J. (2014). Reclaiming discursive practices as an analytic focus: Political implications. *Foucault Studies*(17), 173-192.

Bacchi, C., & Bonham, J. (2016). Poststructural Interview Analysis: Politicizing "personhood". In C. Bacchi & S. Goodwin (Eds.), *Poststructural Policy Analysis : A Guide to Practice.* . New York: Palgrave Macmillan.

Bacchi, C., & Goodwin, S. (2016). *Poststructural Policy Analysis : A Guide to Practice*. New York: New York: Palgrave Macmillan.

Backman, E., Granlund, M., & Karlsson, A.-K. (2019). Documentation of everyday life and health care following gastrostomy tube placement in children: a content analysis of medical records. *Disability and Rehabilitation*, 1-11. doi:10.1080/09638288.2019.1573383

Barnett, A., Dilkes-Frayne, E., Savic, M., & Carter, A. (2018). When the brain leaves the scanner and enters the clinic: The role of neuroscientific discourses in producing the problem of “addiction”. *Contemporary Drug Problems, 45*(3), 227-243.

Baum, F. (2008). *The New Public Health* (3 ed.). Australia: Oxford University Press.

Baxter, P., & Jack, S. (2008). Qualitative case study methodology: Study design and implementation for novice researchers. *The Qualitative Report, 13*(4), 544-559.

Bay, U., Haynes, A., & Western, D. (2019). Thinking what we do: reflexively testing post-structural theoretical concepts with social work practitioners and fieldwork educators. *Social Work Education*, 1-13.

Begotka, A., Long, B., Goday, P. S., & Silverman, A. H. (2018). Caregiver impressions of clinical effectiveness of an intensive behavioral feeding program. *Clinical Practice in Pediatric Psychology, 6*(3), 248.

Bonham, J., & Bacchi, C. (2017). Cycling ‘subjects’ in ongoing-formation: The politics of interviews and interview analysis. *Journal of Sociology, 53*(3), 687-703.

Borowitz, K. C., & Borowitz, S. M. (2018). Feeding Problems in Infants and Children: Assessment and Etiology. *Pediatric Clinics of North America, 65*(1), 59-72. doi:https://doi.org/10.1016/j.pcl.2017.08.021

Bourke-Taylor, H. M., Jane, F., & Peat, J. (2019). Healthy mothers healthy families workshop intervention: A preliminary investigation of healthy lifestyle changes for mothers of a child with a disability. *Journal of Autism and Developmental Disorders, 49*(3), 935-949.

Bourke-Taylor, H., Howie, L., Law, M., & Pallant, J. F. (2012). Self-reported mental health of mothers with a school-aged child with a disability in Victoria: A mixed method study. *Journal of Paediatrics and Child Health, 48*(2), 153-159.

Brady, M. (2014). Ethnographies of neoliberal governmentalities: From the neoliberal apparatus to neoliberalism and governmental assemblages. *Foucault Studies*(18), 11-33.

Braithwaite, J. (2018). Changing how we think about healthcare improvement. *BMJ, 361*, k2014. Retrieved from https://www.bmj.com/content/bmj/361/bmj.k2014.full.pdf

Braithwaite, J., & Goulston, K. (2004). Turning the health system 90 down under. *The Lancet, 364*(9432), 397-399.

Braithwaite, J., Runciman, W. B., & Merry, A. F. (2009). Towards safer, better healthcare: harnessing the natural properties of complex sociotechnical systems. *BMJ Quality & Safety, 18*(1), 37-41.

Bride, B. E., Radey, M., & Figley, C. R. (2007). Measuring compassion fatigue. *Clinical Social Work Journal, 35*(3), 155-163.

Browne-Yung, K., Ziersch, A., Baum, F., Friel, S., & Spoehr, J. (2020). General Motor Holden's closure in Playford, South Australia: Analysis of the policy response and its implications for health. *Australian Journal of Public Administration, 79*(1), 76-92.

Bryant-Waugh, R. (2013). Feeding and eating disorders in children. *Current Opinion in Psychiatry, 26*(6), 537-542.

Bryant-Waugh, R., & Kreipe, R. E. (2012). Avoidant/restrictive food intake disorder in DSM-5. *Psychiatric Annals, 42*(11), 402-405.

Bueger, C. (2014). Pathways to practice: praxiography and international politics. *European Political Science Review, 6*(3), 383-406. doi:10.1017/s1755773913000167

Carlson, E. D., Engebretson, J., & Chamberlain, R. M. (2005). The Evolution of Theory: A Case Study. *International Journal of Qualitative Methods, 4*(3), 20-39. doi:10.1177/160940690500400302

Carrasco, J. (2018). Political dimensions in the actions of health-care practitioners: Reflections for occupational science based on the Chilean psychiatric reform. *Journal of Occupational Science, 25*(4), 509-519. doi:10.1080/14427591.2018.1519869

Carruth, B. R., Ziegler, P. J., Gordon, A., & Barr, S. I. (2004). Prevalence of picky eaters among infants and toddlers and their caregivers' decisions about offering a new food. *Journal of the American Dietetic Association, 104*, 57-64.

Carter, M. (2019). Political discourse in the hospital heterotopia. *Nursing Philosophy, 20*(4). doi:10.1111/nup.12263

Champagne, T. (2011). Attachment, trauma, and occupational therapy practice. *Occupational Therapy Practice, 16*(5), C1-C8.

Chia, R. (1996). The problem of reflexivity in organizational research: Towards a postmodern science of organization. *Organization, 3*(1), 31-59.

Cooke, L., Higgins, C., & McCrann, Ú. (2017). Managing common feeding difficulties in toddlers and pre-school children. *Paediatrics and Child Health (United Kingdom), 27*(8), 366-370. doi:10.1016/j.paed.2017.04.001

Cousins, M., & Hussain, A. (1984). *Foucault*. London: Macmillan

Coveney, J. (2002). What does research on families and food tell us? Implications for nutrition and dietetic practice. *Nutrition and Dietetics, 59*(2), 113-119.

Coveney, J., & Putland, C. (2012). Answering Bacchi: A conversation about the work and impact of Carol Bacchi in teaching, research and practice in public health. In A. Bletsas & C. Beasley (Eds.), *Engaging with Carol Bacchi. Strategic interventions and exchanges* (pp. 71-78): University of Adelaide Press.

Craig, G. M. (2005). Mother knows best: Gastrostromy tube feeding and disabled children. *Psychology of Women Section Review*, 33.

Craig, G. M., & Scambler, G. (2006). Negotiating mothering against the odds: gastrostomy tube feeding, stigma, governmentality and disabled children. *Social Science & Medicine, 62*(5), 1115-1125.

Craig, G. M., Scambler, G., & Spitz, L. (2003). Why parents of children with neurodevelopmental disabilities requiring gastrostomy feeding need more support. *Developmental Medicine and Child Neurology, 45*(3), 183-188.

Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. Crow's Nest Allen & Unwin.

Curtin, M., & Fossey, E. (2007). Appraising the trustworthiness of qualitative studies: Guidelines for occupational therapists. *Australian Occupational Therapy Journal, 54*(2), 88-94.

Cuthill, M., O'Shea, É., Wilson, B., & Viljoen, P. (2014). Universities and the Public Good: A Review of Knowledge Exchange Policy and Related University Practice in Australia. *Australian Universities' Review, 56*(2), 36-46.

Dahlseng, M. O., Andersen, G. L., Da Graca Andrada, M., Arnaud, C., Balu, R., De la Cruz, J., . . . Júlíusson, P. B. (2012). Gastrostomy tube feeding of children with cerebral palsy: variation across six European countries. *Developmental Medicine & Child Neurology, 54*(10), 938-944.

Davies, W., 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.

Davis, A. M., Bruce, A. S., Khasawneh, R., Schulz, T., Fox, C., & Dunn, W. (2013). Sensory processing issues in young children presenting to an outpatient feeding clinic: A retrospective chart review. *Journal of Pediatric Gastroenterology and Nutrition, 56*(2), 156.

Davis, C. S., Snider, M. J., King, L., Shukraft, A., Sonda, J. D., Hicks, L., & Irvin, L. (2019). A Time to Live and a Time to Die: Heterotopian Spatialities and Temporalities in a Pediatric Palliative Care Team. *Health Communication, 34*(9), 931-941. doi:10.1080/10410236.2018.1443262

Dean, M., & Hindess, B. (1998). *Governing Australia: Studies in contemporary rationalities of government*: Cambridge University Press.

Demir, D., Skouteris, H., Dell'Aquila, D., Aksan, N., McCabe, M. P., Ricciardelli, L. A., . . . Baur, L. A. (2012). An observational approach to testing bi-directional parent–child interactions as influential to child eating and weight. *Early Child Development and Care, 182*(8), 943-950.

Department for Health and Wellbeing. (2019). *Changes to Health System Governance. SA Health systems roles and responsibilites.* Adelaide: Government of South Australia

Eddy, K. T., Harshman, S. G., Becker, K. R., Bern, E., Bryant-Waugh, R., Hilbert, A., . . . Menzel, J. (2019). Radcliffe ARFID workgroup: toward operationalization of research diagnostic criteria and directions for the field. *International Journal of Eating Disorders, 52*(4), 361-366.

Edwards, S., Davis, A. M., Ernst, L., Sitzmann, B., Bruce, A., Keeler, D., . . . Hyman, P. (2015). Interdisciplinary Strategies for Treating Oral Aversions in Children. *Journal of Parenteral and Enteral Nutrition, 39*(8), 899-909. doi:10.1177/0148607115609311

Evans, J., & Rodger, S. (2008). Mealtimes and bedtimes: Windows to family routines and rituals. *Journal of Occupational Science, 15*(2), 98-104.

Fennig, M., & Denov, M. (2019). Regime of Truth: Rethinking the Dominance of the Bio-Medical Model in Mental Health Social Work with Refugee Youth. *British Journal of Social Work, 49*(2), 300-317. doi:10.1093/bjsw/bcy036

Ferrari, R. (2015). Writing narrative style literature reviews. *Medical Writing, 24*(4), 230-235.

Ferreira, F. R., Prado, S. D., Carvalho, M. C. V. S., & Kraemer, F. B. (2015). Biopower and biopolitics in the field of food and nutrition. *Revista de Nutricao, 28*(1), 109-119. doi:10.1590/1415-52732015000100010

Fiese, B. H., Foley, K. P., & Spagnola, M. (2006). Routine and ritual elements in family mealtimes: Contexts for child well-being and family identity. *New Directions for Child and Adolescent Development,* (111), 67-89.

Flacks, S. (2019). Dangerous drugs, dangerous mothers: Gender, responsibility and the problematisation of parental substance use. *Critical Social Policy, 39*(3), 477-497.

Flynn, S. (2019). Rethinking debates in narrative methods: Narrative orthodoxy and research challenges with children with intellectual disability. *Scandinavian Journal of Disability Research, 21*(1).

Fogarty, W., Lovell, M., Langenberg, J., & Heron, M.-J. (2018). *Deficit discourse and strengths-based approaches: Changing the narrative of Aboriginal and Torres Strait Islander health and wellbeing*. The Lowitja Institute, Melbourne.

Fook, J., White, S., & Gardner, F. (2006). Critical Reflection: A review of contemporary literature and understandings. In S. White, J. Fook, & F. Gardner (Eds.), *EBOOK: Critical Reflection in Health and Social Care*. Retrieved from http://ebookcentral.proquest.com/lib/flinders/detail.action?docID=295530.

Foucault, M. (1973). *The birth of the clinic*. London: Routledge.

Foucault, M. (1981). The order of discourse. In R. Young (Ed.), *Untying the text: A post-structuralist reader* (pp. 48-78). Boston: Routledge & Kegan Paul.

Foucault, M. (1984). Polemics, politics and problematizations: An interview with Michel Foucault. In P. Rabinow (Ed.), *The Foucault Reader* (pp. 381-390). New York: Pantheon Books.

Foucault, M. (1988). Autobiography: Michel Foucault, 1926-1984. History of the Present. 1991a Govemmentality. In G. Burchell, C. Gordon, & P. Miller (Eds.), *The Foucault effect: Studies in govemmentality.* (pp. 87-104).

Foucault, M., & Miskowiec, J. (1986). Of other spaces. *Diacritics, 16*(1), 22-27.

Franklin, L., & Rodger, S. (2003). Parents' perspectives on feeding medically compromised children: Implications for occupational therapy. *Australian Occupational Therapy Journal, 50*(3), 137-147.

Freire, P. (2018). *Pedagogy of the oppressed*: Bloomsbury publishing USA.

Gagnon, M. L. (2011). Moving knowledge to action through dissemination and exchange. *Journal of Clinical Epidemiology, 64*(1), 25-31. Retrieved from https://www.jclinepi.com/article/S0895-4356(09)00243-1/fulltext

Gardner, J. (2017). Patient-centred medicine and the broad clinical gaze: Measuring outcomes in paediatric deep brain stimulation. *BioSocieties, 12*(2), 239-256. doi:10.1057/biosoc.2016.6

Garro, A., Thurman, S. K., Kerwin, M. E., & Ducette, J. P. (2005). Parent/caregiver stress during pediatric hospitalization for chronic feeding problems. *Journal of Pediatric Nursing, 20*(4), 268-275.

George, E., Mackean, T., Baum, F., & Fisher, M. (2019). Social determinants of Indigenous health and Indigenous rights in policy: A scoping review and analysis of problem representation. *International Indigenous Policy Journal, 10*(2).

Gill, J., & Liamputtong, P. (2009). 'Walk a mile in my shoes': Researching the lived experience of mothers of children with autism. *Journal of Family Studies, 15*(3), 309-319.

Goday, P. S., Huh, S. Y., Silverman, A., Lukens, C. T., Dodrill, P., Cohen, S. S., . . . Gisel, E. (2019). Pediatric feeding disorder: consensus definition and conceptual framework. *Journal of Pediatric Gastroenterology and Nutrition, 68*(1), 124.

Gordon, C. (1991). Governmental rationality: An introduction. *The Foucault effect: Studies in governmentality, 1*, 52.

Gosa, M. M., Dodrill, P., Lefton-Greif, M. A., & 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*(2S), 956-966.

Graham, I. D., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W., & Robinson, N. (2006). Lost in knowledge translation: time for a map? *Journal of Continuing Education in the Health Professions, 26*(1), 13-24.

Gray, D. E. (2013). *Doing research in the real world*: Sage.

Greenhalgh, T., Howick, J., & Maskrey, N. (2014). Evidence based medicine: a movement in crisis? *BMJ, 348*.

Greer, A. J., Gulotta, C. S., Masler, E. A., & Laud, R. B. (2007). Caregiver stress and outcomes of children with pediatric feeding disorders treated in an intensive interdisciplinary program. *Journal of Pediatric Psychology, 33*(6), 612-620.

Greig, G., Entwistle, V. A., & Beech, N. (2012). Addressing complex healthcare problems in diverse settings: Insights from activity theory. *Social Science & Medicine, 74*(3), 305-312.

Gunson, J. S., Warin, M., Zivkovic, T., & Moore, V. (2014). Participant observation in obesity research with children: Striated and smooth spaces. *Children's Geographies, 14*(1), 20-34.

Halcomb, E. J., & Davidson, P. M. (2006). Is verbatim transcription of interview data always necessary? *Applied Nursing Research, 19*(1), 38-42.

Hall, J. (2015). Australian health care—the challenge of reform in a fragmented system. *New England Journal of Medicine, 373*(6), 493-497. Retrieved from https://www.nejm.org/doi/full/10.1056/NEJMp1410737?url_ver=Z39.88-2003&rfr_id=ori%3Arid%3Acrossref.org&rfr_dat=cr_pub%3Dpubmed

Hall, R. (2008). *Applied social research: Planning, designing and conducting real-world research*: Macmillan Education AU.

Henderson, J., Javanparast, S., Baum, F., Freeman, T., Ziersch, A., Mackean, T., & Fuller, J. (2019). The governance of primary mental health planning by Primary Health Networks. *Australian Journal of Social Issues, 54*(3), 267-284.

Hennink, M., Hutter, I., & Bailey, A. (2010). *Qualitative Research Methods*: Sage.

Hesse-Biber, S. N. (2017). *The practice of qualitative research* (3rd ed.): Thousand Oaks, California: Sage.

Hewetson, R., & Singh, S. (2009). The lived experience of mothers of children with chronic feeding and/or swallowing difficulties. *Dysphagia, 24*(3), 322-332.

Hodges, B. D., Martimianakis, M. A., McNaughton, N., & Whitehead, C. (2014). Medical education… meet Michel Foucault. *Medical Education, 48*(6), 563-571.

Holstein, J. A., & Gubrium, J. F. (2011). The constructionist analytics of interpretive practice. *The SAGE Handbook of Qualitative Research, 4*, 341-358.

Houghton, C., Casey, D., Shaw, D., & Murphy, K. (2013). Rigour in qualitative case-study research. *Nurse Researcher, 20*(4).

Howe, T.-H., & Wang, T.-N. (2013). Systematic review of interventions used in or relevant to occupational therapy for children with feeding difficulties ages birth–5 years. *American Journal of Occupational Therapy, 67*(4), 405-412.

Huberman, M. (1994). Research utilization: The state of the art. *Knowledge and Policy, 7*(4), 13-33.

Indigenous Allied Health Australia. (2015). *Cultural Responsiveness in Action: An IAHA Framework*. Retrieved from http://iaha.com.au/wp-content/uploads/2015/08/2015-IAHA-Cultural-Responsiveness-Framework-WEB.pdf

Innvær, S., Vist, G., Trommald, M., & Oxman, A. (2002). Health policy-makers' perceptions of their use of evidence: a systematic review. *Journal of Health Services Research & Policy, 7*(4), 239-244.

Interprofessional Education Collaborative. (2016). Core competencies for interprofessional collaborative practice: 2016 update. *Washington, DC: Interprofessional Education Collaborative*, 1-19.

Johnson, J. L., Bottorff, J. L., Browne, A. J., Grewal, S., Hilton, B. A., & Clarke, H. (2004). Othering and being othered in the context of health care services. *Health Communication, 16*(2), 255-271.

Keren, M. (2016). Eating and feeding disorders in the first five years of life: Revising the DC:0-3R diagnostic classification of mental health and developmental disorders of infancy and early childhood and rationale for the new DC:0-5 proposed criteria. *Infant Mental Health Journal, 37*(5), 498-508. doi:10.1002/imhj.21588

Kerzner, B., Milano, K., MacLean, W. C., Berall, G., Stuart, S., & Chatoor, I. (2015). A practical approach to classifying and managing feeding difficulties. *Pediatrics, 135*(2), 344-353.

Kiefer, L., Frank, J., Di Ruggiero, E., Dobbins, M., Manuel, D., Gully, P. R., & Mowat, D. (2005). Fostering evidence-based decision-making in Canada: examining the need for a Canadian population and public health evidence centre and research network. *Canadian Journal of Public Health/Revue Canadienne de Sante'e Publique*, I1-I19.

Kingston, A. K. (2007). *Mothering special needs: A different maternal journey*: Jessica Kingsley Publishers.

Kitson, A. L. (2018). The fundamentals of care framework as a point-of-care nursing theory. *Nursing Research, 67*(2), 99-107.

Kothari, A., & Wathen, C. N. (2013). A critical second look at integrated knowledge translation. *Health Policy, 109*(2), 187-191. Retrieved from https://www.sciencedirect.com/science/article/abs/pii/S0168851012003004?via%3Dihub

Krassnitzer, L. (2019). The public health sector and Medicare. In E. Willis, L. Reynolds, & T. Rudge (Eds.), *Understanding the Australian Health Care System* (4 ed., pp. 18-36): Elsevier Health Sciences.

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. doi:10.1007/s00431-017-2908-x

Larkin, H., & Pepin, G. (2013). Becoming a reflective practitioner. In K. Stagnitti, A. Schoo, & D. Welch (Eds.), *Clinical and fieldwork placement in the health professions*. South Melbourne, Australia: Oxford University Press.

Lavis, J. N., Posada, F. B., Haines, A., & Osei, E. (2004). Use of research to inform public policymaking. *The Lancet, 364*(9445), 1615-1621. Retrieved from https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(04)17317-0/fulltext

Lawless, A., Coveney, J., & MacDougall, C. (2014). Infant mental health promotion and the discourse of risk. *Sociology of Health & Illness, 36*(3), 416-431.

Liamputtong, P. (2007). *Researching the vulnerable: A guide to sensitive research methods*. London: Sage.

Liamputtong, P. (2009). *Qualitative research methods* (3rd ed.). Melbourne: Oxford University Press.

Lively, E. J., McAllister, S., & Doeltgen, S. H. (2020). Characterizing international approaches to weaning children from tube feeding: A scoping review. *Journal of Parenteral and Enteral Nutrition*. doi:10.1002/jpen.1842

Luck, L., Jackson, D., & Usher, K. (2007). STAMP: components of observable behaviour that indicate potential for patient violence in emergency departments. *Journal of Advanced Nursing, 59*(1), 11-19.

Lukens, C. T., & Silverman, A. H. (2014). Systematic review of psychological interventions for pediatric feeding problems. *Journal of Pediatric Psychology, 39*(8), 903-917.

Manikam, R., & Perman, J. A. (2000). Pediatric feeding disorders. *Journal of Clinical Gastroenterology, 30*(1), 34-46.

Marsac, M. L., Kassam-Adams, N., Delahanty, D. L., Widaman, K. F., & Barakat, L. P. (2014). Posttraumatic stress following acute medical trauma in children: A proposed model of bio-psycho-social processes during the peri-trauma period. *Clinical Child and Family Psychology Review, 17*(4), 399-411.

Marshall, J., Hill, R. J., Wallace, M., & Dodrill, P. (2018). Intervention for feeding difficulties in children with a complex medical history: A randomized clinical trial. *Journal of Pediatric Gastroenterology and Nutrition, 66*(1), 152-158. doi:10.1097/MPG.0000000000001683

Marshall, J., Hill, R. J., Ware, R. S., Ziviani, J., & Dodrill, P. (2015). Multidisciplinary intervention for childhood feeding difficulties. *Journal of Pediatric Gastroenterology and Nutrition, 60*(5), 680-687. doi:10.1097/MPG.0000000000000669

Maximino, P., Machado, R. H. V., Junqueira, P., Ciari, M., Tosatti, A. M., de Cássia Ramos, C., & Fisberg, M. (2016). How to monitor children with feeding difficulties in a multidisciplinary scope? Multidisciplinary care protocol for children and adolescents–pilot study. *Journal of Human Growth and Development, 26*(3), 331-340.

Maynard, K. (2020). Foucault on the Wards: Rediscovering Reflection as a Social Pediatrician in Training. *Academic Medicine, 95*(3), 361-364. doi:10.1097/acm.0000000000003042

Mazze, N., Cory, E., Gardner, J., Alexanian-Farr, M., Mutch, C., Marcus, S., . . . van den Heuvel, M. (2019). Biopsychosocial factors in children referred with failure to thrive: Modern characterization for multidisciplinary care. *Global Pediatric Health, 6*, 1-7. doi:10.1177/2333794X19858526

Mazzei, L. A., & Jackson, A. Y. (2012). Complicating voice in a refusal to “let participants speak for themselves”. *Qualitative Inquiry, 18*(9), 745-751.

McComish, C., Brackett, K., Kelly, M., Hall, C., Wallace, S., & Powell, V. (2016). Interdisciplinary feeding team: A medical, motor, behavioral approach to complex pediatric feeding problems. *MCN The American Journal of Maternal/Child Nursing, 41*(4), 230-236. doi:10.1097/NMC.0000000000000252

McIntyre, E., Jackson Bowers, E., Kalucy, E., Beacham, B., & Raven, M. (2014). *Fact Sheet: Collaborative partnerships in research*: Primary Health Care Research and Information Service.

McKee, K. (2009). Post-Foucauldian governmentality: What does it offer critical social policy analysis? *Critical Social Policy, 29*(3), 465-486.

Mezirow, J. (2003). Transformative learning as discourse. *Journal of Transformative Education, 1*(1), 58-63.

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook*: Sage.

Minichiello, V., Aroni, R., & Hays, T. (2008). *In-depth interviewing: Principles, techniques, analysis* (3 ed.): Pearson Education Australia.

Mitchell, G. L., Farrow, C., Haycraft, E., & Meyer, C. (2013). Parental influences on children's eating behaviour and characteristics of successful parent-focussed interventions. *Appetite, 60*(1), 85-94. doi:10.1016/j.appet.2012.09.014

Mol, A. (2002). *The body multiple: Ontology in medical practice*. Durham: Duke University Press.

Mol, A. (2008). *The logic of care: Health and the problem of patient choice*: Routledge.

Muñoz, J. P. (2007). Culturally responsive caring in occupational therapy. *Occupational Therapy International, 14*(4), 256-280.

Nath, S. (2007). *Final Report: Getting Research into Policy and Practice (GRIPP).* John Snow International Europe.

Njenga, J. (2019). *Managing pregnant women with obesity in country South Australia: The perspectives of primary care maternity providers.* (Doctoral dissertation, Flinders University). Flinders University Theses Collections.

Norris, M. L., Spettigue, W. J., & Katzman, D. K. (2016). Update on eating disorders: current perspectives on avoidant/restrictive food intake disorder in children and youth. *Neuropsychiatric Disease and Treatment, 12*, 213.

O'Malley, P., Weir, L., & Shearing, C. (1997). Governmentality, criticism, politics. *Economy and Society, 26*(4), 501-517.

Oliveira, A., de Lauzon-Guillain, B., Jones, L., Emmett, P., Moreira, P., Ramos, E., . . . Lopes, C. (2015). Birth weight and eating behaviors of young children. *The Journal of Pediatrics, 166*(1), 59-65.e53. doi:http://dx.doi.org/10.1016/j.jpeds.2014.09.031

Orrell-Valente, J. K., Hill, L. G., Brechwald, W. A., Dodge, K. A., Pettit, G. S., & Bates, J. E. (2007). "Just three more bites": an observational analysis of parents' socialization of children's eating at mealtime. *Appetite, 48*(1), 37-45.

Pérez-Escamilla, R., Segura-Pérez, S., & Lott, M. (2017). Feeding guidelines for infants and young toddlers: A responsive parenting approach. *Nutrition Today, 52*(5), 223-231. doi:10.1097/NT.0000000000000234

Petersen, M. C., Kedia, S., Davis, P., Newman, L., & Temple, C. (2006). Eating and feeding are not the same: Caregivers' perceptions of gastrostomy feeding for children with cerebral palsy. *Developmental Medicine & Child Neurology, 48*(9), 713-717.

Pfifferling, J.-H., & Gilley, K. (2000). Overcoming compassion fatigue. *Family Practice Management, 7*(4), 39.

Pink, S. (2015). *Doing sensory ethnography*: Sage.

Popay, J., Rogers, A., & Williams, G. (1998). Rationale and standards for the systematic review of qualitative literature in health services research. *Qualitative Health Research, 8*(3), 341-351.

Richardson, F. (2015). An introduction to inclusive practice. In J. Davis, M. Birks, & Y. Chapman (Eds.), *Inclusive Practice for Health Professionals* (pp. 2-22). Melbourne: Oxford University Press.

Roberts, K., Dowell, A., & Nie, J.-B. (2019). Attempting rigour and replicability in thematic analysis of qualitative research data; a case study of codebook development. *BMC Medical Research Methodology, 19*(1), 66-66. doi:10.1186/s12874-019-0707-y

Rose, N. (1990). *Governing the soul: The shaping of the private self*: Taylor & Frances/Routledge.

Rose, N., & Miller, P. (1992). Political power beyond the state: Problematics of government. *British Journal of Sociology*, 173-205.

Rowland, P., & Kuper, A. (2018). Beyond vulnerability: how the dual role of patient-health care provider can inform health professions education. *Theory and Practice, 23*(1), 115-131. doi:10.1007/s10459-017-9777-y

Russell, M., Jewell, V., Poskey, G. A., & Russell, A. (2018). Enteral feeding and its impact on family mealtime routines for caregivers of children with cerebral palsy: A mixed method study. *Australian Occupational Therapy Journal, 65*(1), 25-34.

Saini, V., Kadey, H. J., Paszek, K. J., & Roane, H. S. (2019). A systematic review of functional analysis in pediatric feeding disorders. *Journal of Applied Behavior Analysis*. doi:10.1002/jaba.637

Saldaña, J. (2011). *Fundamentals of qualitative research*: Oxford University Press.

Sanchez, K., Spittle, A. J., Allinson, L., & Morgan, A. (2015). Parent questionnaires measuring feeding disorders in preschool children: A systematic review. *Developmental Medicine & Child Neurology, 57*(9), 798-807. doi:10.1111/dmcn.12748

Sanders, M. R., & Hall, S. L. (2018). Trauma-informed care in the newborn intensive care unit: Promoting safety, security and connectedness. *Journal of Perinatology, 38*(1), 3-10. doi:10.1038/jp.2017.124

Satter, E. (1995). Feeding dynamics: Helping children to eat well. *Journal of Pediatric Health Care, 9*(4), 178-184.

Sharp, W. G., Jaquess, D. L., Morton, J. F., & Herzinger, C. V. (2010). Pediatric feeding disorders: A quantitative synthesis of treatment outcomes. *Clinical Child and Family Psychology Review, 13*(4), 348-365.

Sharp, W. G., & Stubbs, K. H. (2019). Avoidant/restrictive food intake disorder: A diagnosis at the intersection of feeding and eating disorders necessitating subtype differentiation. *International Journal of Eating Disorders, 52*(4), 398-401.

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? *Journal of Pediatrics, 181*, 116-124.e114. doi:10.1016/j.jpeds.2016.10.002

Shonkoff, J. P. (2010). Building a new biodevelopmental framework to guide the future of early childhood policy. *Child Development, 81*(1), 357-367.

Shrewsbury, D., Mogensen, L., & Hu, W. (2018). Problematizing medical students with disabilities: A critical policy analysis. *MedEdPublish, 7*.

Sidani, S., Reeves, S., Hurlock-Chorostecki, C., van Soeren, M., Fox, M., & Collins, L. (2018). Exploring differences in patient-centered practices among healthcare professionals in acute care settings. *Health Communication, 33*(6), 716-723. doi:10.1080/10410236.2017.1306476

Silva, G. A., Costa, K. A., & Giugliani, E. R. (2016). Infant feeding: Beyond the nutritional aspects. *Jornal de pediatria, 92*(3), 2-7.

Silverman, A. H. (2015). Behavioral management of feeding disorders of childhood. *Annals of Nutrition and Metabolism, 66*(Suppl. 5), 33-42.

Silverman, A. H., Erato, G., & Goday, P. (2020). The relationship between chronic paediatric feeding disorders and caregiver stress. *Journal of Child Health Care*, 1367493520905381.

Spence, D. (2005). Exploring prejudice, understanding paradox and working towards new possibilities. In D. Wepa (Ed.), *Cultural Safety in Aotearoa New Zealand* (pp. 58–67). Auckland: Pearson Education.

Spratling, R., & Lee, J. (2020). Caregivers experiences in symptom management for their children who require medical technology at home. *Journal for Specialists in Pediatric Nursing, 25*(1). doi:10.1111/jspn.12275

St Pierre, E. (2011). Post qualitative research: The critique and the coming after. In N. Denzin & Y. Lincoln (Eds.), *The SAGE handbook of qualitative research* (4 ed., pp. 611-625). Thousand Oaks: SAGE Publications.

Stake, R. E. (1995). *The art of case study research*. Thousand Oaks: Sage Publications.

Stake, R. E. (2009). The case study method in social inquiry. In R. Gomm, Hammersley, M., & Foster, P. (Ed.), *Case study method* (pp. 18-26). London: SAGE Publications Ltd, doi: 10.4135/9780857024367.

Stern, D. (1995). *The motherhood constellation. A unified view of parent-infant psychotherapy*. New York: Basic Books.

Struhkamp, R. (2005). Wordless pain: Dealing with suffering in physical rehabilitation. *Cultural Studies, 19*(6), 701-718.

Tapera, R., Harwood, M., & Anderson, A. (2017). A qualitative Kaupapa Māori approach to understanding infant and young child feeding practices of Māori and Pacific grandparents in Auckland, New Zealand. *Public Health Nutrition, 20*(6), 1090-1098. doi:10.1017/S1368980016002950

Taylor, E. W. (2007). An update of transformative learning theory: A critical review of the empirical research (1999–2005). *International Journal of Lifelong Education, 26*(2), 173-191.

Taylor, R. R. (2020). *The intentional relationship: Occupational therapy and use of self* (2nd ed.): FA Davis.

Taylor, S., Purdy, S. C., Jackson, B., Phillips, K., & Virues-Ortega, J. (2019). Evaluation of a home-based behavioral treatment model for children with tube dependency. *Journal of Pediatric Psychology, 44*(6), 656-668. doi:10.1093/jpepsy/jsz014

Terwiel, A. (2018). What is the problem with high prison temperatures? From the threat to health to the right to comfort. *New Political Science, 40*(1), 70-83. doi:10.1080/07393148.2017.1417213

Thomas, G. (2011). *How to do your case study: A guide for students and researchers*. London: Sage.

Tierney, T. F. (2004). Foucault on the case: The pastoral and juridical foundation of medical power. *Journal of Medical Humanities, 25*(4), 271-290. doi:10.1007/s10912-004-4833-z

Tracy, S. J. (2010). Qualitative quality: Eight “big-tent” criteria for excellent qualitative research. *Qualitative Inquiry, 16*(10), 837-851.

Upshur, R. E. G., Vandenkerkhof, E. G., & Goel, V. (2001). Meaning and measurement: An inclusive model of evidence in health care. *Journal of Evaluation in Clinical Practice, 7*(2), 91-96. doi:10.1046/j.1365-2753.2001.00279.x

Van Bueren, E. M., Klijn, E. H., & Koppenjan, J. F. (2003). Dealing with wicked problems in networks: Analyzing an environmental debate from a network perspective. *Journal of Public Administration Research And Theory, 13*(2), 193-212.

Van Rensburg, A. J., Rau, A., Fourie, P., & Bracke, P. (2016). Power and integrated health care: Shifting from governance to governmentality. *International Journal of Integrated Care, 16*(3). doi:10.5334/ijic.2480

Walter, I., Davies, H., & Nutley, S. (2003). Increasing research impact through partnerships: evidence from outside health care. *Journal of Health Services Research & Policy, 8*(suppl 2), 58-61.

Ward, V., Smith, S., House, A., & Hamer, S. (2012). Exploring knowledge exchange: A useful framework for practice and policy. *Social Science & Medicine, 74*(3), 297-304. doi:http://dx.doi.org/10.1016/j.socscimed.2011.09.021

Warin, M., Jay, B., & Zivkovic, T. (2019). “Ready-made” assumptions: Situating convenience as care in the Australian obesity debate. *Food and Foodways, 27*(4), 273-295. doi:10.1080/07409710.2019.1673004

Wilken, M. (2012). The impact of child tube feeding on maternal emotional state and identity: A qualitative meta-analysis. *Journal Of Pediatric Nursing, 27*(3), 248-255. Retrieved from https://www.pediatricnursing.org/article/S0882-5963(11)00081-9/fulltext

Williams, C., Vandahm, K., Stevens, L. M., Khan, S., Urich, J., Iurilli, J., . . . Williams, D. I. (2017). Improved outcomes with an outpatient multidisciplinary intensive feeding therapy program compared with weekly feeding therapy to reduce enteral tube feeding dependence in medically complex young children. *Current Gastroenterology Reports, 19*(7). doi:10.1007/s11894-017-0569-6

Winston, K. A., Dunbar, S. B., Reed, C. N., & Francis-Connolly, E. (2010). Mothering occupations when parenting children with feeding concerns: A mixed methods study. *Canadian Journal of Occupational Therapy, 77*(3), 181-189.

Woodward, K. (2003). Representations of motherhood. In S. Earle & G. Letherby (Eds.), *Gender, Identity & Reproduction: Social Perspectives* (pp. 18-32). London: Palgrave Macmillan UK.

World Health Organization. (2001). *World Health Organization international classification of functioning, disability and health*. Geneva: World Health Organization

World Health Organization. (2010). *Framework for action on interprofessional education and collaborative practice*. (No. WHO/HRH/HPN/10.3). World Health Organization

World Health Organization. (2019). Ten threats to global health in 2019. Retrieved from https://www.who.int/emergencies/ten-threats-to-global-health-in-2019

Yang, H. R. (2017). How to approach feeding difficulties in young children. *Korean Journal of Pediatrics, 60*(12), 379-384. doi:10.3345/kjp.2017.60.12.379

Yin, R. K. (2018). *Case study research and applications: Design and methods* (6 ed.). Thousand Oaks: California: Sage publications.

APPENDICES

Appendix 1: Literature review summary table

Author	**Year**	**Journal**	**Location**	**Participa nt focus**	**Epistemological framing - How is the problem constructed (biomedical, behavioural, relational or biopsychosocial)? Constructionist, Positivist?**	**Disciplinary /theoretical approach**	**Methodology - Qualitative, Quantitative, Mixed-Methods**	**Interdisciplinary team recommendation**
Aldridge, Dovey, El Hawi, Martiniuc, Martin & Meyer	2018	Infant Mental Health Journal	UK	children under 7 yrs	Behavioural, Positivist	psychology	Quantitative	
Aponte, Brown, Turner, Smith, & Johnson	2019	Children's Health Care	USA	carers of children 2-9 yrs,	Behavioural, Positivist	developmental & behavioural paediatrics	Scoping review	
Backman, Granlund, & Karlsson	2019	Disability and Rehabilitation	Sweden	child -39 children median age 38 months	Biopsychosocial, Constructionist	speech pathology/ ecocultural theory	Mixed methods	
Begotka, Long, Goday, Silverman	2018	Clinical Practice in Pediatric Psychology	USA	carers	Behavioural, Positivist	psychology, interdisciplinary	Quantitative	Y
Borowitz & Borowitz	2018	Pediatric Clinics of North America	USA	n/a	Biomedical	speech pathology and paediatric gastroenterology	Clinical expertise and case examples	Y

Craig	2005	Psychology of Women Section Review	UK	mothers	Biopsychosocial, Constructionist	health sciences/ feminist poststructuralism	Qualitative	
Craig & Scambler	2006	Social Science and Medicine	UK	mothers of 22 children	Biopsychosocial, Constructionist	health sciences, medical sociology/feminist poststructuralism	Qualitative	
Craig, Scambler & Spitz	2003	Developmental Medicine and Child Neurology	UK	mothers	Biopsychosocial, Constructionist	medical sociology and paediatric surgery/ constructionist- social constructionism	Qualitative	
Davies et al	2006	Journal of Family Psychology	USA	n/a	Relational	psychology and paediatrics	Clinical expertise and evidence review	Y
Eddy et al	2019	International Journal of Eating Disorders	International	n/a	Biomedical	multi-disciplinary	Clinical expertise and evidence review	Y but only when complex
Edwards et al	2015	Journal of Parenteral and Enteral Nutrition	USA	n/a	Biomedical	paediatric gastroenterology, multi-disciplinary	Clinical expertise and evidence review	Y-paediatric gastroenterologist, psychologist, dietitian, nurse, speech pathologist (SP), and OT
Franklin & Rodger	2003	Australian Occupational Therapy Journal	Australia	carers 5/8 were parent couples, 3/8 were mothers	Biopsychosocial, Constructionist	OT/ phenomenological theory	Qualitative	
Garro, Thurman, Kerwin, & Ducette	2005	Journal of Pediatric Nursing	USA	female carers	Biopsychosocial, Positivist	psychology and nursing	Quantitative	Y-physicians, nurses, psychologists, SP, OTs, and feeding therapists

Goday et al	2019	Journal of Pediatric Gastroenterology and Nutrition	USA & Canada	n/a	Biopsychosocial	paediatric gastroenterology, multi-disciplinary	Clinical expertise and evidence review	Y
Gosa, Dodrill, Lefton-Greif, & Silverman	2020	American Journal of Speech-Language Pathology	USA	n/a	Biomedical	speech pathology, multi-disciplinary	Clinical expertise and review	Y -carers + developmental physician, SP, OT, dietitian, behavioural psychologist
Greer, Gulotta, Masler, & Laud	2007	Journal of Pediatric Psychology	USA	carers - 121, 114 female and 7 male	Behavioural, Positivist	psychology	Quantitative	Y -gastroenterologist, nutritionist, behavioural psychologist, SP, OT, social worker.
Hewetson & Singh	2009	Dysphagia	South African	mothers	Biopsychosocial	speech pathology/ phenomenology	Qualitative	Y
Howe & Wang	2013	American Journal of Occupational Therapy	USA	children 0-5 years	Biopsychosocial	OT	Systematic review	Y
Keren	2016	Infant Mental Health	International	n/a	Relational	infant mental health	Clinical opinion and review	
Kerzner et al	2015	Pediatrics	USA	children 0-5 and parents	Relational	paediatric gastroenterology, multi-disciplinary	Literature review	
Krom et al	2017	European Journal of Pediatrics	The Netherlands	children	Biomedical	paediatric gastroenterology, multi-disciplinary	Literature review	Y - with experience
Lively et al	2020	Journal of Parenteral and Enteral Nutrition	Australia	children	Relational	speech pathology	Scoping review	
Lukens & Silverman	2014	Journal of Pediatric Psychology	USA	children	Behavioural	psychiatry and paediatrics	Systematic review	Y- Physicians, dietitians, SPs, and OTs deal with core components,

								psychologists needed to deal with the leftover behavioural issues
Manikam & Perman	2000	Journal of Clinical Gastroenterology	USA	n/a	Biopsychosocial	psychology	Clinical expertise and review	Y
Marshall, Hill, Wallace, & Dodrill	2018	Journal of Pediatric Gastroenterology and Nutrition	Australia	children 0-6 yrs	Behavioural, Positivist	speech pathology, multi-disciplinary	Quantitative- randomized clinical trial.	Y
Marshall, Hill, Ware, Ziviani, & Dodrill	2015	Journal of Pediatric Gastroenterology and Nutrition	Australia	children 2-6 yrs	Behavioural, Positivist	speech pathology, multi-disciplinary	Quantitative- randomized clinical trial.	Y paediatrician, SP and nutritionist - concurrently
Maximino et al	2016	Journal of Human Growth and Development	Brazil	children 75% <5years	Biomedical -Positivist	nutrition, multi-disciplinary	Quantitative- descriptive	Y- paediatrician, nutritionist, feeding therapist
Mazze et al	2019	Global Pediatric Health	Canada	children n= 138, mean age 16months	Biomedical- Positivist	paediatrics, interdisciplinary	Quantitative- retrospective, cross-sectional chart review	Y- nurse, paediatrician, OT, dietitian, social worker, often concurrently.
McComish et al	2016	The American Journal of Maternal/Child Nursing	USA	n/a	Biopsychosocial	speech pathology, nursing, dietetics - interdisciplinary	Clinical expertise and review	Y - nurses, physicians, registered dietitians, and feeding therapists (SP, OT & physio). With paediatric gastroenterology nurse practitioners, dietitians, and SP considered integral team members
Norris, Spettigue, & Katzman	2016	Neuropsychiatric Disease and Treatment	Canada	n/a	Biomedical	paediatrics	Clinical expertise and review	Y

Petersen, Kedia, Davis, Newman, & Temple	2006	Developmental Medicine and Child Neurology	USA	carers, n=26, all female	Biopsychosocial, Constructionist	medicine, anthropology, speech pathology	Mixed methods- non experimental design,	
Russell, Jewell, Poskey, & Russell	2018	Australian Occupational Therapy Journal	USA	carers	Biopsychosocial, Constructionist	OT	Mixed methods	Y
Saini, Kadey, Paszek, & Roane	2019	Journal of Applied Behavior Analysis	Canada	children 0-17 majority were 0-6yrs	Behavioural, Positivist	applied disability studies/ behaviour analysis	Systematic review	
Sharp & Stubbs	2019	International Journal of Eating Disorders	USA	n/a	Biomedical	paediatrics	Commentary - clinical expertise	Y- psychologists, medicine, SP/OT and nutrition specialists
Sharp, Volkert, Scahill, McCracken, & McElhanon	2017	Journal of Pediatrics	USA	children 0-18 n= 593	Biomedical, Positivist	paediatrics	Systematic review and meta-analysis.	Y- psychologists, nutritionists, medicine, and SP/OT
Sharp, Jaquess, Morton, & Herzinger	2010	Clinical Child and Family Psychology Review	USA	children n= 98	Biomedical, Positivist	paediatrics	Systematic review	Y
Silva, Costa, & Giugliani	2016	Jornal de Pediatria	Brazil	children not with CFDs and parents	Relational	child and adolescent health, paediatrics	Literature review	
Silverman, Erato, & Goday	2020	Journal of Child Health Care	USA	carers - 850, 92% mothers	Behavioural, Positivist	psychology, paediatric gastroenterology	Quantitative	Y- gastroenterologists, dieticians, SPs, child psychologists

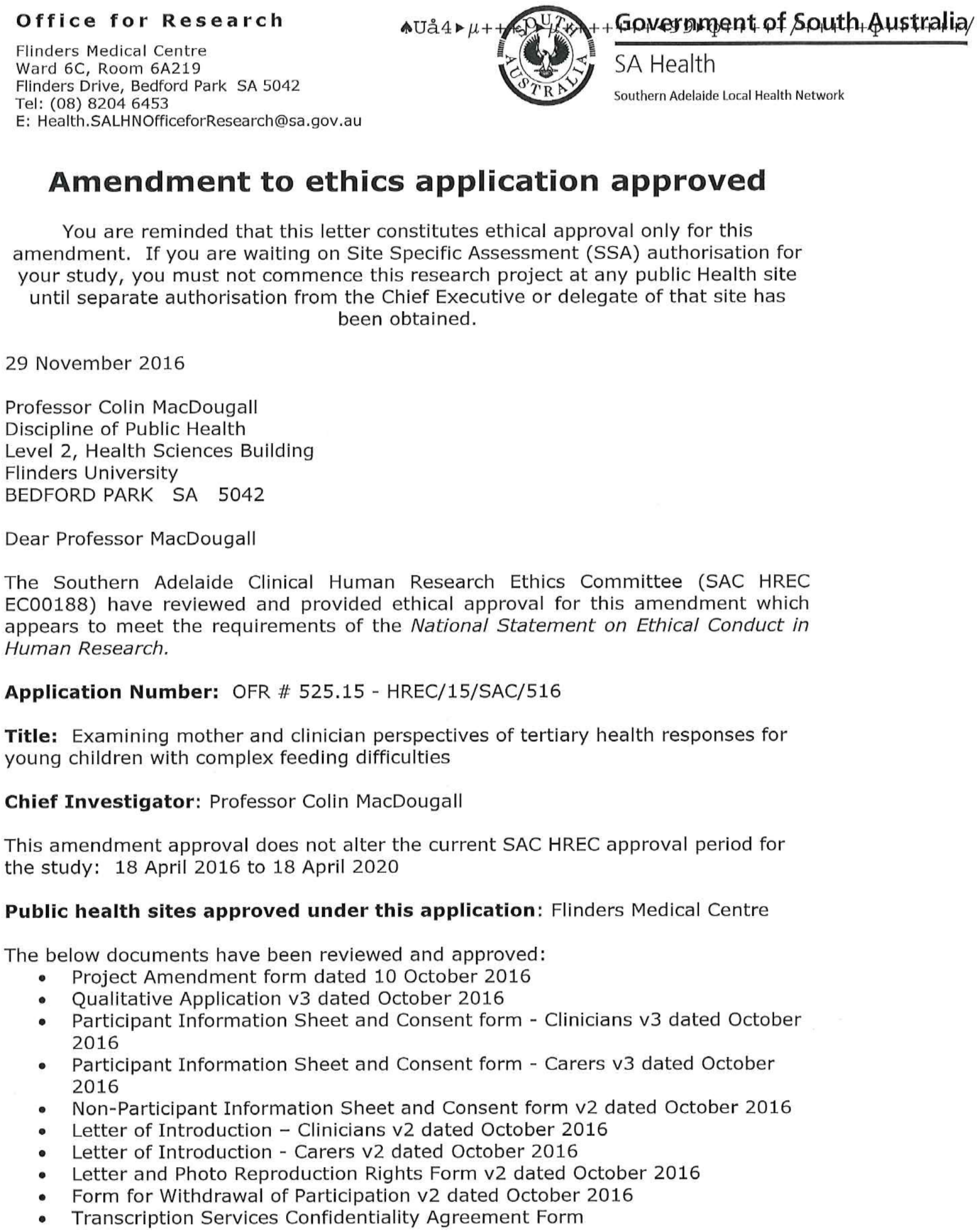
Spratling & Lee	2020	Journal for Specialists in Pediatric Nursing	USA	carers n=9, all women	Biopsychosocial, Constructionist	nursing	Qualitative Interpretive phenomenology	
Tapera, Harwood, & Anderson	2017	Public Health Nutrition	NZ	grandparents of non CFDs children	Biopsychosocial, Constructionist	medicine	Qualitative	
Taylor, Purdy, Jackson, Phillips, & Virues-Ortega	2019	Journal of Pediatric Psychology	NZ	children 4-14 years	Behavioural, Positivist	psychology/ applied behaviour analysis	Quantitative, single subject experimental design	Y-psychologist, paediatrician, SP, dietitian
Williams et al	2017	Current Gastroenterology	USA	children (median age 26 mo)	Biomedical, Positivist	medicine, paediatric gastroenterology	Quantitative- retrospective cohort-controlled study design	Y
Winston, Dunbar, Reed, & Francis-Connolly	2010	Canadian Journal of Occupational Therapy	USA	mothers	Biopsychosocial, Constructionist	OT	Mixed methods	
Yang	2017	Korean Journal of Pediatrics	Korea	n/a	Biomedical	paediatrics	Clinical expertise and review	

Expert opinion

Literature reviews

Primary research

Appendix 2: Ethics approval



Office for Research
Flinders Medical Centre
Ward 6C, Room 6A219
Flinders Drive, Bedford Park SA 5042
Tel: (08) 8204 6453
E: Health.SALHNOfficeforResearch@sa.gov.au

Government of South Australia
SA Health
Southern Adelaide Local Health Network

Amendment to ethics application approved

You are reminded that this letter constitutes ethical approval only for this amendment. If you are waiting on Site Specific Assessment (SSA) authorisation for your study, you must not commence this research project at any public Health site until separate authorisation from the Chief Executive or delegate of that site has been obtained.

29 November 2016

Professor Colin MacDougall
Discipline of Public Health
Level 2, Health Sciences Building
Flinders University
BEDFORD PARK SA 5042

Dear Professor MacDougall

The Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC EC00188) have reviewed and provided ethical approval for this amendment which appears to meet the requirements of the *National Statement on Ethical Conduct in Human Research.*

Application Number: OFR # 525.15 - HREC/15/SAC/516

Title: Examining mother and clinician perspectives of tertiary health responses for young children with complex feeding difficulties

Chief Investigator: Professor Colin MacDougall

This amendment approval does not alter the current SAC HREC approval period for the study: 18 April 2016 to 18 April 2020

Public health sites approved under this application: Flinders Medical Centre

The below documents have been reviewed and approved:

- Project Amendment form dated 10 October 2016
- Qualitative Application v3 dated October 2016
- Participant Information Sheet and Consent form - Clinicians v3 dated October 2016
- Participant Information Sheet and Consent form - Carers v3 dated October 2016
- Non-Participant Information Sheet and Consent form v2 dated October 2016
- Letter of Introduction – Clinicians v2 dated October 2016
- Letter of Introduction - Carers v2 dated October 2016
- Letter and Photo Reproduction Rights Form v2 dated October 2016
- Form for Withdrawal of Participation v2 dated October 2016
- Transcription Services Confidentiality Agreement Form

TERMS AND CONDITIONS OF ETHICAL APPROVAL
As part of the Institution's responsibilities in monitoring research and complying with audit requirements, it is essential that researchers adhere to the conditions below and with the *National Statement chapter 5.5.*

Final ethical approval is granted subject to the researcher agreeing to meet the following terms and conditions:

1. The approval covers the ethics component of the application. Please submit a copy of the approved amendment to the local RGO for acknowledgement
2. If University personnel are involved in this project, the Principal Investigator should notify the University before commencing their research to ensure compliance with University requirements including any insurance and indemnification requirements.
3. Compliance with the *National Statement on Ethical Conduct in Human Research* (2007) & the *Australian Code for the Responsible Conduct of Research* (2007).
4. To immediately report to SAC HREC anything that may change the ethical or scientific integrity of the project.
5. Report Significant Adverse events (SAE's) as per SAE requirements available at our website.
6. Submit an annual report on each anniversary of the date of final approval and in the correct template from the SAC HREC website.
7. Confidentiality of research participants MUST be maintained at all times.
8. A copy of the signed consent form must be given to the participant unless the project is an audit.
9. Any reports or publications derived from the research should be submitted to the Committee at the completion of the project.
10. All requests for access to medical records at any SALHN site must be accompanied by this approval email.
11. To regularly review the SAC HREC website and comply with all submission requirements, as they change from time to time.
12. Once your research project has concluded, any new product/procedure/intervention cannot be conducted in the SALHN as standard practice without the approval of the SALHN New Medical Products and Standardisation Committee or the SALHN New Health Technology and Clinical Practice Innovation Committee (as applicable) Please refer to the relevant committee link on the SALHN intranet for further information.
13. Researchers are reminded that all advertisements/flyers need to be approved by the committee, and that no promotion of a study can commence until final ethics and executive approval has been obtained. In addition, all media contact should be coordinated through the FMC media unit.

Yours sincerely

A/Professor Bernadette Richards
Chair, SAC HREC

Appendix 3: Clinician participant information and consent form

---

Participant Information Sheet/Consent Form

(for Clinicians)

Title: 'Examining carer and clinician perspectives of tertiary health responses for young children with complex feeding difficulties'

Researcher:
Ms Sandra Mortimer, School of Health Sciences, Flinders University
Ph: 72218286 E: sandra.mortimer@flinders.edu.au
Supervisors:

Professor Colin MacDougall, School of Health Sciences, Flinders University
Ph: 72218412, E: colin.macdougall@flinders.edu.au
Dr Jessie Gunson, School of Health Sciences, Flinders University
Ph: 8201 7646, E: jessie.gunson@flinders.edu.au
Dr Brian Coppin, Flinders Medical Centre
Ph: 8204 4459, E: brian.coppin@sa.gov.au

Location: Flinders Medical Centre

Part 1 What does my participation involve?

1 Introduction

You are invited to take part in this research project, which is called *'Examining carer and clinician perspectives of tertiary health responses for young children with complex feeding difficulties'*. You have been invited because you are a member of the Flinders Medical Centre Paediatric Feeding Assessment Team.

This Participant Information Sheet/Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to be involved in the research described
- Consent to the use of your personal information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2 What is the purpose of this research?

Description of the study:

This study will examine both carers' and clinicians' perspectives of the tertiary health service responses for young children with complex feeding difficulties to gain a deeper understanding of the issues involved. Your opinion and perspective will be valued and respected and you will have opportunities to confirm and shape the direction of the research. This project is supported by Flinders University Discipline of Public Health.

Purpose of the study:

This project aims to understand more about how services for young children with complex eating difficulties are developed, delivered and responded to in a hospital setting by examining carers' and clinicians' perspectives. It aims to look at how eating issues are considered and understood by both carers and clinicians and the ways this may affect how clinical recommendations are developed and delivered by clinicians and responded to and implemented by carers. Findings from both clinicians and carers will help inform thinking about how health service experiences can promote better health.

The results of this research will be used by the researcher, Sandra Mortimer, to obtain a Clinical Doctorate in Public Health degree.

3 What does participation in this research involve?

What will I be asked to do?

You will be asked to take part in one in-depth interview; observations in your workplace in either a clinic, individual or group session and one final group feedback session. In terms of the time commitment, the in-depth interview will be at the beginning of the research time period and be for approximately 60 minutes. The group session will be at the end of the research time period and will last approximately 60 minutes. Observations of clinic, individual or group sessions will be undertaken at your convenience and it is anticipated that these will not take up any additional time although some follow up email questions may result from these observations. All of these sessions will occur at your workplace. Your manager has given approval for these to be conducted during work time.

The interviews, observation and group session will be recorded using a digital voice recorder. Once recorded, the interview will be transcribed and stored as a computer file and then destroyed once the results have been finalised. This research project has been designed to make sure the researchers interpret the results in a fair and appropriate way and avoids anyone jumping to conclusions.

4 Other relevant information about the research project

This research is focussing on **Flinders Medical Centre Paediatric Feeding Assessment Team.** No other sites are involved. All clinicians working as part of this team are being invited to participate.

5 Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your relationship with Flinders University or Flinders Medical Centre.

6 What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research; however, possible benefits may include greater knowledge and insights gained from the opportunity to reflect on and share your experiences as a clinician working with young children with complex feeding difficulties. Collated and de- identified information gained from the perspectives of the carers will be provided to you. It is anticipated that this information will be helpful in planning and further developing your services for young children with eating difficulties. Sharing your experiences will provide valuable information about health services.

7 What are the possible risks and disadvantages of taking part?

The researcher anticipates few risks or discomforts from your involvement in this study.

If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the researcher.

8 What if I withdraw from this research project?

If you do consent to participate, you may withdraw at any time. If you decide to withdraw from the project, please notify a member of the research team before you withdraw. A member of the research team will inform you if there are any special requirements linked to withdrawing. If you do withdraw, you will be asked to complete and sign a ‘Withdrawal of Consent’ form; this will be provided to you by the research team.

If you decide to leave the research project, the researchers will not collect additional personal information from you, although personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected up to the time you withdraw will form part of the research project results. If you do not want your data to be included, you must tell the researchers when you withdraw from the research project.

9 Could this research project be stopped unexpectedly?

It is unlikely that this research project may be stopped unexpectedly. Possible reason for this may be: the researcher is unable to continue or there are substantial changes to the service.

10 What happens when the research project ends?

You will be provided with a written summary of the findings of the research project. This will form the basis of the discussion at the final group feedback session.

Part 2 How is the research project being conducted?

By signing the consent form, you consent to the research team collecting and using personal information about you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential. Any identifying information in the recordings of sessions will be removed and the typed-up file stored on a password protected computer that only the investigator, Sandra Mortimer, and the research team will have access to. Your comments will not be linked directly to you –pseudonyms will be used instead of real names. Findings will be reported in general terms and you will not be identified by your professional background. As you are a member of a small team however, it may be possible that your identity is able to be determined. As you will be taking part in a group session, while the researcher will respect confidentiality and anonymity, the researcher will have no control over other participants in the group. Verbal agreement will be gained between all participants that they will maintain the confidentiality of the discussion.

Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law. The personal information that the research team collect and use is from the interview and observation transcripts.

A professional transcription company will be involved in transcribing information from the interviews. The people involved will be asked to sign a confidentiality agreement which outlines the requirement that your name or identity not be revealed and that the confidentiality of the material is respected and maintained.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your express permission. In any published information pseudonyms will be used, findings will be reported in general terms and you will not be identified by your professional background.

In accordance with relevant Australian and/or South Australia privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

12 Complaints and compensation

If you suffer any distress or psychological injury as a result of this research project, you should contact the research team as soon as possible. You will be assisted with arranging appropriate treatment and support.

13 Who is organising and funding the research?

This research project is being conducted by Sandra Mortimer and supported by Flinders University. No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

14 Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC).

The ethical aspects of this research project have been approved by the Southern Adelaide Clinical Human Research Ethics Committee. This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

15 Further information and who to contact

If you are interested in being part of this research project or would like more information please contact: **Sandra Mortimer on ph 72218286 or email sandra.mortimer@flinders.edu.au.**

You can also contact the following people:

Research Supervisors:

Professor Colin MacDougall, School of Health Sciences, Flinders University
Ph: 72218412, E: colin.macdougall@flinders.edu.au
Dr Jessie Gunson, School of Health Sciences, Flinders University
Ph: 8201 7646, E: jessie.gunson@flinders.edu.au
Dr Brian Coppin, Flinders Medical Centre
Ph: 8204 4459, E: brian.coppin@sa.gov.au

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Complaints contact person

Name	*Paula Davies*
Position	*Manager, Office for Research*
Telephone	*8504 6061*
Email	*Health:SALHNofficeforresearch@sa.gov.au*

Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC name	*Southern Adelaide Clinical*
HREC Executive Officer	*Damian Creaser*
Telephone	*8204 6453*
Email	*Health:SALHNofficeforresearch@sa.gov.au*

Local HREC Office contact (Single Site -Research Governance Officer)

Name	*Dawn Jennifer*
Position	*Research Governance Officer*
Telephone	*8204 6139*
Email	*Health:SALHNofficeforresearch@sa.gov.au*

This research project has been approved by the Southern Adelaide Clinical Human Research Ethics Committee (Project number 525.15). For more information regarding ethical approval of the project the Executive Officer of the Committee, Damien Creaser, can be contacted by telephone on 8204 6285, or by email; damian.creaser@sa.gov.au

Thank you for taking the time to read this information sheet and I hope that you will accept this invitation to be involved.

Consent Form

Title: 'Examining carer and clinician perspectives of tertiary health responses for young children with complex feeding difficulties'

Researcher:
Ms Sandra Mortimer, School of Health Sciences, Flinders University
Ph: 72218286 E: sandra.mortimer@flinders.edu.au
Supervisors:
Professor Colin MacDougall, School of Health Sciences, Flinders University
Ph: 72218412, E: colin.macdougall@flinders.edu.au
Dr Jessie Gunson, School of Health Sciences, Flinders University
Ph: 8201 7646, E: jessie.gunson@flinders.edu.au
Dr Brian Coppin, Flinders Medical Centre
Ph: 8204 4459, E: brian.coppin@sa.gov.au

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project.

I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print)____

Signature __________________________ **Date** __________________________

Declaration by Researcher†

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher (please print)____

Signature ___________________________________ **Date** ____________________________________

† An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

Appendix 4: Carer participant information and consent form

Participant Information Sheet/Consent Form

(for Carers)

Title: 'Examining carer and clinician perspectives of tertiary health responses for young children with complex feeding difficulties'

Lay Title: 'Carer and clinician perspectives of hospital responses for young children with complex feeding difficulties'

Researcher:
Ms Sandra Mortimer, School of Health Sciences, Flinders University
Ph: 72218286 E: sandra.mortimer@flinders.edu.au
Supervisors:
Professor Colin MacDougall, School of Health Sciences, Flinders University
Ph: 72218412, E: colin.macdougall@flinders.edu.au
Dr Jessie Gunson, School of Health Sciences, Flinders University
Ph: 8201 7646, E: jessie.gunson@flinders.edu.au
Dr Brian Coppin, Flinders Medical Centre
Ph: 8204 4459, E: brian.coppin@sa.gov.au

Location: Flinders Medical Centre

Part 1 What does my participation involve?

1 Introduction

You are invited to take part in this research project, which is called *'Examining carer and clinician perspectives of tertiary health responses for young children with complex feeding difficulties'*. You have been invited because you are a carer of a child who is involved with the Flinders Medical Centre Paediatric Feeding Assessment Team.

This Participant Information Sheet/Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local health worker.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to be involved in the research described
- Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2 What is the purpose of this research?

Description of the study:
This study will examine both carers' and clinicians' perspectives of the tertiary health service responses for young children with complex feeding difficulties to gain a deeper understanding of the issues involved. Your opinion and point of view will be valued and respected and you will have opportunities to confirm and shape the direction of the research. This project is supported by Flinders University, Discipline of Public Health.

Purpose of the study:
This project aims to understand more about how services for young children with complex eating difficulties are developed, delivered and responded to in a hospital setting by examining carers' and clinicians' perspectives. It aims to look at how eating issues are considered and understood by both carers and clinicians and the ways this may affect how clinical recommendations are developed and delivered by clinicians and responded to and put in place by carers. Findings from both clinicians and carers will help inform thinking about how health service experiences can promote better health.
The results of this research will be used by the researcher, Sandra Mortimer, to obtain a Clinical Doctorate in Public Health degree.

3 What does participation in this research involve?

This research involves three parts. You can choose to be involved in all three parts or just start with part one and see how it goes from there. The three parts are as follows:

Part 1: Is an in-depth interview that will take about 60 minutes and will ask questions of you about your experience of having a child with complex feeding difficulties; what it is like for you as a carer and your experiences of the services you have encountered through Flinders Medical Centre including those provided by the Paediatric Feeding Assessment team, speech pathology, occupational therapy, dietetics and paediatrics. At this first interview you will be asked to bring up to four photographs that help provide a picture of what it is like for you to have a child with complex eating difficulties. These photos will then be used as a discussion place to start talking about these issues. You can choose any photographs you like and you can also choose not to bring any photographs. The first interview will be held in a location and at a time of your choice. It is fine to be in your home and with your child/ren around. If, however, you would prefer to talk without your child/ren being present, a suitable time and location to make this possible can be negotiated.

Part 2: Is an observation session in your home of a mealtime experience with you and your young child. This observation will allow the researcher to gain even more information about your experiences and will help to form more specific and meaningful questions that will be asked of you in a second interview either immediately after the meal or at a time and location of your choice soon after the observation. Photographs may be taken during this mealtime to help us remember what happened and to encourage discussion in the follow up interview. You will be involved in choosing if any photographs are taken. The follow up interview will last for approximately 60 minutes and can be in a location and at a time of your choice.

Part 3: The final part of the study is another shorter interview where a written summary of findings based on the interview and observations will be presented back to you for you to check and make sure it represents you and your experiences. You will have the opportunity to offer any last information. This would last for approximately 30 minutes.

The interviews and observation will be recorded using a digital voice recorder. During the interviews and observations the researcher may make some notes and may ask questions for clarification purposes. Any notes taken or recordings will be made available on request.
You can refuse to have photographs taken or used.

Once recorded, the interview will be transcribed and stored as a computer file and then destroyed once the results have been finalised. This research project has been designed to make sure the researchers interpret the results in a fair and appropriate way and avoids anyone jumping to conclusions.

4 Other relevant information about the research project

This research is focussing on **Flinders Medical Centre Paediatric Feeding Assessment Team.** No other sites are involved. All English speaking carers of young children who have involvement with this team are being invited to participate.

5 Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. You can choose to only be part of the first part of the project.
If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your relationship with Flinders Medical Centre or any services that you receive.

6 What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research; however, possible benefits may include the opportunity to reflect on and share your experiences as a carer of a young child with complex feeding difficulties. People in similar situations to you have reported finding the experience of being involved in such a study to be a positive one. Collated and de- identified information will be provided to the clinicians at Flinders Medical Centre Paediatric Feeding Team. It is anticipated that this information will be helpful in planning and further developing services for young children with eating difficulties.
There is no payment for your involvement in this study but a small token of appreciation will be provided following completion of part three of the study to thank you for your time and acknowledge the inconvenience this may have caused you.

7 What are the possible risks and disadvantages of taking part?

The researcher anticipates few risks from your involvement in this study. Talking about your experiences, however, may bring up strong feelings. If you become distressed as a result of this, the interview or observation can be ended and you will be supported and offered options for seeking free counselling and support. Your wellbeing and that of your child will be of utmost importance throughout this study.
If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the researcher.

8 What if I withdraw from this research project?

If you do consent to participate, you may withdraw at any time. If you decide to withdraw from the project, please notify a member of the research team before you withdraw. A member of the research team will inform you if there are any special requirements linked to withdrawing. If you do withdraw, you will be asked to complete and sign a 'Withdrawal of Consent' form; this will be provided to you by the research team.
If you decide to leave the research project, the researchers will not collect additional personal information from you, although personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected up to the time you withdraw will form part of the research project results. If you do not want your data to be included, you must tell the researchers when you withdraw from the research project.

9 Could this research project be stopped unexpectedly?

It is unlikely that this research project may be stopped unexpectedly. Possible reason for this may be: the researcher is unable to continue or there are substantial changes to the service.

10 What happens when the research project ends?

You will be provided with a written summary of the findings of the research project. This will form the basis of the discussion at the final short interview session**.**

Part 2 How is the research project being conducted?

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential. Any identifying information in the recordings of sessions will be removed and the typed-up file stored on a password protected computer that only the investigator, Sandra Mortimer, and the research team will have access to. Your comments will not be linked directly to you –pseudonyms will be used instead of real names. Findings will be reported in general terms. The members of the Flinders Medical Centre Paediatric Feeding Assessment Team will not know if you are a participant in this research, however it may be possible that due to your unique circumstances, the clinicians can identify you from the collated information. If you have concerns about this please discuss it with the researcher. Should I wish to use any of the photos that have been taken during the research project for presentations, reports or publications about the study I will contact you first to seek permission. You will have the opportunity to request that any or all of the photos taken are not used in presentations, reports or publications if you prefer.

Information will be kept in strictest confidence throughout the research process. The only exception to this would be if during the course of the study the researcher has reason to believe a child is at risk. The researcher is a mandated notifier which means they have an obligation to report any instances of suspected child abuse or neglect. The researcher must also comply with Information Sharing Guidelines and so if I witness any feeding practice that is harmful or places your child at risk I am obliged to inform the medical treating team.

Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law. The personal information that the research team collect and use is from the interview and observation transcripts.

A professional transcription company will be involved in transcribing information from the interviews. The people involved will be asked to sign a confidentiality agreement which outlines the requirement that your name or identity not be revealed and that the confidentiality of the material is respected and maintained.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your express permission. In any published information fake names will be used and findings will be reported in general terms.

In accordance with relevant Australian and/or South Australia privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

12 Complaints and compensation

You may feel some distress from participation in this study. If this occurs you may withdraw from this study if you wish and your care will not be affected in any way. By participating in this study you do not give up any of your legal rights. If you suffer any distress or psychological injury as a result of this research project, you should contact the research team as soon as possible. You will be assisted with arranging appropriate treatment and support.

13 Who is organising and funding the research?

This research project is being conducted by Sandra Mortimer and supported by Flinders University. No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

14 Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the Southern Adelaide Clinical Human Research Ethics Committee. This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

15 Further information and who to contact

If you are interested in being part of this research project or would like more information please contact **Sandra Mortimer on ph 72218286 or email:** sandra.mortimer@flinders.edu.au**.**

If you have any problems which may be related to your involvement in this project, complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you can contact the researcher, or any of the following people:

Research Supervisors:
Professor Colin MacDougall, School of Health Sciences, Flinders University
Ph: 72218412, E: colin.macdougall@flinders.edu.au
Dr Jessie Gunson, School of Health Sciences, Flinders University
Ph: 8201 7646, E: jessie.gunson@flinders.edu.au
Dr Brian Coppin, Flinders Medical Centre
Ph: 8204 4459, E: brian.coppin@sa.gov.au

Complaints contact person

Name	*Paula Davies*
Position	*Manager, Office for Research*
Telephone	*8504 6061*
Email	*Health:SALHNofficeforresearch@sa.gov.au*

Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC name	*Southern Adelaide Clinical*
HREC Executive Officer	*Damian Creaser*
Telephone	*8204 6453*
Email	*Health:SALHNofficeforresearch@sa.gov.au*

Local HREC Office contact (Single Site -Research Governance Officer)

Name	*Dawn Jennifer*
Position	*Research Governance Officer*
Telephone	*8204 6139*
Email	*Health:SALHNofficeforresearch@sa.gov.au*

This research project has been approved by the Southern Adelaide Clinical Human Research Ethics Committee (Project number 525.15). For more information regarding ethical approval of the project the Executive Officer of the Committee, Damien Creaser, can be contacted by telephone on 8204 6285, or by email; damian.creaser@sa.gov.au

Thank you for taking the time to read this information sheet and I hope that you will accept this invitation to be involved.

Consent Form

Title: 'Examining carer and clinician perspectives of tertiary health responses for young children with complex feeding difficulties'

Researcher:
Ms Sandra Mortimer, School of Health Sciences, Flinders University, Ph: 72218286, E: sandra.mortimer@flinders.edu.au

Supervisors:

Professor Colin MacDougall, School of Health Sciences, Flinders University, Ph: 72218412, E: colin.macdougall@flinders.edu.au

Dr Jessie Gunson, School of Health Sciences, Flinders University, Ph: 8201 7646, E: jessie.gunson@flinders.edu.au

Dr Brian Coppin, Flinders Medical Centre, Ph: 8204 4459, E: Brian.Coppin@sa.gov.au

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this full research project as described and understand that I am free to withdraw at any time during the project without affecting my future care. I agree that this consent also covers my child.

I understand this research takes part in 3 parts;

- **Part 1: In-depth interview**
- **Part 2: Observation session in my home followed by a second interview**
- **Part 3: Final short summary interview**

I indicate my consent by ticking the parts I agree to participate in as follows:

☐ **Part 1 only**
☐ **Part 1 at this stage but am willing to consider the other steps after Part 1**
☐ **Parts 1, 2 and 3**

I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print)____

Signature ____________________________________ **Date** ____________________________________

Declaration by Researcher[†]

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher (please print)____

Signature ____________________________________ **Date** ____________________________________

[†] An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

Appendix 5: Briefing document to help inform the redesign of the paediatric clinic waiting room

18th April 2017

Briefing Document regarding Flinders Medical Centre Paediatric Clinic Waiting Room

For the attention of Dr Brian Coppin, Clinical Director, Dept. Paediatrics and Child Health, Flinders Medical Centre

Prepared by: Sandra Mortimer, Doctor of Public Health candidate, Course Coordinator and Lecturer in Occupational Therapy, School of Health Sciences, Faculty of Medicine, Nursing and Health Sciences, Flinders University, Telephone: (+61 8) 7221 8286, Email: sandra.mortimer@flinders.edu.au

Background Context

Over the past three months (September 2016 – March 2017) I have observed client and patient experiences in the Paediatric Clinic waiting room as part of my qualitative study examining carer and clinician perspectives of tertiary health service responses for young children with complex feeding difficulties. This study is being undertaken as part of a clinical doctorate in Public Health and has approval from Southern Adelaide Clinical Human Research Ethics Committee (project number 525.15).

A sensory ethnographic approach was taken. This type of research is able to provide rich, fine-grain evidence of people's lived experience that is often not able to be achieved through surveys or interviews. I sat in the waiting room on twelve occasions varying in times from 10 to 40 minutes and observed and took notes on the experiences that unfolded while waiting for my participants to attend their various clinic sessions. Particular attention was paid to sensory aspects including the sounds, smells, feel, sights and the interactions.

Waiting rooms are important gateways to clinical services within hospitals. It is known that paediatric waiting rooms in particular have specific challenges, requirements, and functions (Sherman, Shepley, & Varni, 2005). Waiting room experiences can affect perceptions of the quality of care received and satisfaction with care. While the physical environment impacts on children and carer experiences, the social interactions and communication with and between staff and patients are also very important.

Observations

In the Flinders Medical Centre (FMC) Paediatric Clinic waiting room carers invariably arrived looking harassed, flustered and commented on the difficulties of finding a car park. Many arrived apologising for being late. Carers could then typically be divided into two groups; veterans and newcomers. Veterans could be distinguished by their world- weary, resigned expressions; they came prepared with prams packed with books, food, drinks, toys, entertainment for their children and themselves. They sat patiently with a sense of expectation that they were in for a long wait. The children knew the ropes and either sat passively with their carer/s or went to explore the toys on offer.

Newcomers looked more nervous and unsure, frequently looking around the room, responding to each door opening and each loud sound. They appeared on high alert, looking for cues to decipher the code of how this new world worked. Children stayed closer to carers or tugged carers toward the toys. These carers became noticeably more anxious as they waited and the children frequently became fractious and more demanding.

Toys were readily available in the waiting room and all appeared in good condition. They appeared to be interesting for children and of a developmentally appropriate range. The toys were available at a central, accessible point. Small tables and chairs in the middle of the adult seats facilitated children choosing and bringing toys back closer to carers. Books were also easily available. The condition of the books was more variable with some missing pages or components. Carer resources were available in the form of magazines, information pamphlets and flyers advertising courses. Most carers were observed to engage with their mobile phones while waiting.

Overall, the physical environment of the waiting room appeared somewhat dated and muted. There was very little colour or appeal for young children. Those features that had a child focus eg the superman needed updating. The toys were of excellent quality within the waiting room but there were very few toys within the clinic rooms and those that were there were often missing key components eg a hammer toy without the hammer.

Attendees of the Paediatric Feeding Clinic had some specific needs. They often needed to tube feed their children following the session. There was no private space for this to occur and carers were observed to perch awkwardly on the chairs in the noisy waiting room trying to feed their child. This involved either gavage feeding or connecting to a pump. These attendees also needed to weigh their children each visit and this experience frequently evoked fear and distress in the children and anxiety in the carers. It was observed on a number of occasions and with different families that this was initiated within the general clinic room and therefore publicly witnessed. Carers and children then went with the nurse to a separate weighing room from where the cries of the child would sound around the whole waiting room. The carer and child would then emerge back into the public space to try to settle and recover before their session visit. Carers in my study reported finding the process of weighing their child in this situation extremely difficult and stressful.

Overall, the clinic conveyed a sense of busyness and bustle with much going on behind closed doors. Often sounds of distress (children yelling or crying) would emanate from these closed doors further adding to a sense of anxiety within the waiting space. Signs on walls stated; ‘no nuts’, ‘no eating or drinking’, ‘children in this clinic may have allergies’. There were no signs welcoming the attendees or indicating the expected wait time. Individually each specialist using the clinic welcomed and farewelled their clients. However, it was observed that there was limited welcoming or farewelling of attendees by the clinic administrative or nursing staff. The feel of the clinic changed dramatically depending on which staff were in attendance. One particular nurse stood out as being welcoming and supportive and when she was on duty the clinic had a more relaxed feel with carers and children tending to talk to each other more. This nurse noticed when carers or children appeared worried or were in need of something. She was frequently observed to individually check in with everyone in the waiting room. She found the additional coloured pencils, chatted to older children who were waiting for their younger siblings and carers and checked in with attendees offering a smile and greeting. On days when this level of engagement, attention and responsiveness was not in evidence the attendees appeared more anxious, did not interact with each other and there were more examples of tension, for example, carers becoming cross or impatient with their children’s behaviour and children being less cooperative.

Recommendations:

- As well as the physical aspects of the waiting room environment, consideration also be given to a focus on the social and relational aspects of the waiting room experience.
- Evidence and principles regarding designing children’s waiting and health care spaces be consulted and considered.
- Staff and clients (carers and children) be involved in generating ideas for updating and renovating the waiting space.
- Staff and clients (carers and children) be involved in a process for considering the social and relational aspects of the waiting room experience.

Some specific suggestions based on my observations include:

- The literature be consulted in regard to specific design principles including consideration of noises levels, use of music, incorporation of nature, consideration of colour schemes and opportunities for perceived control.
- Updated colour scheme for waiting room.
- Each clinic room to contain a box of toys with a range of ages or toys to be stored in a central place in age range boxes so clinicians can easily access appropriate toys.
- Welcoming and positive posters and images of a diverse and inclusive range of children and families be displayed in the waiting room.
- Staff be encouraged to welcome attendees and form a connection with them as they enter the space. Particular attention be paid to new attendees. This could be done by way of a personalised spiel that explains the expected waiting time for today's session, orients them to the room and includes use of toys, access to toilet, seeking help if needed. The purpose of this spiel is to connect with the attendees and reduce their level of anxiety.
- Staff be encouraged to check in with attendees during their time waiting and to farewell them more actively as they leave.
- Consideration be given to a private and comfortable space for breast, bottle or tube feeding children.
- Consideration be given to a separate space for negotiating the pre and post weighing stress. Information being provided to carers about what to expect and how to support their child during this process with a focus on the importance of emotionally supporting a child through such an experience and ideas of ways to do this.

The following resources and references may be useful to support ongoing work in this space:

Sherman, S. A., Shepley, M. M., & Varni, J. W. (2005). Children's environments and health-related quality of life: Evidence informing pediatric healthcare environmental design. *Children Youth and Environments*, *15*(1), 186-223. Retrieved from: http://www.jstor.org/stable/10.7721/chilyoutenvi.15.1.0186

Lipschutz, L. (2015). Top 10 Considerations for Designing a Pediatric Waiting Room. Retrieved from: file:///D:/Research/Briefing%20Document/Top%2010%20Considerations%20for%20Designing%20a%20Pediatric%20Waiting%20Room%20_%20Array%20Architects.html

Simpson, J. (2011). Seven Qualities of Excellent Pediatric Waiting Rooms: Does Yours Measure Up? Retrieved from: http://www.kidspaceinteriors.com/KidSpace/Pediatric-Waiting-Room.html

Appendix 6: Process for clinic observations and post-observation follow up

Process for Observations of Clinicians

- Get permission – consent form signed
- Record – audio recorder
- Take notes

Following session:

- Write field notes
- Note any challenging issues or tension points
- Summarise – 2 key points from the session for follow up with clinicians

Post Observation follow up:

Follow up with clinicians post observation to gain their perspective of that session. Either in person or by phone or email.

Ask the following quick questions:

1. Was this a typical session?
2. What challenges did they experience?
3. What were the positive moments they noticed?
4. I noticed /was really interested in (key observation 1…). Can you tell me more about what was going on there?
5. I noticed /was really interested in (key observation 2…). Can you tell me more about what was going on there?

Appendix 7: Interview question guides

INITIAL SEMI STRUCTURED INTERVIEW QUESTIONS WITH CLINICIANS

Thank you for your time today. Ok to audio record. Explain process re transcribed professional. Confidentiality agreement. De- identified. Won't be referred to by gender, profession or name. Findings will be reported on in general terms.

I'm interested in your experiences as a clinician working with young children with complex feeding difficulties

1. How long have you worked in this area?
   - Has this been an area of particular interest for you? Why?
   - Do you have children of your own?

2. What things do you think contribute to young children developing feeding difficulties?
   Prompts: Are there any other….social, family, physical, environmental, individual factors?

3. What makes up a complex feeding difficulty? What makes them so complex?

4. What informs your thinking and clinical decision making about this area of practice?
   What do you call upon…? (– knowledge, expertise, experiences, evidence – personal, clinical)

5. Tell me about how you work with young children with feeding difficulties? (pragmatics ie details of services and approach to families and approach to children)

6. How do you see your role?

7. What works in your practice with families with complex feeding difficulties? (successes)

8. What doesn't work? Where do you get stuck? (frustrations)

9. How do you come up with clinical recommendations/suggestions/homework?
   - Prompts: what knowledge ,skill, training do you call upon

10. How do you know what works and what doesn't?

11. Tell me about the shining moments in your work?

12. Tell me about the frustrations and disappointments in your work?

13. What do you think are some of the barriers for families engaging in this service?

14. If money and time were no object how would you ideally like to work with this group? Why?

15. What stops you from doing that?

16. What would be a good session and time to observe your practice to get a deeper insight into the way you work?

Thank you for your time

INITIAL SEMI STRUCTURED INTERVIEW QUESTIONS WITH CARERS

Consent forms, audio, confidentiality, Record and back up with phone

I'm really interested in hearing about your experiences as a mother of a young child with complex feeding difficulties generally and also about your experiences with the services at PFA clinic and team at FMC.

1. Were you able to bring in any photos? If so... I'd love to see them to get an idea of what this issue is like for you. Can you tell me about these photos? So why did you choose these?
   If not..Can you paint me a picture of /what does a typical day in your household look like?

2. Perhaps let's start with you telling me about your child…
   (prompts; age, diagnosis, time spent in hospital, problems…)

3. What's it like to be *Child's* mum/dad/carer?

4. What things do you think have contributed to *Child* developing these feeding difficulties? (Prompts: Are there any other….social, family, physical, environmental, individual factors?)

5. What do you think makes up a complex feeding difficulty? What makes them so complex?

6. Are there any particular sources of information that you have found helpful in making sense of what goes on for *Child?*

7. What do you call upon in making sense of what goes on for *Child?*
   (Explore for – knowledge, expertise, experiences, evidence)

8. Tell me about your experiences with FMC PFAT. (Clarify/refer to who has been seen and what sort of services. And over what time frame)

9. Tell me about their approach to families and children with complex feeding difficulties

10. How do you see your role in this? What is it like for you?

11. What works in their practice with families with complex feeding difficulties? (successes)

12. What doesn't work? (frustrations)

13. How do you respond to their clinical recommendations/ suggestions/homework? (easy/hard to do, realistic, does it make a difference? Why/ why not?)

14. How do you know what works and what doesn't?

15. Tell me about the shining moments in your life with *Child*?
16. Tell me about the shining moments in your "therapy" with *Child*?
17. Tell me about the frustrations and disappointments in your life with *Child*?
18. Tell me about the frustrations and disappointments in your "therapy" with *Child*?
19. I am interested in the difference between the feeding sessions when you are at the clinic or part of individual or group sessions and what it is like for you at home. Can you tell me what you think about that?
20. What do you see as some of the barriers to engaging with services for your child?
21. If money and time were no object how would you ideally like services to work with you? Why?

Clarify next step in Process. Different response if consented to Part 1 only (check willingness to be involved in Part 2). If full consent clarify re Observation and follow up interview

POST MEALTIME OBSERVATIONS SEMI STRUCTURED INTERVIEW QUESTIONS WITH CARERS

These questions will be recursively defined and will depend on the experience of the mealtime observation. These questions provide a guide.

Thank you for allowing me into your house. Can I just start by giving you a sense of what I noticed? Provide feedback and comments (eg how hard the mum works, how challenging it was, how much love comes through when you sit down as a family etc) to reassure the mother that I wasn't sitting in judgement and I did notice what was happening.

How typical a mealtime was that for you?

How much do you think my presence influenced things for your child, the rest of the family, you?

Some of the things I noticed and wondered about and wanted to ask you more about are….

If photos were taken use these as prompts to discuss and explore the topic more fully

Follow up questions based on observation

I am also interested in how different it is between the feeding sessions as part of the clinic or individual or group sessions and what it is like for you at home. Can you tell me more about that?

Are there any times when *Child* has eaten well?

What sense do you make of what goes on for *Child*?

These struggles over mealtimes – what do you think they are about? What goes on for you? What goes on for *Child*? What goes on for the rest of the family? Where does that come from do you think? What were mealtimes and expectations about eating like for you growing up? Wondering with process.

How do you think that is understood by the clinicians?

How hard or easy is it to put in place the recommendations/ suggestions/homework at home?

Do you think the clinicians know that?

What would you like them to know?

Clarify next step. Summary Interview –face to face if full consent, seek consent for summary interview if staged process.

Discuss phone and email options.

Appendix 8: Vignettes

These vignettes are based on the experiences of three carers in this study. These carers were chosen as they reflected a range of participants and experiences with the PFAT. They also represented different points along the carer's journeys through the health care system. Jane is a mother who worked fulltime while caring for her three children, her son had just successfully tube weaned, Rachel is a mother caring full time for her five children, her youngest twin daughter was still dependent on nasogastric tube feeding via a pump, and Fardin is a father from Bangladesh, who was a full time student in Australia and primary carer, his son had been successfully tube weaned for a few months. These vignettes were not intended to represent all of the experiences of the carers involved in this study.

Vignette 1: Jane and Jack

This vignette is written based on information gained from one in-depth interview, one inpatient tube wean observation, one home mealtime observation, three clinic session observations involving speech pathology, occupational therapy and dietetics, two PFAT clinic observations, one paediatric clinic waiting room observation, PFAT team meeting to discuss inpatient tube wean, and one follow up interview.

> *"It's just a basic - you know, you're supposed to be able to feed your child and your child's supposed to put on weight and grow... It's just a, you know, a basic thing with raising a child..."*

Jane works fulltime in a demanding role. Her husband also works fulltime. They have three children: five-year-old Grace and two-year-old twins, Jack and Emily. Jack was born with a rare condition; Russell-Silver syndrome (RSS). This syndrome effects growth rates both inutero and after birth. Babies with RSS have a low birth weight and often fail to grow and gain weight at the expected rate. The exact incidence of RSS is unknown but worldwide estimates range from 1 in 30,000 to 1 in 100,000 people. For Jack this means that he has had difficulty with feeding and putting on weight his whole life. His digestive system has difficulty processing food and he has little appetite. His head growth is normal while the rest of him is very small and thin. He has recurrent and frequent episodes of low blood sugar (hypoglycaemia) as a result of his feeding difficulties. RSS is also associated with an increased risk of delayed development, speech and language problems, and learning disabilities. So far none of these features seem to be impacting on Jack. He is a bright, sociable little boy, full of laughter and energy. Jane is a devoted mother, a staunch advocate, a woman whose 24-hour focus is the wellbeing of her son. She battles stereotypes of motherhood that make assumptions based on "the old fashioned, traditional way with the woman at home watching the children".

The journey to understanding what was going on for Jack was a slow and difficult one. He was not diagnosed with RSS until he was 19months old as he doesn't have some of the more obvious characteristics of RSS. The complexity of young children's feeding difficulties and the interplay of contributing factors compounded the process of diagnosis. Jack stopped growing in utero at 29 weeks resulting in an emergency Caesarean at 34 weeks. Both he and his twin sister, Emily, were tube fed via nasogastric (n-g) tubes from birth and both came home with them while they established sucking. Jane breast fed both the babies for their first 12 months. Jack was very slow to feed and to put on weight. Emily was able to come off her naso-gastric tube, but Jack still needed his. They were both breastfed, but Emily put on weight and Jack did not. Jane recalls this time as a focus on feeding, supplementing, measuring, weighing while trying to increase Jack's weight. They were being monitored through the neonate unit of WCH, and also through Child and Family Health service (CAFHS). Jane remembers being constantly asked about her milk supply despite the fact that she was feeding twins and Emily was putting on weight and growing well. This was one of the first indicators that when a child is not putting on weight the mother is the first "problem" to be explored. Jack was discharged from W&CH as he managed to achieve a satisfactory growth trajectory and Jane's older daughter, Grace, was undergoing surgery for hip dysplasia. But Jack's weight gain did not last long. Reflecting back on this experience, Jane felt that she was discharged too soon and without referral to a paediatrician or specialised support for ongoing monitoring. The monitoring was left to her, and with twin babies and a three year old with additional health issues, Jane feels that she did not monitor Jack's weight gain well enough. This is one of many sources of guilt that she experiences. Jack developed a respiratory infection and when they presented to FMC the hospital staff were really concerned with his weight and growth. They immediately wanted to admit him and insert another naso-gastric tube but for Jane this represented another long battle to wean him from the tube and so she resisted the idea. Jane's language regarding the naso-gastric tube shows the way in which it was perceived. She immediately focussed on how difficult it would be to "get rid of it".

She managed his weight gain through a now familiar process of monitoring and fortifying calorie intake and presenting regularly to outpatients. Her mother was dying in England and she took the twins with her to say goodbye to her mother. During this difficult time Jack lost weight and then on their return to Adelaide, Jack suddenly stopped breastfeeding. At the time he was eating solids. Jane recalls that while he was not eating as much as his twin sister, he was still eating a range of foods. Jane persisted with offering him her breast, but he refused to drink. His giving up breastfeeding appeared to throw this precarious balance out of kilter and within days he had his first episode of hypoglycaemia. Jane noticed he was cold and clammy, and she rushed him to FMC where he was immediately admitted and put on an naso-gastric tube. He was 14months old and this was Jane and Jack's first connection with the clinicians of the PFAT in the form of the paediatrician. As part of trying to work out what was going on for Jack during this admission, chromosome testing was completed. The results confirmed that Jack was in the seven to ten per cent of children with RSS who have two copies of Chromosome 7. For Jane this meant that he was on the milder end of the spectrum of issues that children with RSS can experience.

Jane sees herself as an advocate for her child. Having a child with a rare condition means that she is often working with health professionals who do not know about the condition and she has needed to educate herself so that she can educate them. She has joined Facebook groups and finds Facebook "an amazing resource… and really, really useful to be able to link up with other parents…" She is a member of a number of Australian and international Facebook groups related to RSS. Jane uses the connections she has through Facebook to get advice and support from other parents of children with RSS and says that it is particularly useful for reinforcing her own thinking and supporting her to take on or stand up to the medical world. She is connected to the MAGIC foundation, a parent run organisation who describe themselves as a global leader in endocrine health, advocacy, education, support, and events. They have produced a guidebook about RSS that she has found helpful. The Facebook groups are moderated by members of the MAGIC foundation and so Jane feels like they are credible sources of information. She is aware of the first international Consensus Statement regarding the diagnosis and management of RSS that was recently published in Nature. Jane has ensured the members of the PFAT are aware of and refer to this consensus statement.

Jane finds it incredibly frustrating to talk with people who do not consider her as the expert on her child and while she has mostly had positive experiences with FMC, and especially with the PFAT, she has had to advocate strongly for what she knows is right for Jack. An example of this was the inpatient tube wean experience where typically parents are advised to only offer 3 meals and 2 snacks per day and avoid allowing their child to graze. Jane was concerned that this would not work for Jack as RSS means he has low appetite and hypoglycaemia. She felt that she had to keep saying this and it was only because he had repeated hypoglycaemic experiences during the tube wean process that they really listened to her and sanctioned her choice to allow him to graze. This role of advocate has not come easily to Jane; "and that's hard for me because I'm not a naturally pushy person and I get, I get quite emotional when I have to be pushy..."

Not only has Jane had to take on this challenging and tiring role of advocate within the PFAT and FMC but also with WCH as many of the clinics and services that affect young children with CFDs are located there. Endocrinology and the metabolic unit is based at WCH, as is paediatric gastroenterology. They may have clinics at FMC but children can be seen more quickly through W&CH. Jane's experience though was that these WCH clinics were run by registrars who were much less likely to listen to her. Being the expert on your child is a double-edged sword. On one hand you want to be listened to, your ideas and opinions considered but Jane also has frequently experienced experts asking her what they should do or what she wanted from them.

For her this feels like an additional burden; she already carries the responsibility of feeding her child and the pressure of getting him to put on weight. She needs experts to listen to her and then make plans with her based on their knowledge and expertise. Services across two hospitals also means two different sets of medical records and in Jane’s experience neither were up to date. She becomes the carrier of current knowledge, the only person who has a complete set of information. This then adds to her frustration if she is not listened to.

Jane describes being Jack’s mum as a balancing act. She needs to balance the needs of Jack with the needs of her other two children. She needs to balance the needs of twins; one with feeding difficulties, one without. She is constantly balancing Jack’s calorie intake to maximise weight gain and frequency of meals to reduce the likelihood of hypoglycaemic episodes. On top of this, she balances the roles of mother and fulltime worker, mother and advocate and she balances the reality of life as a fulltime worker with three young children and the social expectations that come with being a mother including the pressure and expectation to eat healthy meals together as a family. Jane is ever mindful of the pressures and judgement associated with mothering a child who struggles to put on weight. She reflects on the relief of having one of the twins put on weight as it added concrete evidence that it was not something she was doing wrong. She often called upon her previous experiences of successfully ‘growing’ her older daughter as further proof of her competence. She expresses the pain of things not working for Jack, of having to go against her ideals of baby led weaning as she had to supplement Jack’s feeds in the desperate battle for weight gain. She describes a strong sense of blame, judgement and guilt. Parenting a child who has feeding issues and consequent growth issues is a challenging and draining task. The problem is very visible; the child is often very small and thin, they have a naso-gastric tube taped to their face. People can see that something is wrong. The thing that is wrong is a fundamental aspect of caring for a child, in Jane’s words; “It's just a basic - you know, you're supposed to be able to feed your child and your child's supposed to put on weight and grow... It's just a, you know, a basic thing with raising a child...” From this comes the judgement and the guilt. Prior to the tube wean Jane was always trying to get Jack to eat, and this meant eat anything, so that his weight and his blood sugar levels did not fall. She describes going out armed with arrowroot biscuits and packets of Cheezels (some of the few foods Jack would reliably eat) and being surrounded by mothers with young children with sultanas, sliced apple, and cheese sticks. She describes the frustration and exhaustion of feeling embarrassed and judged; “it’s constantly thinking somebody's judging you for what you're feeding your child.”

In one clear example of this judgement, staff at FMC made a mandatory notification to child protection services for her failing to take Jack to an appointment when he was “failing to thrive”. The police turned up at her husband’s door when she and the children were in England on the occasion of her mother’s death. This action was taken despite the fact that she was engaged in services, had rung to cancel her appointment, had explained the circumstances, and had rescheduled Jack’s appointment. Jane and her husband lodged a complaint which was successfully responded to, but from that time on she described herself as defensive in her involvement with health services. Her experiences of the PFAT clinics are coloured by this lens. While she herself did not feel judged by the team she was very aware that others may have done so. Having so many people in the room asking questions was an intimidating and overwhelming process to be part of. She also questioned the value of having the child present during the clinic session and for her that often meant the twins. She felt that she needed to juggle attending to her children’s needs, answering questions being asked by so many people and asking questions or making her points clear. It was **despite** the clinic processes and appointment format, not because of them, that Jane felt listened to, respected, and included as an important part of the team

In April 2017, four months post tube wean Jane and Jack attended a follow up session with the PFAT and he was declared an official graduate of the tube wean process. Jane reported on his progress; his increased interest in food, his ability to sit at the table with his siblings and out-eat them. His weigh-in results confirmed that he has successfully maintained his weight tube free. Jane reported that she had finally received approval through W&CH for Jack to start on growth hormone treatment to promote his growth and his ability to store glucose. There was a sense of joint celebration and shared delight in these successes. For Jane the tube wean was very significant. Jack had his naso-gastric tube in for 15months and Jane described that over this time she had to remove herself from the pain of dealing with it and just get on with it; the worry regarding night time choking, the constant discomfort she was sure Jack was experiencing, the flushing of the tube each evening, the regular taping, the frequent trips to hospital to replace the tube scheduled every six- eight weeks but happening more often as Jack would accidentally pull the tube out. Jane describes how she felt when the tube was finally removed and she saw him without it; "I just felt this huge rush of love". She was also convinced that having the naso-gastric tube in for so long contributed to his feeding difficulties, that he did not like the feel of eating with the tube in place. It took him 4-6 weeks to relearn how to eat but now he is eating a range of foods and showing no signs of difficulty with chewing or swallowing. The next challenge they faced was the nightly growth hormone injections and hoping that these work to increase his capacity to store glucose and reduce the need for 10pm corn starch supplements to prevent dangerous drops in his blood sugar levels (BSL) overnight. In the meantime, Jane continues to sleep on a futon in Jack's room so that she can monitor and respond to the first whimpers he makes that indicate he is experiencing a BSL drop.

Vignette 2: Rachel and Ellie

This vignette is based on information gained from one in-depth interview, two Paediatric clinic waiting room observations, two PFAT clinic sessions, two Dietitian session observations one Home Mealtime (MT) observation and follow up interview.

> *"And I think I cried the whole time I was feeding her. Because I just, like - I cannot believe she's eating."*

Rachel, her partner and their five children (James -9years, Katie - 5years, Brooke -2years, twins; Rosie and Ellie – 17months) live with her parents in a large house with separate sleeping and living zones and a shared kitchen. Rachel's parents offered for them to move in when she was pregnant with the twins. The decision was carefully considered and the process of how it would work was discussed prior to the move. It is an arrangement that seems to work well for all of them. Rachel's parents help out with the children, but they also have their own separate spaces and can retreat when they need their own time. They share household responsibilities with Rachel taking on the majority of the cooking. Both her parents work part time, her partner was in the process of setting up a new business and was away overseas for an extended period of time and Rachel cared for her family fulltime. Rachel believes living with her parents has been a really important factor in her ability to cope; "I think I've been able to stay a lot calmer and happier because I've been here. I think if I was on my own, I'd probably be losing my hair [laugh], very sleep-deprived and a little more irritated."

Rosie and Ellie were born 8 weeks premature and both needed naso-gastric (n-g) tubes to support their early feeding and weight gain. Rosie caught up quickly and was able to be discharged home after 6 weeks. Rosie "went straight forward, started finger food and started eating. She just went from strength to strength." Ellie was a different story. She was a lethargic baby with a limited suck reflex and a very sensitive gag reflex. Feeding took a long time and a lot of effort and then she vomited frequently and copiously. She developed oral thrush and that combined with reflux and vomiting lead to her developing a severe oral aversion. She wouldn't allow anything near her face or mouth and these factors all contributed to her developing a CFD and having to be fed via naso-gastric tube. Rachel reflected wistfully on the few images of Ellie without her tube; "We like when the photos were photos when the tube's gone." "She's never had it removed sadly". The only times Ellie's tube has been out have been when she or her siblings accidently pulled it out and it needed to be reinserted immediately via a trip to the hospital.

Ellie needed to stay in hospital an extra two weeks to stabilise her weight. Rachel reflects on this being the first of many difficult decisions she has had to make regarding her twin girls who are so very different. She received conflicting medical advice; some saying to take Rosie home and be with her three other children;

one doctor saying she needed to stay with Ellie or she would risk damaging their relationship. She made the hard decision to take Rosie home and visit Ellie as often as she could. This was also the first of many difficult decisions she has had to make regarding balancing the needs of one child with CFDs with those of her 4 other children. She remembers the challenges in trying to visit Ellie; she had to fit in around travel time and school and child care drop off and pick up times, crèche at the hospital was only available for 2 hours, the neonate hospital environment was not suitable for busy, active young children, she also needed to meet the needs of her other newborn baby Rosie. She experienced the pressure and expectation to be by her baby's side whilst struggling to juggle the demands of a young family. Each time she left she was asked if she was coming back. In her ever-positive way Rachel states: "Visiting was very hard. But we got in everything we could".

Rachel's first few months at home with Ellie were very stressful. Despite being a confident and relaxed 4th time mother Rachel rapidly realised that her well-developed skills and knowledge didn't apply to little Ellie. She found herself struggling to respond to the most basic needs of a baby; those of food and comfort. Ellie required a strict regimen of pump-based tube feeding to maintain her weight but this had to be closely monitored and precariously balanced to avoid triggering vomiting. This has meant very slow feeds; "the two-day feeds are about an hour, but the night feed goes for 11 hours……with me changing it twice." She is on a special thickened formula that lasts only 4 hours and tends to clog in the tube requiring regular flushing. Ellie's sensitivity to vomiting means that once she has finished an hour-long tube feed, she needs to remain still in a reclined position for a further hour. Ellie's life is strictly scheduled around these slow feeds and post feed restrictions;

> *Most of it two, two and a half hours she's in the chair, and then she comes back out, and by the time she's had a play, we've had a bum change, we've had a feed, we've done that, she's back in for another two and a half hours… It's been hard. And then at night-time, she's just started to get going and we've had to put her in her cot. And she'll squirm and worm in there sometimes up to an hour. She won't sleep, because she's still ready to go. But if I don't start her [on the pump] early enough and she wants to get up in the morning, she vomits if it's too early.*

Rachel has relied on television and music as a distractor to keep Ellie still during and after the feeds. It is a constant balancing act. The slower the feed goes in, the less likelihood of vomiting and the quicker she can move around after her feed. This would be difficult enough to manage with just one child. But Rachel has four other children whose needs have to be met. She keeps a spare car seat so she can quickly swap it over when Ellie inevitably vomits on the way to pick up her older brother and sisters from school and child care. She has become very creative with bedding design to minimise washing and changing in the middle of the night. Rachel's fear of triggering Ellie's vomiting is very real and informs many of her daily decisions. She is constantly calculating rates of flow, amount of formula and timing of feeds to optimise calorie intake and reduce vomiting risk. Initially this was all done in close consultation with the dietitian, but now Rachel makes these decisions with confidence and calls on the dietitian for advice when needed.

When I comment at her level of knowledge and skill, she reflects that it was not always so. She remembers being terrified; "I did a lot of panicking in the beginning not knowing what to do." She was often unable to stop Ellie crying because the very act of picking her up to comfort her would trigger her vomiting and her precious calories would be wasted. She was always aware of just how critical it was for Ellie to maintain her weight. Rachel reflected on how difficult it was in the first few months when Ellie was distressed and unable to be comforted; "any other kid, they scream; you shove a dummy in their mouth; you give them a bottle; you pick them up and you cuddle them. A lot of the time I have not been able to do that with her. If I pick her up early on, she would vomit straightaway. I couldn't cuddle her. I put her in bed. She's screaming at the top of her lungs. I go in there. I pat her head. I can't pick her up. She's on her feet. She's going to vomit. It's unsettling." Add to this the four other children including her twin, Rosie, also "wanting attention. The other kid's bringing homework home and the other one's tugging on my legs. It is a juggling act. To please everybody. And there have been times where I've just kind of wanted to go out the door and go, I'm not coming back in. Not going back in. And then you go, I've got to go back in.”

In the early months Rachel felt scared and alone and didn’t know how to get support. She tried her GP and the 24hour phone support lines but the specialised nature of CFDs and tube feeding meant she was always referred back to FMC and told to present to emergency. With four other children and working family members to consider she found the process of deciding if she needed to go to hospital and then actually having to present to the emergency department incredibly difficult. She had established a positive relationship with the dietitian but this person worked part time and not having access to her from Thursday to Monday was a challenging time for Rachel. Rachel feels strongly that a 24 hour contact point with supports who can access the specific details about her child and offer specialised advice and reassurance would have been very helpful for her;

> *… a point of contact, no matter what time of the day it was, even a call to say, look, my baby - I can't calm her down. This is what she's doing. Can you - what can I do? I don’t know what to do. I can't pick her up, because I'm worried she's going to vomit. She's at full pelt. She's waking the house up. I'm crying my eyes out and I don’t know what to do.*

Rachel’s early experiences with the neonatal services reflected times of worry and confusion. She felt that she was often provided with vague information about what was going on for Ellie and that there was a lack of follow up regarding referrals or investigations which resulted in her feeling increasingly anxious. She also felt that her experiences at home were not valued. Clinicians based their assessments on what they saw in the clinic rather than on what she told them had happened since her last appointment. If Ellie didn’t vomit in an appointment, the seriousness of her vomiting was dismissed, so much so that Rachel resorted to videoing what was going on at home and presenting this as corroborating evidence; “So I started saying, you know what? I'm going to show you what it's like [laughs]. Because you're not getting it. There's something not right, and I wanted them to investigate a lot”.

Rachel reflects on that time and wishes she had been told more clearly that there weren’t any definite answers, they will just have to wait and see, that she may grow out of it; “…getting that across is kind of where you stop mums from sending into that panic zone.” Rachel felt that she needed clearer information about what was going on and what the next steps would be. She didn’t find internet sources helpful and because Ellie didn’t have a specific condition contributing to her CFDs she wasn’t able to tap into support groups of other carers that she found relevant. She needed to rely on the clinical experts and needed to be kept informed and educated and she felt this happened when her care was transferred to the PFAT team. She felt respected and listened to. They were really interested in finding out about her child and what was going on for them as a family. They validated her role and the work she did and the progress she made. Rachel is very proud of the work she has done with Ellie and the progress she has made and it was really important to her to have this acknowledged and reflected back to her.

> *They wanted to know her specifically, which is what I liked. They weren’t looking at her as another baby with a tube. They were looking at what her issues were, where they'd arised [sic] from, what we were doing to help her with it… and how much she'd changed.*

Rachel felt that this was a reciprocal process; “I think that was my role, was teaching them about her …They were learning from me as well…” She took on the information from the clinicians and felt able to interpret and apply it at home even though she felt that they didn’t necessarily have a clear picture of what her home situation was really like. The process of mutual trust and reciprocity that was the basis of how the PFAT engaged with Rachel helped her feel empowered to understand and interpret what was going on for Ellie and to be able to try different things at home. She felt reassured, she started to understand the subtle cues Ellie was giving out, she developed strategies and skills in adjusting and balancing tube feeding and in introducing food and things started to settle down. “So I've - I've always felt that I'm able to take what they say, try it. If it doesn’t work, either change it or go back to them and ask for the next thing.”

Ellie is still tube fed and is making slow progress. Rachel clearly differentiates the process of feeding (the operations and mechanics of tube feeding) with that of eating and works with patience and persistence to build and encourage Ellie to eat. For her this means incorporating food ‘therapy’ into everyday life, gently offering new food options, making it fun, paying close attention to Ellie’s cues and never forcing her. Rachel remembers the shining moment when Ellie at 10 months of age ate her first mouthful of food; “And I think I cried the whole time I was feeding her. Because I just, like - I cannot believe she's eating.” Rachel’s story reflects the slow and unpredictable nature of CFDs. Things will go really well for a while and Ellie will explore new foods orally and increase the range of foods she eats. Then things deteriorate again; she becomes ill, her vomiting increases, she stops eating, she loses weight. Ellie is still dependent on the tube feeds for more than 80% of her calorie intake and until she can orally consume liquids and a much wider range of foods tube weaning will not be considered. Rachel worries about the implications of this but tries not to predict or hope too much. She actively works to take things as they come and keep her expectations realistic;

> *I think the thing that gets me through the most is I don’t look at it like it needs to be done. I look at it that it's going to get done, but we have to be patient. And I don’t get my hopes up. You know, when I first started doing this and they were all telling me, don’t get your hopes up. It's going to take time. I'm, like well, if she's different this time next year, I'm grateful for that. And, like, with this feeding thing, I said, you know, I'm grateful that it could happen, but I don’t expect it to happen this year. It'll happen next year.*

Rachel has built a caring and strong bond with little Ellie and is fiercely proud of what they have achieved together. She reflects that has been a two-way process and that they have both had a role to play in how things have gone. Rachel has taken the information and support she gained from the PFAT clinicians and mirrored this in her interactions with her family members and most especially Ellie. There is a strong sense that in being supported by the clinicians she has been able to support Ellie. Her final comment to me as I left after the interview highlights how important this is to Rachel; “ I’d like to find that doctor [who told her she would damage her relationship with Ellie if she took Rosie home and left Ellie in hospital] and say see- we don’t have a bad relationship- we have a great relationship!”

Vignette 3: Fardin and Nazir

This vignette is based on information gained from one in-depth interview, one PFAT Clinic session observation, one Paediatric clinic waiting room observation, one MT Observation and one follow up interview.

> *“He's gaining quite good. So that's the moment I feel like okay - probably the days are getting better for us so that's the moment actually I feel like okay, I feel better.”*

Fardin is from Bangladesh and has been living in Australia for the past four years while undertaking doctoral studies. His wife, Safina, is also from Bangladesh and is studying for her doctorate on a part time basis. They have 2 young sons, Nazir, 3 years, and Asif, 1 year, who were both born in Australia. They speak both Bengali and English as a family and live in a small rental unit. Fardin is a quietly spoken, warm and intelligent man and devoted father. He has applied his research skills and enquiring mind to try and fathom the puzzle that has been his son’s difficulties with eating and gaining weight. Fardin and Safina have shared caring responsibilities for their children but Fardin has taken the lead in interacting with health services for Nazir and has taken on most of the caring for Nazir since his brother was born. In Fardin's words, Nazir "is more attached to me. I mean he was attached to mum until brother was born, but after brother born he was more attached to me and I take care of him for feeding and playing, bathing and things. Actually we're both taking care of him, but he usually sleeps with me, prefer to have food with me and things like that."

Nazir was doing well for the first 6 months of his life. He was fully breast fed and his weight tracked along the 10th percentile but when solids were introduced and breast feeding reduced, he lost weight. He was never really interested in food and only ate very small amounts. He tended to only eat low calorie foods and didn't accept formula when it was introduced as a supplement. Fardin and Safina were busy juggling the demands of a young baby and their studies and did not have any meal time or bedtime routines established. They worked hard to get Nazir to eat, often distracting him with television or books as they offered food or milk or formula. Sometimes he would eat, often he wouldn't. He slowly but steadily lost weight and was admitted to FMC for the first time at 14 months of age. A naso-gastric (n-g) tube was inserted which Fardin described as "… very stressful. It was absolutely a very stressful event. We were crying and things like that." This prompted Fardin to contact his mother in Bangladesh for support and in talking with her he discovered that as a baby and young child he had also eaten very little and been very underweight. The equivalent medical services were not available in Bangladesh but Fardin's mother took him to see many doctors trying to work out what was happening for her son; "… they ended up a similar sort of answer. I mean I didn't have any medical condition or anything, but for some reason I was not taking food." Fardin reported that he remained very thin until well into college and that he still doesn't eat very much.

Fardin found it reassuring that his mother had been through a similar experience and that despite similar difficulties, frustrations and lack of answers, he had turned out just fine. His mother also offered him spiritual comfort and encouraged him to pray for support. Nazir quickly gained weight while being naso-gastrically fed but when the tube was removed, and he was discharged he rapidly lost weight again. This was to be a pattern for the next 18months. Fardin and Nazir met various PFAT clinicians individually and was working with them to understand what was going on for Nazir. Despite Fardin's best efforts to implement the feeding advice he was given regarding routines and types of foods; his experience was that sometimes Nazir would eat and sometimes he wouldn't. He also found it difficult to implement routines in his life. To be able to study effectively while supporting his wife in caring for two young children, Fardin relied on a highly flexible daily pattern which was incongruent with the strict mealtime and bedtime routines recommended by the PFAT clinicians. Nazir again lost weight, was admitted and a naso-gastric tube inserted. He rapidly gained weight and was discharged with the tube in place. This time he was to be tube fed overnight and to try to develop his food range and eating skills during the day. Even though the tube was confronting, and Nazir needed closer monitoring in case he pulled the tube out, Fardin felt relieved and more relaxed because he knew Nazir was getting the calories he needed during his overnight feeds. Nazir gained 1.5kgs in the 1 month he had the tube in place but again this was short lived.

As Nazir was able to gain weight, it seemed that he didn't have any problems with his digestive system and he could absorb nutrients. Investigations were conducted by the PFAT and nothing conclusive was identified. Frustratingly there seemed to be no obvious reason why Nazir continued to lose weight when not tube fed. For Fardin this was a very difficult time, he was juggling his study, his wife was pregnant, and he was struggling to understand what was going on. There was a huge focus on Nazir's weight, and this was all consuming, worrying, stressful and frustrating. Nazir developed a fear of the hospital and especially anyone in uniform as he associated them with the traumatic experience of having the tube inserted. He would cry, scream or withdraw when he needed to be in the hospital. On Nazir's third admission, Fardin worked with the PFAT clinicians as a team and underwent a structured inpatient tube wean process where the tube was removed, and his mealtimes were observed and supported by the team and specific advice was offered. This time Fardin stayed with Nazir because his second son had just been born. Fardin found this process really helpful in improving his understanding of how to deal with things;

> I mean they didn't give any magic or anything that actually helped. But the things actually worked better because - because they are working as a team and when they are talking on a particular issue, everyone is putting their own input. So it gives us a better understanding actually how to deal with that.

Fardin felt that the PFAT clinicians listened to him and worked with him to solve problems. They had particular advice they offered and sometimes this worked and sometimes it didn't but Fardin did not expect it to all apply to him; "… every kid is different so I shouldn't expect okay whatever they are saying this is like a bible." He felt able to exercise his own agency within the process of interacting with the PFAT. The team "…were actually trying to help us and they're trying to understand our frustrations actually. This is quite helpful".

Working with the clinicians and the tube weaning process in particular gave Fardin the confidence and determination to apply regular mealtime routines and introduce milk to Nazir. He slowly but surely introduced ever increasing amounts of cow's milk and linked it into his everyday routines. With perseverance Nazir started to accept cow's milk and now happily drinks milk twice a day; "I don't push him but gradually, gradually… It is working and he knows that okay this is my milk time so we used to say okay, it's milk now. He understands that."

For the past 8-9 months Nazir has maintained his weight without the tube. Fardin attributes this to two things; firstly, Nazir is slowly learning to eat food, have regular structure to his mealtimes and sit in a high chair to eat. Secondly, he is continuing to drink full cream cow's milk twice a day. Success was defined and reinforced by Nazir's weight gain; "so when actually he started gaining and maintaining his weight I feel a bit confident." Fardin's own feelings are closely linked to the weight gain of his son; "He's gaining quite good. So that's the moment I feel like okay - probably the days are getting better for us so that's the moment actually I feel like okay, I feel better." In reflecting back on this time and his role as a father, Fardin could see both the positive and negative aspects. He found solace in connecting with his own childhood story and the experiences his mother went through;

> Actually I feel like it's - I enjoy, but sometimes because of my workload and studies and everything sometimes it's stressful, especially when he was in the hospital. I was like - yeah, it was very hard, but because of the stories of my life - I mean I was a kid - like similar story - so I feel like okay, it's probably okay because my mum has gone through with similar experiences. So I feel like it is stressful but still I'm happy.

Fardin reflected on the differences between Australian and Bangladesh culture regarding children and food. In Bangladesh children are not expected to be independent in eating, to sit in a highchair and feed themselves. It is more likely that they will sit on an adult's lap and be fed. There are not set mealtimes; a child will be offered food when they appear hungry. Mothers are more likely to be fulltime carers of the children with extended family (grandparents, aunts, uncles, cousins) living in the same house and sharing care and responsibility for the children. Fardin considers that having more people to care for children is of benefit to their development and he has missed the involvement of extended family in his life in Australia; "I think for the development it is quite good. I mean from every prospect - from feeding, for other development, for learning, playing - it's good, but because we don't have an option for that there's nothing to do."

While Fardin feels like the cultural differences between Australia and Bangladesh are huge he is very clear that Nazir's feeding difficulties have not been related to cultural factors but have been based on medical issues. In trying to make sense of Nazir's feeding difficulties, Fardin has developed strong relationships with the PFAT clinicians and asked lots of questions. He attempted all that was asked of him while holding realistic expectations about what was possible given his family's circumstances. He frequently expressed frustration as to the lack of a clear medical explanation for his son's inability to eat and maintain weight but over the 2 years he has been on this journey and with things beginning to resolve for Nazir, Fardin appears to have been able to let this go. He more recently talks about multiple factors contributing to his son's CFDs including Nazir's behaviour, a possible genetic aspect and his and his wife's actions and responses. While not undermining the difficulties they have experienced, he expresses a philosophical view of his overall experience in coming to terms with Nazir's feeding difficulties; "I feel like this is more like a part of everyone's life. I mean people have a difficult time and over time it will go away and you'll have a better time."

Appendix 9: Example of WPR coding process

Example preliminary codes for document data analysis		
Code label	Description	Examples
Power evident	examples of authoritarian language, examples of hierarchy within health system, some people or information privileged over others	Doc 1 a) “they may be **required** to eat and drink throughout the assessment” Doc 1b) paediatrician only team member named Doc 1b) “so **we** can get the most out of this appointment”
Family inclusive	evidence of inclusion of family beyond parent/carer and child, evidence of the implications for the family, questions about the family	Doc 2 “and also an opportunity to set goals with the families of children”
Focus on parent/carer/	evidence of focus on parent/carer/s and their role, inclusion of parent/carer/s, evidence of the implications for the parent/carer/s, questions about the parent/carer/s	Doc 5 You and your child’s feeding journey
Child only	evidence of focus on child only, no mention of impact on family or parents/carers	Doc 1b) The Feeding Assessment Team (FAT) is for children with complex feeding disorders… Doc 2 assessing children with complex feeding disorders
Biomedical focus	evidence of focus on medical problems only, use of technical medical language when family friendly language could have been used, evidence of medical model influence	Doc 1c) All medical questions Doc 1c) “receiving medication for depression or has done so in the past” Doc 4 “current feed regime”
Emotional Focus	evidence of focus on emotional considerations, questions or information about emotional wellbeing and impacts	Doc 5 “a roller-coaster of emotions” “you may be feeling worried about going home, and confused about where to from here”
Social Focus	evidence of focus on social considerations, questions or information about social wellbeing and impacts	Doc 6 X no questions re attendance at kindy, school, or Child care
Lack of Diversity	language that reflects a lack of diversity in family make up, refers to parents, not carers, offers mother and father as only options, doesn’t reflect cultural or language diversity	Doc1b) “If you do not speak English, request an interpreter from SA Health and the department will make every effort to provide you with an interpreter in your language.” In tiny font at bottom.- No way to do this
Teamwork	evidence of team collaboration and shared decision making	Doc 2 Multi -disciplinary team incorporating a paediatrician, speech pathologist, dietitian and OT.
Severity messages	Language that emphasises severity of conditions, evidence of defining the problem as one of severity	Doc 2 “who have not responded to standard care”
X	Not present, or no evidence to support this not happening	

WPR CODING EXAMPLES

Examples of binaries in discourses:

- Success/failure
- Right /wrong
- Private/ public = parent/hospital

Examples of key concepts:

Health = physical health not holistic health encompassing mental health
Disorder – how does something come to be a disorder?
Feeding vs eating: doc1

Examples of categories:

- Mum/Dad vs carer

Effects:

Interconnected and overlapping

Discursive:

If the focus is on the child's physical health only what is overlooked?
Impact on family, carers, mothers especially, siblings

Subjectification Effects:

When families are from a different cultural background this is foregrounded as the issue: 'it's a cultural issue'. Eg Dad refutes that vs team buying into that. But with no exploration as to how might culture be impacting on this child and family's eating patterns?

Lived effects

Material impact of PR
Siblings and fathers emotional wellbeing and health
Ongoing impact of unaddressed trauma re relationship to food, to each other, to bodies

Applying initial codes in document analysis										
Document	Power evident	Family inclusive	Focus on parent/carer/s	Child only	Medical focus	Emotional Focus	Social Focus	Lack of Diversity	Teamwork	Severity messages
Doc 1a Appoint letter	"they may be required to eat and drink throughout the assessment"				A multi-d feeding Ax – what is that?	X	X	Dear Parent		
1b Info sheet	"so we can get the most out of this appointment" Power balance with the team" " you can expect to be seen by.." "May be allocated.." Teaching hospital, expect to see students, advise in advance – nothing re parents rights to say no on the day …requiring input from multiple	X expectation that alternative care will be arranged for other siblings, No invitation to bring along a supportive other		The Feeding Assessment Team (FAT) is for children with complex feeding disorders requiring input from multiple health professionals.	Paedn only one named	X No indication that requiring a child to eat in this session may cause stress for child and family. No consideration of name and impact	X	Can request an interpreter but no way to easily do this. In tiny font at bottom of page "If you do not speak English, request an interpreter from SA Health and the department will make every effort to provide you with an interpreter	X Reference to members of core team paed, SP, Dn and others- OT, Physio	complex feeding disorders

	health professionals Paedn only one named							in your language.”		
1c Questionnaire	No space to invite comments and gain agency of family Power and control sits with team – we will ask what is important	“It also asks about how your child’s feeding or medical problems may be affecting you, your child and your family” This is stated in the preamble but not actually done- no questions that address this		Purpose a picture of your child’s …	Pregnancy and birth history only asks about birth nothing about pregnancy All medical questions receiving medication for depression or has done so in the past NOT has experienced depression	X no opportunities to comment on how it was for the carer Y specific section on Q10. My levels of stress when trying to feed my child and at mealtimes: In general, the level of stress surrounding mealtimes in our house is…. First implies on the person filling in the form assumed to be ?, second part is more	X	More diverse parent or carer in intro but the only options are Mo and Fa for details Primary Caregivers for this child are: (i.e. parent, foster parent, relative, babysitter etc Stated but not followed through		

					defined by medical model receiving care for anorexia or any other type of eating disorder. NOT has experienced difficulties with easting and their relationship to food as an example	family inclusive but isn't what is asked to rate		Anyone in the household but then the options are Mo, Fa and other		
Document	Power evident	Family inclusive	Focus on parent/carer/s	Child only	Medical focus	Emotional Focus	Social Focus	Lack of Diversity	Teamwork	Severity messages
Doc 2	are generally viewed as elective admissions and as such are subject to cancellation if the ward is at capacity	..but rather a planning of therapy and also an opportunity to set goals with the families of children who have not	2 of 6 referral criteria focus on role of parent Patient-carer dyad has capacity to manage tensions /	The team provides a consultative service assessing children with complex feeding disorders and arranges suitable	complex feeding disorders	X	X	Y	Multi -d team incorporating a paediatrician, speech pathologist, dietitian and OT.	Complex, who have not responded to standard care. highly complex

	hierarchy of privilege: Referrals are only accepted from FMC paediatricians or paediatric allied health (GP referrals not accepted)- implications for family	responded to standard care.	change in feeding tasks Parent able to allow some autonomy on part of the child	therapy and intervention.						feeding disorders and tube dependent children.
Doc 3				Y	Y	X	X			
Doc 4				Y	Y Current feed regime	X	X			
Doc 5	We know from experience... The changes we have made.. power claimed by team no acknowledgement that we is a team of child, family and PFAT team		You and your child's feeding journey		Less here- eating is used more often not feeding	Feelings are acknowledged: a roller-coaster of emotions you may be feeling worried about going home, and confused about where to from here		Doesn't specify parent as Mo or Fa only, is more inclusive		

	The use of you in the next sentence, makes the previous we seem to be only about the team of health professionals									
Document	Power evident	Family inclusive	Focus on parent/carer/s	Child only	Medical focus	Emotional Focus	Social Focus	Lack of Diversity	Teamwork	Severity messages
Doc 6		X No information sought about family	X No information sought re parents other than name	Our Aim: To provide a team approach to the assessment and management of children with complex feeding difficulties.		Details of previous Axs from psychologists are requested	X Nothing re attendance at kindy, school, CC etc	X parents defined as Mo and Fa Aboriginal and Torres Strait Islander and GOM status requested Family court order interpreter required	To provide a team approach to the	with complex feeding difficulties

Applying WPR coding in document analysis											
Doc	Q1	Q2	Q3	Q4	Examples of binaries in discourses	Examples of key concepts	Examples of categories	Discursive Effects Q5	Subjectification Effects Q5	Lived effects Q5	Q6
Doc 1	A physical problem that effects a child’s ability to feed Problem resides with the child – all the questions focus on the child and are specific re problems not open ended to ask how did that go/? What was that like for you? Diminishes other constructio	Children have problems separate to a family, community Illness is a medical condition not a lack of health Health and wellbeing are not the focus Severity of issues sits with the amount and type of treatment rather than the impact on the family	Medical dominance	Emotional, social, Diverse family - parent only, NESB	1c Success/failure in breast and bottle feeding Only asking about the not successful experiences not asking re what went well	Feeding vs eating, Health as physical Languages changes in 1c between feeding and eating	Patient and their parent vs health professional – we will tell you what to do, Dictatorial language “they may be required to eat and drink throughout the assessment”	If the focus is on the child’s physical health only what is overlooked? Impact on family, carers, mothers especially, siblings If eating and depression are defined as medical illnesses requiring treatment and medication	Parents as responsible for this	Material impact of focus only on physical child	These docs are the first contact betw families and this team. Scene and culture and values are set through these 3 docs. Hospitals as ‘precious’ privileged places to be accommodated – power of the sickness system

	ns of the issue eg environmental, social etc	and community						who is missed?			
Doc	Q1	Q2	Q3	Q4	Examples of binaries in discourses	Examples of key concepts	Examples of categories	Discursive Effects	Subjectification Effects	Lived effects	Q6
Doc 2	Physical impact on child Parent has a role: defined as capacity to manage tensions/change in feeding tasks Able to allow some autonomy on part of child			How to assess Q1? Who determines		‘Allow autonomy in child’ ‘Capacity to manage tensions/change in feeding tasks’ Feeding tasks rather than support eating	Level of HPs – hierarchies eg GP lower than FMC AHPs		Parent s who can do as per Q1 will be ok Parents who are judged to be this way are responsible		
Doc 3	A medical process involving the physical child requiring medical and AH			No mention of psychologist or SW as part of team to be							

	intervention			notified re inpatient wean Nursing, OT,PT, Play therapist included							
Doc 4	A medical process related to Current feed regime										
Doc 5	This document creates the impression that a feeding difficulty effects more than just the child Has physical effects but also emotional implications for the parents and the family.	Doesn’t specify parent as Mo or Fa only, is more inclusive Journey with stops and starts, not a smooth road, Getting support for parents, time out, someone to talk to as a parent will help to	Invested team, lack of reflection time Situated within the Medical model trying to embrace a biopsychosocial model, medical domina	Missing the whole family and their agency in this. How can they be involved? What are their hopes and goals and dreams, how are they reflected here?		Languages changes to mostly eating Warmer more natural language					Handed directly to families after tube wean process

	It is a journey shared by parents/carer and child Eating and learning to eat is the focus – not feeding Team are running the show “we” as proprietorial rather than collaborative. We and you -Keeps the power balance with the team	support child’s eating. That parents will be able to get help, have someone they can talk to, have the capacity (social and financial and pragmatic) to be able to have “time out”. That the parent has the physical, mental, financial, social and emotionally resources to achieve this	nce. Team led by a paediatrician Funding models that pay for an occasion of service (requires a code, a label) not an outcome eg of a well child, a child with a healthy relationship to food								
Doc 6	A medical process involving the child happens in isolation to/separate from the			Family emotional or social contexts							

	family community context										

Appendix 10: Adapted WPR version for clinical practice

Analysing clinical practice: What’s the problem represented to be?

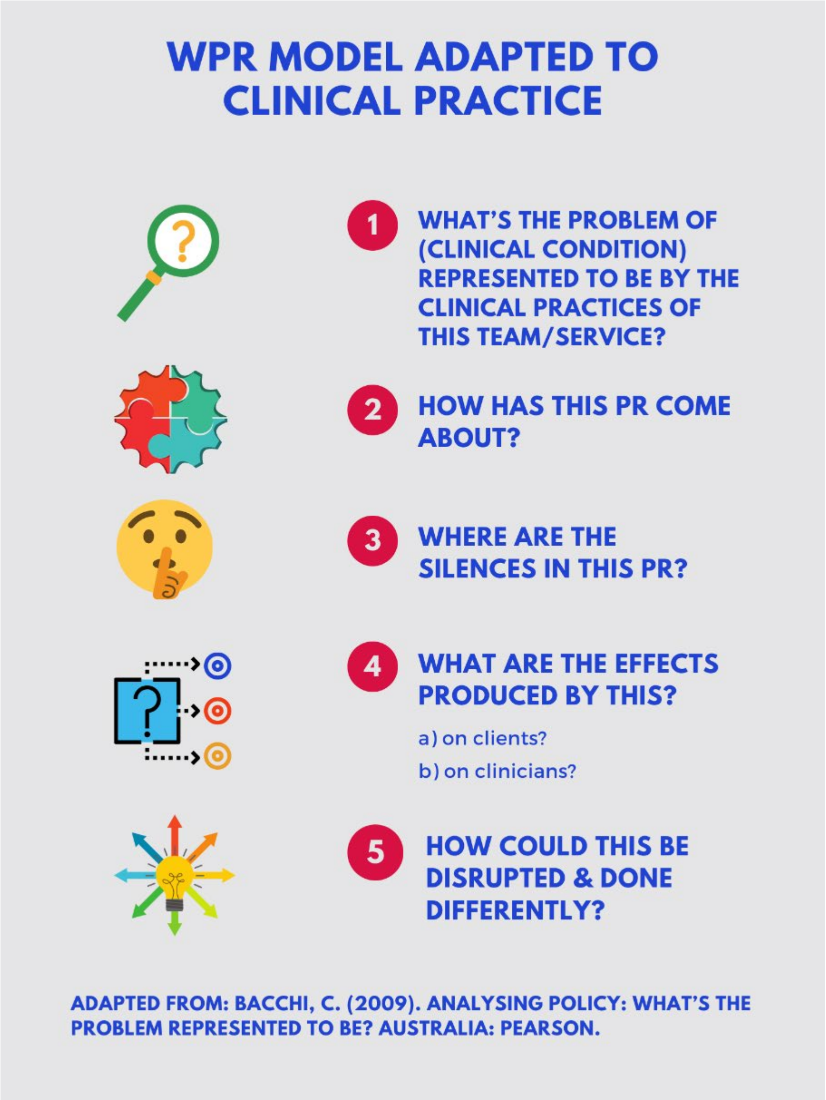
A proposed WPR version for clinical practice

SANDRA MORTIMER

ADAPTED FROM: BACCHI (2009)

Introduction

This document provides an explanation and guide to applying the adapted What's the problem represented to be? (WPR) model (Bacchi, 2009) to clinical practices. I developed this model as part of my clinical doctorate in Public Health. This model is adapted from Carol Bacchi's (2009) seminal work in policy analysis. In adapting this to clinical practices I have made changes to the language and simplified the questions. The following five questions have been adapted based on my doctoral research project. The aim of this approach is to support clinicians and managers to critically reflect on health care practices. This model provides a tool to structure a respectful and curious questioning of clinical practices through examining assumptions and broader structural influences that may be at play and the effects of these on both clients and clinicians. This is based on a poststructural theoretical approach that seeks to question, challenge, and disrupt and in doing so open new possibilities for health care improvement. These questions can be undertaken systematically or in an integrated fashion depending on the relevance for the clinical issue being examined. Question 2 is a more theoretical question and could either be completed as the second step, omitted, or completed at the end of the process. The details in this document explain each of these questions, their purpose and provide specific examples of what to look for and how to apply.



WPR MODEL ADAPTED TO CLINICAL PRACTICE

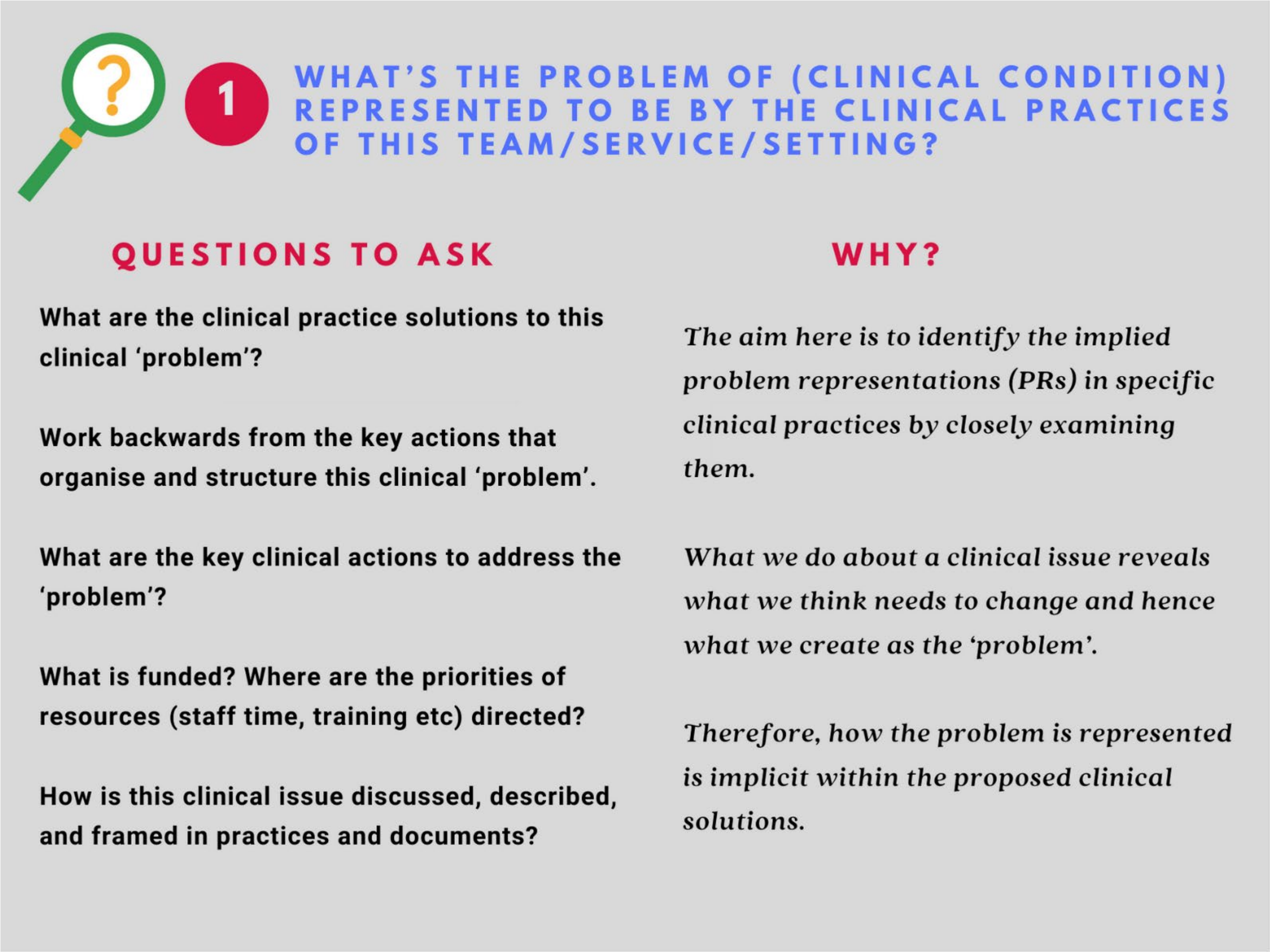
1. **WHAT'S THE PROBLEM OF (CLINICAL CONDITION) REPRESENTED TO BE BY THE CLINICAL PRACTICES OF THIS TEAM/SERVICE?**
2. **HOW HAS THIS PR COME ABOUT?**
3. **WHERE ARE THE SILENCES IN THIS PR?**
4. **WHAT ARE THE EFFECTS PRODUCED BY THIS?**
   a) on clients?
   b) on clinicians?
5. **HOW COULD THIS BE DISRUPTED & DONE DIFFERENTLY?**

ADAPTED FROM: BACCHI, C. (2009). ANALYSING POLICY: WHAT'S THE PROBLEM REPRESENTED TO BE? AUSTRALIA: PEARSON.

Explanation of terminology

Problematisation is the process by which something is put forward or created as a problem.

Problem representation (PR) is the implied problem in a problematisation.



1 WHAT'S THE PROBLEM OF (CLINICAL CONDITION) REPRESENTED TO BE BY THE CLINICAL PRACTICES OF THIS TEAM/SERVICE/SETTING?

QUESTIONS TO ASK

What are the clinical practice solutions to this clinical 'problem'?

Work backwards from the key actions that organise and structure this clinical 'problem'.

What are the key clinical actions to address the 'problem'?

What is funded? Where are the priorities of resources (staff time, training etc) directed?

How is this clinical issue discussed, described, and framed in practices and documents?

WHY?

The aim here is to identify the implied problem representations (PRs) in specific clinical practices by closely examining them.

What we do about a clinical issue reveals what we think needs to change and hence what we create as the 'problem'.

Therefore, how the problem is represented is implicit within the proposed clinical solutions.

2

HOW HAS THIS PROBLEM REPRESENTATION COME ABOUT?

QUESTIONS TO ASK

- **What key current and historical knowledges shape the ways this clinical problem is being thought about and responded to? Where does this come from?**
- **What broader policies, systems and structures influence our practice?**
- **When we talk or write about this clinical issue and/or our clients/patients, what language do we use?**
- **How do the systems and processes in our clinical practices respond to this ‘problem’? What does that assume of your clients/patients?**
- **How do the systems and processes in our clinical practices treat our clients/patients?**
- **What kinds of information do we gather and why, what do you do with this information? What do we measure and why?**

2

HOW HAS THIS PROBLEM REPRESENTATION COME ABOUT?

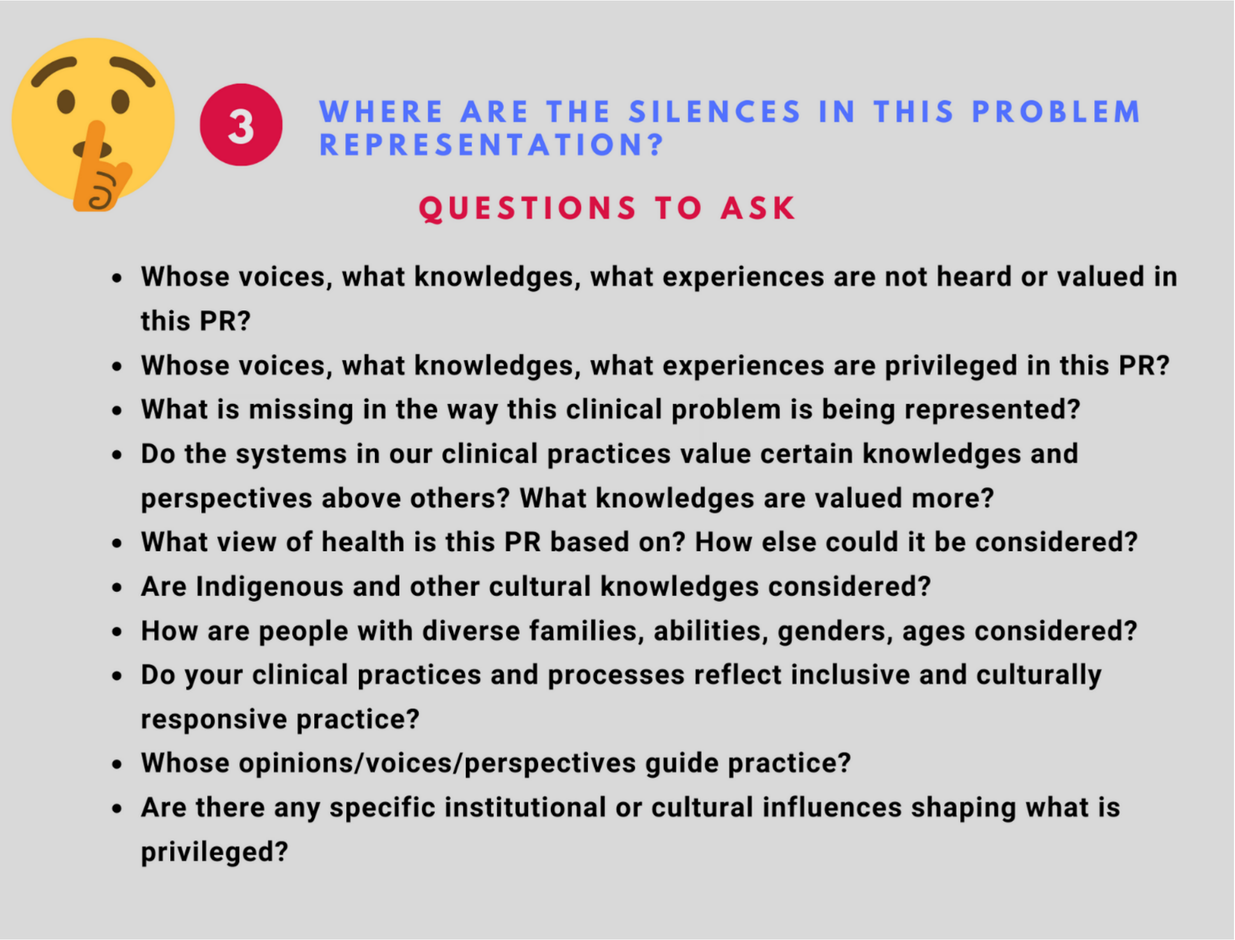
WHY?

This question provides a mechanism to consider the conditions that allow this particular problem representation to take shape and assume dominance. This allows a way to examine systems and structures and to take blame away from individuals, from the dedicated clinicians doing their very best to provide services.

This allows us to trace the history of a current problem representation and challenge the idea that it was always responded to in this way.

Systems within our clinical practices organise or influence our patients/clients to be certain kinds of ‘political’ subjects. This can be determined through considering our policies and what we count or measure. What are the consequences if they do not do these things?

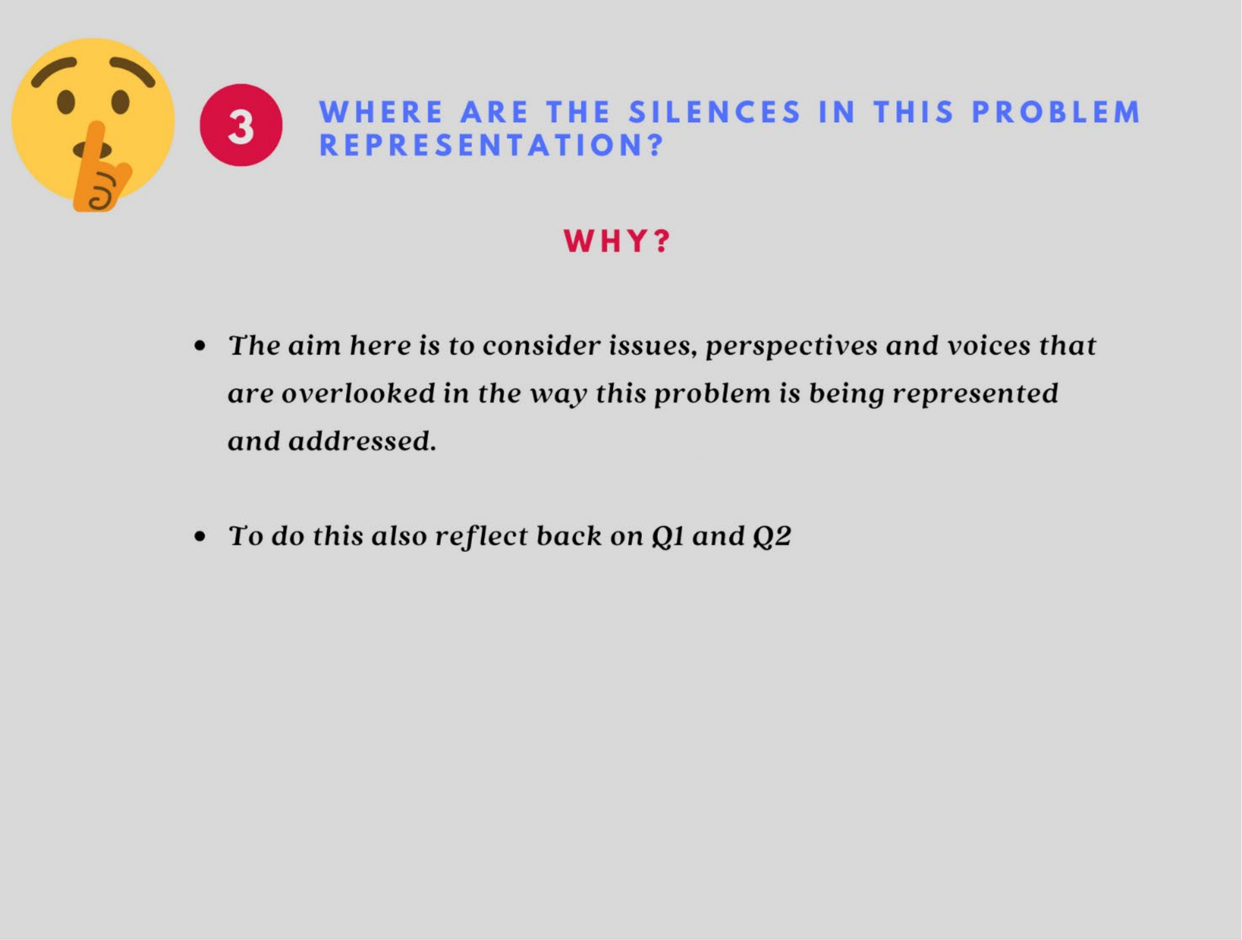
Examples may be: attendance policies, information gathering and exchange processes



3 WHERE ARE THE SILENCES IN THIS PROBLEM REPRESENTATION?

QUESTIONS TO ASK

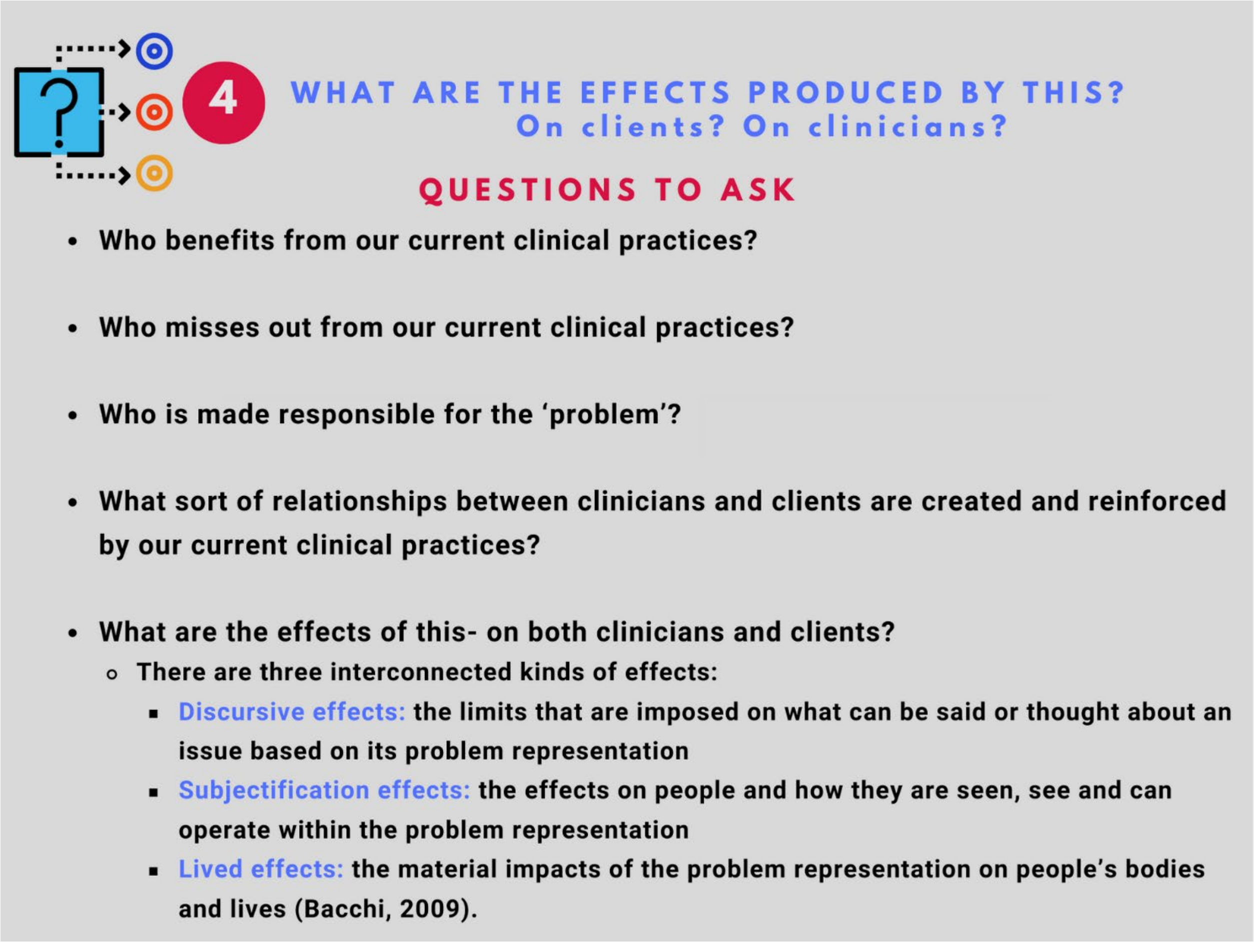
- **Whose voices, what knowledges, what experiences are not heard or valued in this PR?**
- **Whose voices, what knowledges, what experiences are privileged in this PR?**
- **What is missing in the way this clinical problem is being represented?**
- **Do the systems in our clinical practices value certain knowledges and perspectives above others? What knowledges are valued more?**
- **What view of health is this PR based on? How else could it be considered?**
- **Are Indigenous and other cultural knowledges considered?**
- **How are people with diverse families, abilities, genders, ages considered?**
- **Do your clinical practices and processes reflect inclusive and culturally responsive practice?**
- **Whose opinions/voices/perspectives guide practice?**
- **Are there any specific institutional or cultural influences shaping what is privileged?**



3 WHERE ARE THE SILENCES IN THIS PROBLEM REPRESENTATION?

WHY?

- *The aim here is to consider issues, perspectives and voices that are overlooked in the way this problem is being represented and addressed.*
- *To do this also reflect back on Q1 and Q2*



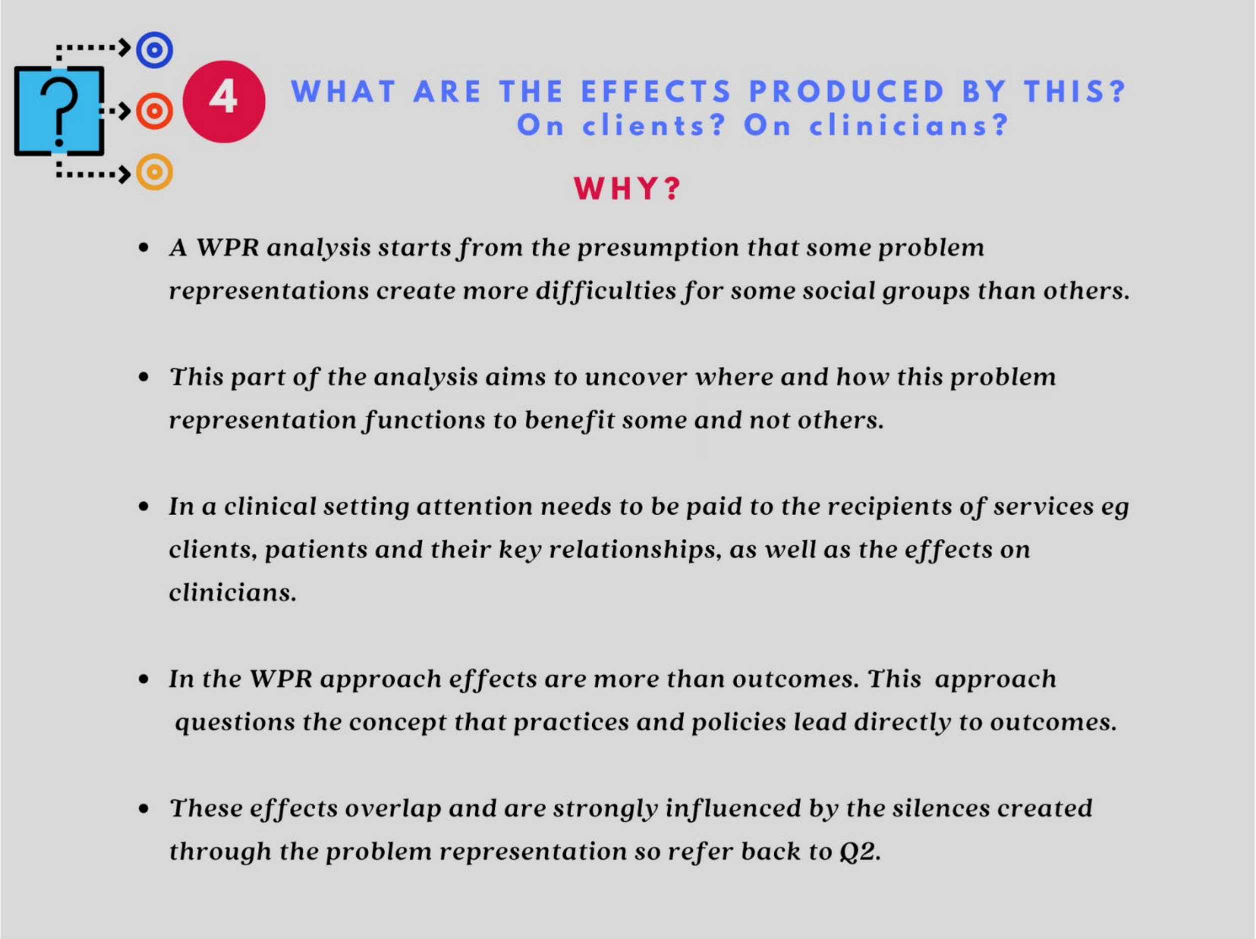
4

WHAT ARE THE EFFECTS PRODUCED BY THIS?

On clients? On clinicians?

QUESTIONS TO ASK

- **Who benefits from our current clinical practices?**
- **Who misses out from our current clinical practices?**
- **Who is made responsible for the 'problem'?**
- **What sort of relationships between clinicians and clients are created and reinforced by our current clinical practices?**
- **What are the effects of this- on both clinicians and clients?**
  - **There are three interconnected kinds of effects:**
    - **Discursive effects:** **the limits that are imposed on what can be said or thought about an issue based on its problem representation**
    - **Subjectification effects:** **the effects on people and how they are seen, see and can operate within the problem representation**
    - **Lived effects:** **the material impacts of the problem representation on people's bodies and lives (Bacchi, 2009).**



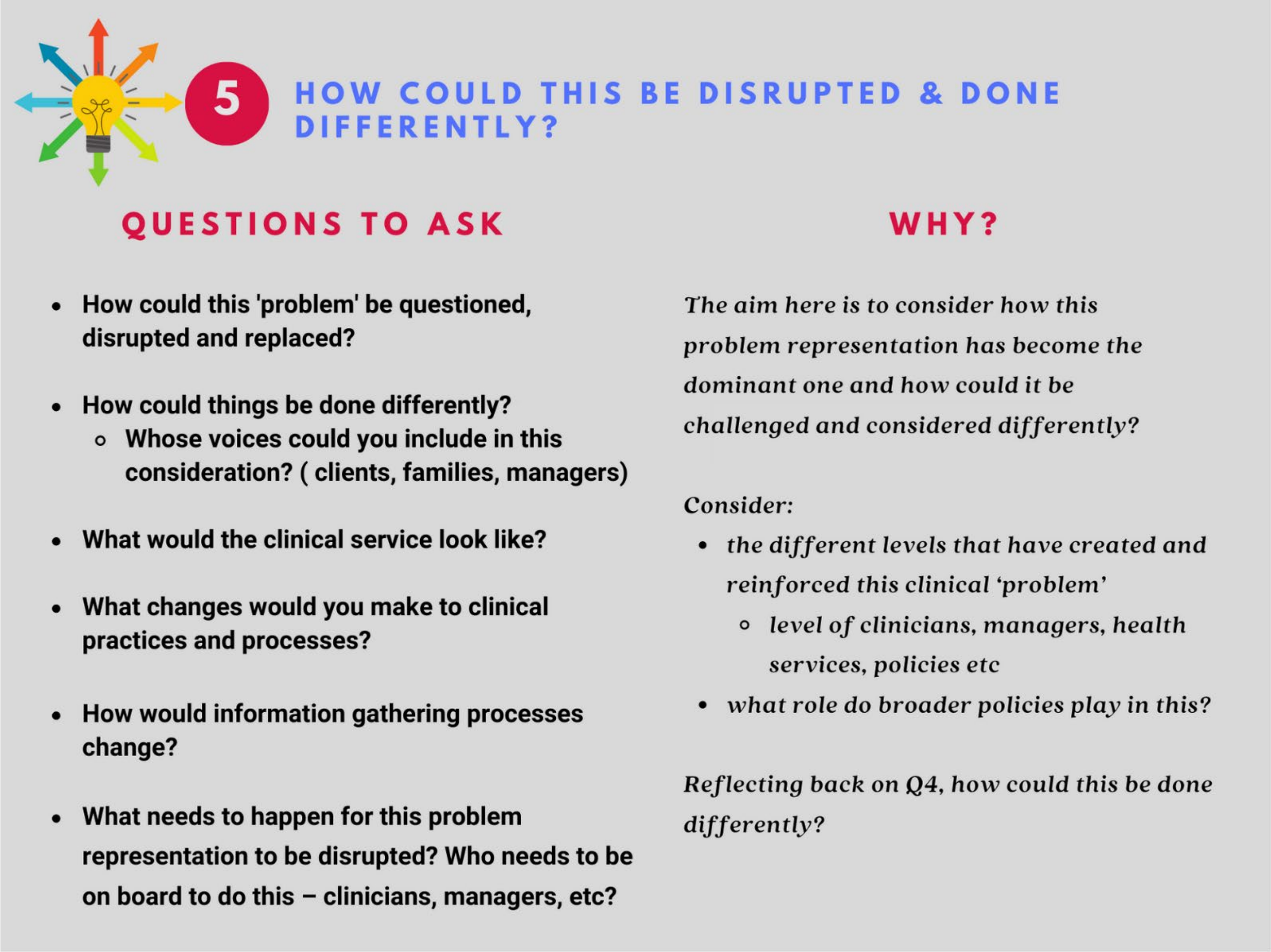
4

WHAT ARE THE EFFECTS PRODUCED BY THIS?

On clients? On clinicians?

WHY?

- *A WPR analysis starts from the presumption that some problem representations create more difficulties for some social groups than others.*
- *This part of the analysis aims to uncover where and how this problem representation functions to benefit some and not others.*
- *In a clinical setting attention needs to be paid to the recipients of services eg clients, patients and their key relationships, as well as the effects on clinicians.*
- *In the WPR approach effects are more than outcomes. This approach questions the concept that practices and policies lead directly to outcomes.*
- *These effects overlap and are strongly influenced by the silences created through the problem representation so refer back to Q2.*



5 HOW COULD THIS BE DISRUPTED & DONE DIFFERENTLY?

QUESTIONS TO ASK

- **How could this 'problem' be questioned, disrupted and replaced?**
- **How could things be done differently?**
  - **Whose voices could you include in this consideration? (clients, families, managers)**
- **What would the clinical service look like?**
- **What changes would you make to clinical practices and processes?**
- **How would information gathering processes change?**
- **What needs to happen for this problem representation to be disrupted? Who needs to be on board to do this – clinicians, managers, etc?**

WHY?

The aim here is to consider how this problem representation has become the dominant one and how could it be challenged and considered differently?

Consider:

- *the different levels that have created and reinforced this clinical 'problem'*
  - *level of clinicians, managers, health services, policies etc*
- *what role do broader policies play in this?*

Reflecting back on Q4, how could this be done differently?

Bacchi, C. (2009). *Analysing policy: What's the problem represented to be?* Australia: Pearson

Appendix 11: Summary of research findings for participants

Executive Summary

Examining health care practices for young children with complex feeding difficulties and their families: What's the problem represented to be?

Research Aims:

This research examined the clinical practices of a paediatric feeding assessment service (PFAS) located within a tertiary hospital in Adelaide to achieve the following three aims:

1. To critically examine and compare how the problem of complex feeding difficulties is being represented in clinical practices and experienced by carers,
2. To analyse how problem representations influence experiences and practices of health care, and
3. To reflect on the contribution and extension of the What's the problem represented to be? (WPR) approach (Bacchi, 2009) to clinical practices.

Background:

Care for young children with complex feeding difficulties (hereafter CFDs) is inextricably embedded in the health system. These children are at risk and often seriously ill from their inability to consume enough nutrients to grow and thrive. They require specialised medical and allied health care. These children and their families experience significant challenges in the present and are at risk of experiencing several preventable physical, cognitive, psychological, social, and emotional difficulties in the future. They require multiple health care encounters over an extended period, often from birth. I set out to closely examine and understand the health care encounters and clinical practices surrounding these children and families. From a public health perspective, I was interested in understanding the systems operating around these children, their carers, and their clinicians and how these affect the care they receive.

Design:

I examined the clinical practices associated with caring for young children with CFDs by interviewing and observing carers and clinicians. I first applied and adapted the Foucault-influenced poststructural theoretical and analytic framework, What's the problem represented to be? (WPR) developed by Carol Bacchi to this clinical health care setting and deconstructed the ways that the clinical issue of CFDs was problematised and the effects of this on carers, children, clinicians, and practices. I then examined these findings through a 'health as care' lens informed by the work of Annemarie Mol (2008). This enabled me to consider good health care practices at the level of clinician, carer, and team.

Methods:

I conducted in-depth interviews, home and clinic observations with carers and clinicians over a seven-month period.

Results:

I identified the implied problem representation (PR) by closely examining how this clinical issue was discussed, described, and framed in clinical practices and service documents. I then compared the clinician and carer data to identify the effects of this problem representation. A CFD was represented as a serious physical problem that affects a child's ability to put on weight. The implied 'problem' was the weight of the child. This drove a focus on the child's weight which resulted in silences surrounding the traumatic, emotional, and everyday life effects of living with CFDs and carers' knowledge and expertise. The client/clinician relationship, power imbalances and the functioning of an interdisciplinary team were some of the unexamined constructs.

I identified the broad structural factors that made it possible for this problem representation to come about. Some of these included neoliberal influences on health care policy, biomedical dominance, social and cultural discourses of food, mothering, normality; funding models and structures; team and clinical practices reflecting technologies of governing. I also examined the effects of this problem representation on carers and clinicians. Some of these included carers needing to become highly specialised medical technicians to manage their child's physical needs and distance themselves emotionally from the daily pain and suffering of their child. Carers' sense of their own wellbeing became inextricably connected to their child's weight. Clinicians experienced overwork and lack of autonomy in an underfunded service. They were constrained in their practices but found ways to subvert systems and build positive relationships with each other and their clients.

Conclusions:

This research makes a practical and theoretical contribution to the consideration of health care practices strongly connected to the messy everyday reality of living or working with a condition. I developed an adapted WPR model that can be applied in tertiary education and clinical practice settings to support critical review and reflection of health care practices and team functioning for current and future clinicians. My application of this model to the PFAS identified specific recommendations to system responses, environments and practices that aim to reconceptualise the client as central to the team, support empowerment, relationships and trust between carers and children; carers and clinicians; and between clinicians; and reflect, understand, and value the everyday experiences of carers and children. More broadly, I examined and described good health care practices and the roles of clinician, client, team, and the importance of reflective practice. The adapted WPR model offers a tool to support critical review with sensitivity and care as a contribution towards improving health care practices and outcomes.

Acknowledgements:

I would like to acknowledge and thank the clinicians and carers who shaped, strengthened, and embraced this research with generosity and openness allowing me to develop deep insights into your experiences which have been invaluable to this research. Spending time with you in your clinics and homes was an absolute privilege. The messy everyday work and life experiences I witnessed stayed with me as I wrote my thesis and motivated me to strive towards developing a model for review of clinical practices that did not lose sight of the everyday complexities of caring for and working with people.

Sandra Mortimer, DPH Candidate, College of Medicine and Public Health, Flinders University, 12 March 2021

Detailed Summary of Research Findings

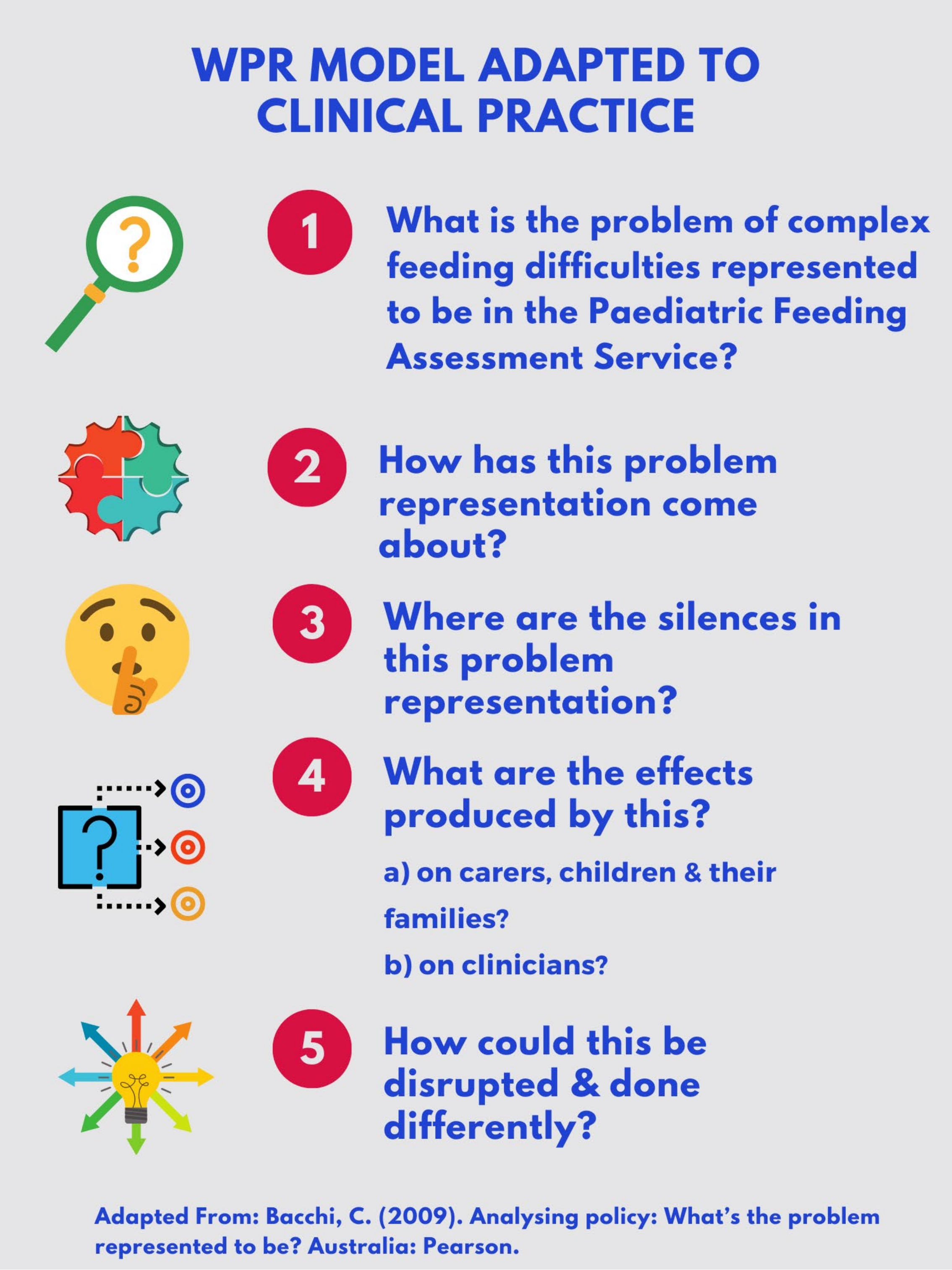
This summary provides a formal feedback mechanism to participants in the research study entitled, *Examining carer and clinician perspectives of tertiary health responses for young children with complex feeding difficulties.* In this summary I provide information about the findings of this qualitative study and identify the way the problem of CFDs is represented within the practises of the Paediatric Feeding Assessment Team (PFAT), how this has come about and the potential effects of this for carers and clinicians. I also identify ways things could be done differently. These findings are based on analysis of documents, in-depth interview transcripts and clinic and home observation field notes. Data were analysed by applying a theoretical framework adapted from Bacchi's What's the problem represented to be? (WPR) approach to policy analysis (Bacchi, 2009) to determine how the problem of CFDs was represented by the clinical practices of the team and how this was then experienced by the carers. Figure 1 shows the model adapted to the clinical practices of the Paediatric Feeding Assessment Service (PFAS). I chose this type of analysis to provide a different way of examining health care conditions and practices in the hope that new insights would emerge. I applied this analytic approach to the clinician data and then the carer data and then compared these. I have used infographics to concisely present a snapshot of my findings.

While this study focused on the PFAT, carers also reported on their experiences more broadly and particularly their experiences prior to encountering the team. It is important to note that this analysis could not be confined to the carers experiences of only the PFAT as this team operated within a broader system which occurred across two major hospitals, and typically included contact with neonatologists, paediatricians, gastroenterologists, allergists, nurses, OTs, physiotherapists, speech pathologists, dietitians and occasionally social workers and psychologists, before they encountered the PFAT.

Explanation of terminology

Problematisation is the process by which something is put forward or created as a problem.

Problem representation (hereafter PR) is the implied problem in a problematisation.



WPR MODEL ADAPTED TO CLINICAL PRACTICE

1. What is the problem of complex feeding difficulties represented to be in the Paediatric Feeding Assessment Service?
2. How has this problem representation come about?
3. Where are the silences in this problem representation?
4. What are the effects produced by this?

   a) on carers, children & their families?

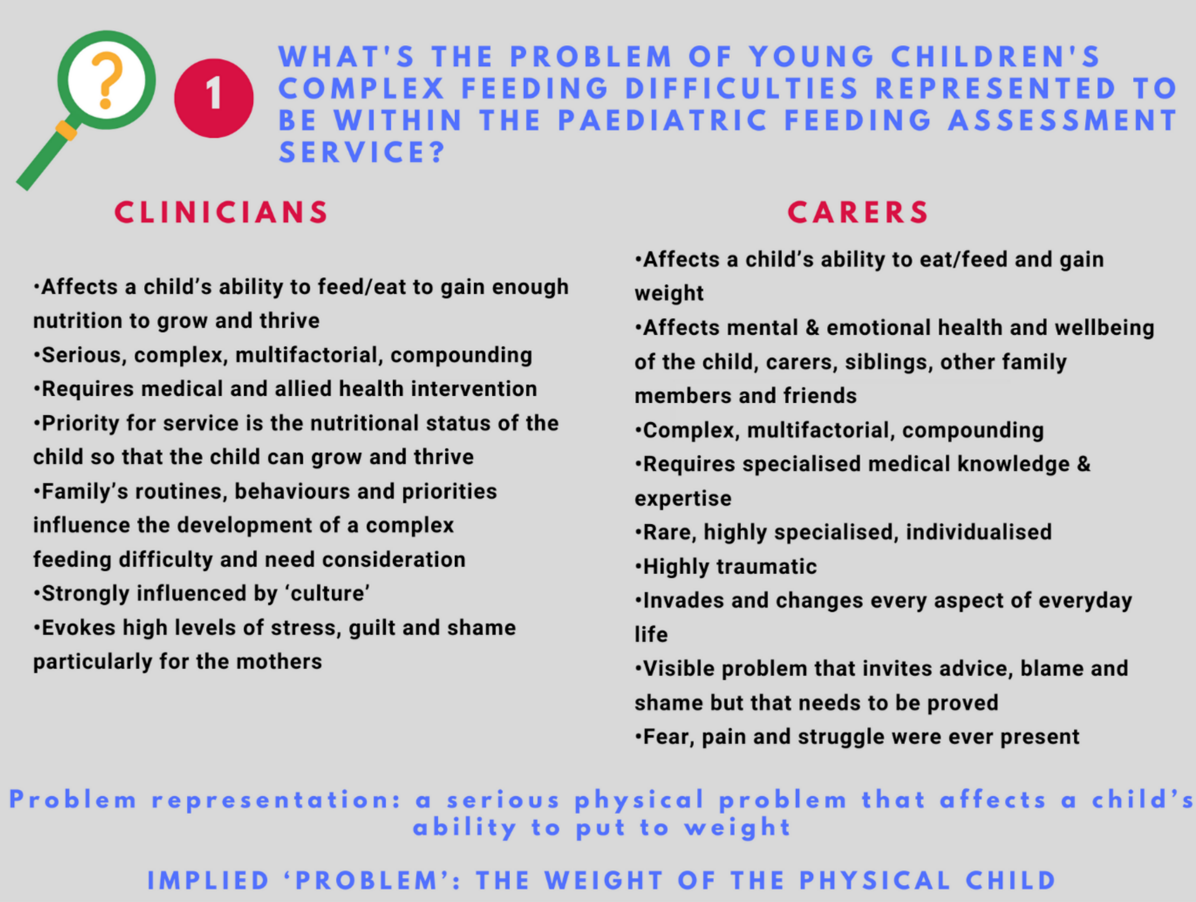
   b) on clinicians?
5. How could this be disrupted & done differently?

Adapted From: Bacchi, C. (2009). Analysing policy: What's the problem represented to be? Australia: Pearson.

Figure 1 Adapted WPR model applied to PFAS

What’s the problem of CFDs represented to be within the clinical practices of the Paediatric Feeding Assessment team?

The aim of this section was to identify the PRs in specific clinical practices by closely examining how this clinical issue was discussed, described, and framed in clinical practices and service documents. What we do about a clinical issue reveals what we think needs to change and hence what we define as the ‘problem’. Therefore, how the problem is represented is implied within the proposed clinical solutions.



1 WHAT'S THE PROBLEM OF YOUNG CHILDREN'S COMPLEX FEEDING DIFFICULTIES REPRESENTED TO BE WITHIN THE PAEDIATRIC FEEDING ASSESSMENT SERVICE?

CLINICIANS

- Affects a child’s ability to feed/eat to gain enough nutrition to grow and thrive
- Serious, complex, multifactorial, compounding
- Requires medical and allied health intervention
- Priority for service is the nutritional status of the child so that the child can grow and thrive
- Family’s routines, behaviours and priorities influence the development of a complex feeding difficulty and need consideration
- Strongly influenced by ‘culture’
- Evokes high levels of stress, guilt and shame particularly for the mothers

CARERS

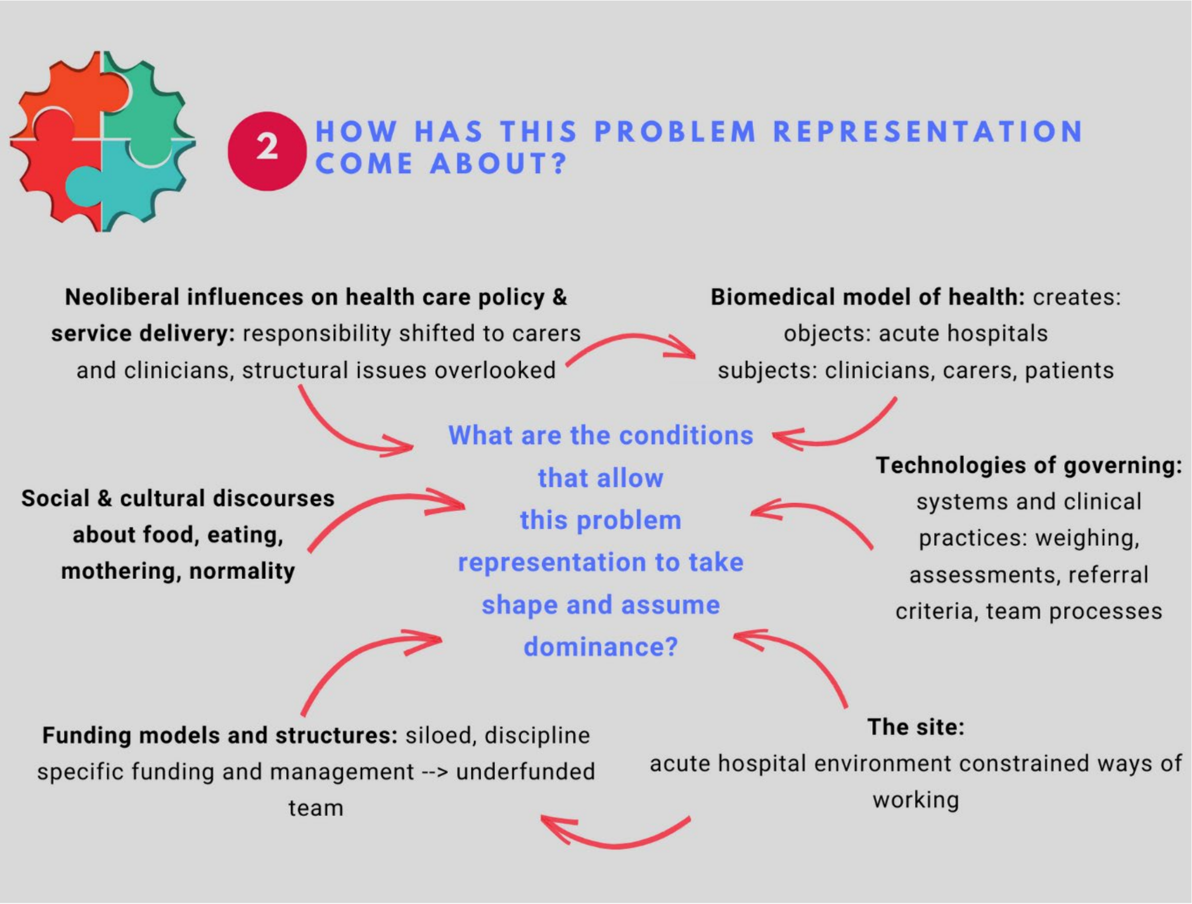
- Affects a child’s ability to eat/feed and gain weight
- Affects mental & emotional health and wellbeing of the child, carers, siblings, other family members and friends
- Complex, multifactorial, compounding
- Requires specialised medical knowledge & expertise
- Rare, highly specialised, individualised
- Highly traumatic
- Invades and changes every aspect of everyday life
- Visible problem that invites advice, blame and shame but that needs to be proved
- Fear, pain and struggle were ever present

Problem representation: a serious physical problem that affects a child’s ability to put to weight

IMPLIED ‘PROBLEM’: THE WEIGHT OF THE PHYSICAL CHILD

How has this come about?

This section provides a mechanism to consider the conditions that allow this particular PR to take shape and assume dominance. This allows a way to examine systems and structures and to take blame away from individuals, from the dedicated clinicians doing their very best to provide services.



2 HOW HAS THIS PROBLEM REPRESENTATION COME ABOUT?

Neoliberal influences on health care policy & service delivery: responsibility shifted to carers and clinicians, structural issues overlooked

Biomedical model of health: creates: objects: acute hospitals subjects: clinicians, carers, patients

What are the conditions that allow this problem representation to take shape and assume dominance?

Social & cultural discourses about food, eating, mothering, normality

Technologies of governing: systems and clinical practices: weighing, assessments, referral criteria, team processes

Funding models and structures: siloed, discipline specific funding and management --> underfunded team

The site: acute hospital environment constrained ways of working

What are the silences and their effects?

The aim here was to consider issues, perspectives and voices that may have been overlooked in the way this problem has been represented and addressed, and their effects on both carers and clinicians. There were silences about the clinician/client relationship, what this meant and how it would operate. Carers reported how difficult it was to learn and negotiate this new relationship and how powerless and frustrated they often felt. They reported that this impacted on their children's care and their own emotional state. Clinicians appeared unaware of the challenge this presented to carers. This has the potential to relegate children with CFDs, their carers and families to a less powerful role in the clinical exchange which may influence; the agency and self-determination of carers, difficulties in being heard and believed, effective exchange of information and the consequent development of effective relationships and service responses. The perspectives of the broader family and cultural considerations were also silenced. This has the potential to miss opportunities for full clinical information gathering, service planning and service delivery options to create more nurturing and sustainable home environments to support these young children with CFDs.

Additionally, trauma and its effects were silenced within this representation of the problem resulting in health system practices that continue to retraumatise children and carers. For many of these children and carers the impact of this trauma on their ongoing relationships, their relationships to their own bodies, their relationships to food, their ability to feel safe and to trust was not addressed in current service responses. Similarly, mental health was silenced meaning that service responses to address the effects of this were also missing. The immediate effects of this were seen in carers reports of high stress levels, anxiety, poor sleep, and living with fear and pain. The potential future effects for these families require consideration.

For clinicians their experience of overwork as a result of underfunding has been silenced. The effects of this were on work satisfaction, stress, and innovation. It also influenced their ability to complete their work in a timely manner. For clients, this represented a risk of compromised care because the systems constrained the clinicians' ability to work at their best resulting in services that were potentially less effective.

Siloed decision-making structures and funding models have resulted in an underfunded interdisciplinary service. The team do not have the appropriate levels of autonomy, leadership, and resource allocation to enable their work to progress and improve and consequently child and carer outcomes are potentially compromised. The lack of resources in the team has resulted in a corresponding lack of time for reflective practices such as team-based planning and review. In this way systems, processes and practices continue to operate in unexamined ways, and possibilities for disruption are minimised. Some of the silences and effects are captured in the following images.

3 SILENCES: CARER'S EXPERIENCE OF THE PROBLEM REPRESENTATION

- Carer's voices, knowledges, expertise were often silenced
- Medical knowledge and expertise was privileged over all other forms
- Daily experiences of the carers and children were silenced
- Clinic experiences were privileged
- Emotional, mental health and trauma was silenced
- Physical symptoms were privileged
- Child was privileged over carer and family
- Cultural implications were silenced
- Feeding was experienced as a process to instil calories and weight and privileged over eating

"which is why I started - I took videos of how she was screaming to the point of vomiting, and I took photos and all that, just because the doctors seemed to – 'she's been fine. We don't know what you're talking about'." Rachel

"people ask you, how are you, and I can say that things are shit [laughs], but beyond that it's all about trying to fix [Summer] because she's the end goal." Emily

4a SUBJECTIFICATION EFFECTS OF THE PROBLEM REPRESENTATION ON CARERS

- Drives an all consuming pressure to achieve a precarious and precious calorie intake and weight status which requires the carer to assume the role of technician:
    - Needing highly technical, specialised knowledge & skills in managing tube changes, pumps, tapes, calculating calorie input and timing of feeds
    - Balancing calories in vs vomiting risk
    - Enculturation to medical world as part of becoming an expert and advocate– reflected in their language and skills
    - Emotions removed/distanced to deal with practicalities, fear and pain

"It can be really easy to get bogged down in the chore aspect of all of it without getting emotionally involved. Which is - it sounds awful, but if I dwell every day on how much pain she's in I'd never get out of bed in the morning." Emily

"First time I did it, I - gagged, and I went, oh, no. I couldn't believe I did it. But saving a hospital trip, I'm - I've got a lot more comfortable." Rachel

4a LIVED EFFECTS OF THE PROBLEM REPRESENTATION ON CARERS

- **Carers' wellbeing (feelings- anxiety, fear, happiness, stress levels, mental health) became inextricably linked to child's weight status**
- **Carers presented with thinly veiled desperation to acute distress**
- **Carers reported high levels of stress, fear, isolation**
- **Impacted on everyday life for the whole family**

"it was, you know, blood from the nose and the mouth and he would choke, and I was like ……it's just too horrible an experience." Karen

"He's gaining quite good. So that's the moment I feel like okay -probably the days are getting better for us so that's the moment actually I feel like okay, I feel better." Fardin

"…quite honestly I am skating on thin ice. It's really hard to maintain a positive mental sort of state when you're dealing with all of this, and you are so sleep deprived. I don't eat properly, I don't drink properly, I don't sleep properly. I don't shower when I want to." Emily

4b SUBJECTIFICATION EFFECTS OF THE PROBLEM REPRESENTATION ON CLINICIANS

- **Impacted on their autonomy, work satisfaction, stress, enthusiasm, and innovation.**
- **Impacted on their ability to complete their work in a timely manner and this had flow on effects to the quality of clinical care.**
- **Constrained the ways they could practice- home visits, intense services, reflective practice**

"So, yeah, we don't get that time to reflect as a team and I think that we could do so much better if we had more time to work together and we had more time to reflect" C3

"I'd like to be able to do services more intensely. So maybe see people in their own homes or be out in the community so that we could be doing work in a less stressful way" C1

"I've got all these good ideas, but things happen very slowly, and especially in the public system. [Laughs] So it's, um, yeah, I think it would take more dedicated funding and that's - in this environment it's nigh on impossible really." C4

How could things be done differently?

Even though the PFAT operated within and was part of the broader health system which influenced the development of this problem representation, there appeared to be ways that the PFAT team disrupted this through their responses to and interactions with the carers. The carers unanimously reported feeling listened to and responded to positively by this specialised team. The carers reported that this team was unique in a system where the norm was not to be listened to, believed, or valued. They talked about the contact with the team being a relief and described them as a “one stop shop for all your feeding needs”.

Aspects of the team’s functioning that worked for the carers included the attention they paid to the carers and children. This translated to the carers feeling that the team members were genuinely invested in getting to know them and their child. Additionally, the carers all reported that the team worked with them, valued their opinions and involved them in decision making. They explained things well without using medical jargon. They were also flexible and responsive to working around the special needs of the families. The practical benefits of a team approach were very clear to the carers. But it was more than practicalities, their language and approach validated the carers’ experiences of both struggles and successes and the team were proactive in advocating for the carers with other specialists.

This all contributed to the carers feeling seen and heard in a health system where they often felt invisible and powerless. This occurred because of the team members’ expertise, approach, and communication skills and despite rather than because of the structure and processes of the PFAT clinic. All the carers reported finding their appointments at the PFAT clinic overwhelming. The clinic room was small, with no obvious child focus, toys, if available, were tucked away and often not brought out. It was crowded with each of the four discipline team members plus there were often students involved and this left no room for a child to explore or play. The children were often distressed and this manifested itself in clinging to their parents or becoming busy and disruptive and so the carers’ focus was pulled between responding to their child’s needs and listening to the team, answering questions and contributing to the discussion. When assessment of the child’s eating needed to happen there was often limited space or the required food or equipment (adapted cups, thickened formula etc.) were not on hand. Carers used terms like “chaotic” and “disruptive” and raised the point that there was a risk of people feeling judged with the structure of the clinic.

Carers were asked what an ideal service for their children would look like and their responses to this question provide insight into the way things could be done differently. The carers talked about the initial processes of coming to terms with having a child with CFDs and how isolated and scared they were. They suggested that a 24hour point of contact for advice and reassurance with a clinician who was experienced in feeding difficulties and who had access to their child’s medical notes would have been very valuable. Universal services, general practitioners and helplines were of no use and everyone referred them back to the emergency department. Carers discussed the challenges of taking their children to the emergency department as the first step when you weren’t sure what to do. It places a burden on other family members, as well as the need to take time off work, find care for other children and put their child through the trauma of yet another hospital visit and then there were wait times of anywhere from 2-18 hours.

All the carers talked about needing additional support and advice that focused on the everyday realities of caring for a child with CFDs and felt that this translation from hospital to home was lacking in current service models. They needed the clinicians to understand their unique circumstances and tailor their services responses to these. They felt this could have been addressed better if assessment and intervention services were offered in their homes. This would have served to reduce the trauma experienced by children in attending hospital-based services and ensure the team understood what their home environments and routines were like. Carers also talked about the pressure they felt to get their children to eat when they were at home and the challenges of mealtimes. In hospital-based sessions they didn’t feel this pressure and feeding was fun but that didn’t translate to feeding at home. Carers felt that having these pressures acknowledged and support to work through them specific to their own home mealtime challenges would have helped the translation to feeding at home.

Another way that things could be done differently was through carer support groups. All the carers reported feeling isolated and overwhelmed and that the focus of therapy was their child which meant that their needs for practical and emotional advice and support were overlooked. The unique nature of their child’s condition and the challenges this presented in terms of timing, juggling equipment, avoiding vomiting, and the very visual nature of the problem meant that these carers could not easily access and did not feel like they belonged to universal support services. They suggested that an informal support group with other families of children with CFDs would have been beneficial to counter the sense of being so alone and help build their own knowledge and capacity and support each other.

Carers also raised broader health system issues including greater client centred care and streamlining and coordination of services across the health care system. They raised the lack of knowledge about the presentations and impacts of CFDs in general practice which resulted in delays with identification and referral to specialty services. They also raised the issue of very limited paediatric gastroenterology services and that these services spanned two hospitals. This often resulted in very long wait times and the carers bearing the additional burden of keeping both sites up to date. All the carers reflected on their power within the health service encounters and expressed frustration that they were so often peripheral rather than central to the decision-making process regarding the care of their child. Examples of these included; provision of certain equipment, the processes for feeding times during an inpatient tube wean, guiding meal and bedtime routines, timing overnight tube feeds or access to a suitable outdoor play space during a lengthy hospitalisation. All the carers expressed the need to have greater coordination of services and more control and autonomy in the care of their child.

The clinicians were very aware of the lack of coordinated services and the challenges this presented. They all had very clear ideas of what they would prioritise if they had adequate funding. They would like to be able to offer a more intensive service for families that included home based services, opportunities for eating together in more natural environments, more time to reflect and work together as a team and greater connections with community based and other hospital services. They would also prioritise access to mental health services to support the emotional wellbeing of the children and families.

The terms eating and feeding require further examination as they have the potential to convey messages about age, agency, power, and purpose. These terms were used interchangeably or without clarification by clinicians and carers. Examining these terms and how they are used would help clarify intention and set a solid framework for the service. Feeding, in common parlance, has connotations with the very young needing assistance; babies and very young children are fed or feed; young children and adults eat. Within the literature, feeding is considered to be an interaction between the child and their caregiver, while eating comprises actions relating to nutritional oral intake that are performed autonomously by the child (Keren, 2016; Yang, 2017). These two different framings, everyday understanding versus 'expert' understanding as reflected in the clinical setting and the literature, may reflect assumptions in knowledge and understanding that require further attention.

In everyday understanding, the term feeding may carry with it an implication that someone (a carer and most commonly a mother) needs to take responsibility for the feeding of the passive recipient of this process (the baby or child). Whereas eating may be perceived as a much more active process that maintains the agency of the child. The implications of calling this service a feeding assessment service and referring to feeding so frequently may be an implied sense of responsibility conveyed to carers/mothers. The relational and reciprocal process that is meant by feeding in 'expert' understanding may be lost. This may have the unintended effect of increasing the sense of blame and guilt associated with caring for a child with CFDs and overlooking the role of the child as an active participant in the feeding process. A service that responds to young children with CFDs and their families, needs to pay attention to these terms. They need to consider their meanings and examine the assumptions and differences that may be at play between carers and clinicians and what the implications of this may be. This then needs to be explicitly discussed with the clinicians and carers.

he documentation about the service requires review and updating. The document analysis was based on the following documents provided in 2016 and so please disregard this section if these have already been updated.

1. Appointment letter, Information sheet for parents, and Medical, Developmental and Feeding Questionnaire (Doc 1)
2. Information sheet for staff (Doc 2)
3. Inpatient tube wean process checklist (Doc 3)
4. Inpatient tube wean pre-admission information (Doc 4)
5. Inpatient tube wean discharge information sheet (Doc 5)
6. Referral form (Doc 6)

The analysis revealed inconsistencies between the approach of the clinicians revealed through the interview and observation data and reflected in these documents. In particular information gathered about the child privileged physical symptoms and effects, mothers were typically held to be responsible for their child and the language conveyed a power imbalance where the team were represented as the experts rather than the collaborative approach which was so frequently witnessed. By updating these documents to reflect the practice, beliefs, and values of the clinicians more accurately, there are opportunities to set a clear understanding about the approach of the team that reflects a more inclusive and holistic understanding of CFDs.

Summary of recommendations for change:

Recommendations for change are pitched at two levels, actions for managers and supervisors and actions for PFAT members.

There are many system level constraints on the clinical practices of the PFAT. These require actions on behalf of managers and can be summarised as:

- review of funding models and discipline structures that contribute to this underfunded interdisciplinary service
- increasing allocation of clinical services to address trauma and mental health
- consider reviewing practices that would support home based service responses
- working with the clinicians and carers to consider ways to streamline and coordinate services for young children with CFDs across the health care system
- addressing the limited access to paediatric gastroenterology services

At the level of the team these are the key recommendations for change.

Developing system responses, environments, and practices that:

- reconceptualise the client (child and family) as central to the team
- conceptualise a CFD as one that impacts on a child and family's everyday life and affects their physical, mental and emotional health and wellbeing
- examine the use of the terms feeding and eating
- examine the physical environments in which practices occur
- consider opportunities to conduct homebased services
- review service documentation
- support empowerment, relationships, and trust between; carers and children; carers and clinicians; and between clinicians
- reflect, understand, and value the everyday experiences of the carers and children
- acknowledge, reduce, and address trauma
- ensure practices of critical reflection.

Sandra Mortimer,

DPH Candidate, College of Medicine and Public Health, Flinders University,

12 March 2021

References

Bacchi, C. (2009). Analysing policy: What’s the problem represented to be? Australia: Pearson.

Keren, M. (2016). Eating and feeding disorders in the first five years of life: Revising the dc:0-3r diagnostic classification of mental health and developmental disorders of infancy and early childhood and rationale for the new dc:0-5 proposed criteria. Infant Mental Health Journal, 37(5), 498-508. doi:10.1002/imhj.21588

Yang, H. R. (2017). How to approach feeding difficulties in young children. Korean Journal of Pediatrics, 60(12), 379-384. doi:10.3345/kjp.2017.60.12.379