

2012

## Newborns with feeding issues: parental perceptions of the hospital discharge, transition home and the role of speech pathology

Katie Louise Ilich  
*Edith Cowan University*

Follow this and additional works at: [https://ro.ecu.edu.au/theses\\_hons](https://ro.ecu.edu.au/theses_hons)



Part of the [Speech Pathology and Audiology Commons](#)

---

### Recommended Citation

Ilich, K. L. (2012). *Newborns with feeding issues: parental perceptions of the hospital discharge, transition home and the role of speech pathology*. Edith Cowan University. [https://ro.ecu.edu.au/theses\\_hons/50](https://ro.ecu.edu.au/theses_hons/50)

This Thesis is posted at Research Online.  
[https://ro.ecu.edu.au/theses\\_hons/50](https://ro.ecu.edu.au/theses_hons/50)

# Edith Cowan University

## Copyright Warning

You may print or download ONE copy of this document for the purpose of your own research or study.

The University does not authorize you to copy, communicate or otherwise make available electronically to any other person any copyright material contained on this site.

You are reminded of the following:

- Copyright owners are entitled to take legal action against persons who infringe their copyright.
- A reproduction of material that is protected by copyright may be a copyright infringement.
- A court may impose penalties and award damages in relation to offences and infringements relating to copyright material. Higher penalties may apply, and higher damages may be awarded, for offences and infringements involving the conversion of material into digital or electronic form.

### **Use of Thesis**

This copy is the property of Edith Cowan University. However the literary rights of the author must also be respected. If any passage from this thesis is quoted or closely paraphrased in a paper or written work prepared by the user, the source of the passage must be acknowledged in the work. If the user desires to publish a paper or written work containing passages copied or closely paraphrased from this thesis, which passages would in total constitute an infringing copy for the purpose of the Copyright Act, he or she must first obtain the written permission of the author to do so.

Signed \_\_\_\_\_

Dated \_\_\_\_\_

Newborns with feeding issues: parental perceptions of the hospital discharge,  
transition home and the role of speech pathology

Katie Louise Ilich

A report submitted in Partial Fulfilment of the Requirements for the Award of  
Bachelor of Speech Pathology Honours, Faculty of Computing, Health and Science,  
Edith Cowan University.

Submitted November, 2012

I declare that this written assignment is my own work and does not include:

- (i) material from published sources used without proper acknowledgement; or
- (ii) material copied from the work of other students

---

---

### Abstract

This study explored the perceptions of discharge from hospital and the transition home for mothers of newborns with feeding issues. To gain an understanding of their experiences, mothers were interviewed twice, once at discharge and once up to a month later. Participants had a strong desire for their babies to be discharged from hospital, but felt anxious and underprepared. Once home, more questions typically arose. Mothers found this a highly stressful and emotional experience, especially for those without consistent speech pathology involvement. Mothers valued being involved in the decision-making process, and found this an effective coping mechanism. The value of speech pathology involvement during discharge and transition was apparent throughout this study.

*Keywords:* feeding, parental perception, discharge, transition home, speech pathology, qualitative research

Author: Katie Ilich

Supervisor: Associate Professor Deborah Hersh

Co-supervisor: Corina Gill

COPYRIGHT AND ACCESS DECLARATION

I certify that this does not, to the best of my knowledge and belief:

- (i) incorporate without acknowledgement any material previously submitted for a degree or diploma in any institution of higher education;
- (ii) contain any material previously published or written by another person except where due reference is made in the text; or
- (iii) contain any defamatory material.

Signed \_\_\_\_\_

Dated \_\_\_\_\_

**Acknowledgements**

I would like to thank the speech pathology staff at Edith Cowan University for their wisdom and guidance, and especially my supervisor, Deborah, for her help with this project. Thank you to my co-supervisor, Corina, and to Holly and Linda at Princess Margaret Hospital for recruiting participants; I am most grateful. Lastly, thank you to my family for their continued support.

## Table of Contents

Abstract.....	ii
Copyright and Access Declaration.....	iii
Acknowledgements.....	iv
Table of Contents.....	v
Newborns with Feeding Issues.....	1
Method.....	4
Methodology.....	4
Recruitment Sample.....	5
Conduct of the Research.....	7
Analysis .....	8
Results.....	10
Maternal Emotions.....	12
Stress.....	12
Normality.....	14
Confidence.....	15
Life at Home.....	16
Expectations for life at home.....	16
Impact for family members.....	18
The Role of Speech Pathology.....	19
Parental involvement.....	19
Plan.....	20
Communication.....	22
Support.....	26



Discussion.....	28
Discharge.....	28
Transition Home.....	29
The Role of Speech Pathology.....	31
Limitations.....	34
Future Research.....	35
Conclusion.....	37
References.....	38
Appendix A.....	43
Appendix B.....	45
Appendix C.....	47

Newborns with Feeding Issues: Parental Perceptions of the Hospital Discharge,  
Transition Home and the Role of Speech Pathology

Parents, especially those who are expecting their first child, often hold an overly simplified, idealistic expectation of raising a baby (Pancer et al., 2000). Some expectant parents report that they believe ““being a parent will be the best thing that could happen to [them] as a couple”” (Pancer, Pratt, Hunsberger, & Gallant, 2000, p.260). Parents typically experience anticipation and excitement when awaiting the birth of their child, with little contemplation of the potential stress and life adjustments that may arise when raising a healthy baby, let alone one experiencing health issues (Delmore-Ko, Pancer, Hunsberger, & Pratt, 2000; Feldman & Nash, 1984). Fowlie and McHaffie (2004) suggest that expectant parents rarely seriously consider the likelihood of their child being admitted to a neonatal unit upon birth. Even when neonatal screens identify abnormalities, and parents are informed of a congenital disorder, parents report that they still feel underprepared and stressed by their baby’s admission to a neonatal ward. Fowlie and McHaffie (2004) report that this stress may be due to a lack of information and understanding of their child’s condition, the unfamiliar environment of the hospital, the appearance and condition of their child, and the financial, environmental and physical demands of having their child in hospital.

Hewetson and Singh’s (2009) research similarly suggests that a major theme for mothers of newborns with feeding problems is the difference between the expectations and reality of mothering and feeding their babies. Their research suggests that mothers may experience difficulty identifying as a mother, due to the difficulty or impossibility of feeding, causing them to question their mothering abilities. This can often result in mothers believing that they have failed, and feeling

inadequate or judged by others, including relatives, healthcare professionals and friends (Hewetson & Singh, 2009). These authors also report the theme of maternal failure, with a sense of disempowerment, with many mothers reporting that they felt overwhelmed. The loss of their ideal expectations and bonding opportunities were compounded by feeling physically and emotionally exhausted from coping with their feeding experiences (Hewetson & Singh, 2009). Judson (2004) reports a strong desire from mothers for their child to be normal, and their sense of loss when required to tube feed their baby. In relation to feeding issues caused by disability, Graungaard and Skov (2006) report that parents experience feelings of uncertainty and powerlessness, but with hope of improvement and change in the future. Mathisen, Carey and O'Brien (2012) suggest that mothers' perceptions and emotions whilst their newborn is in hospital with feeding issues vary and fluctuate, but most found this to be a highly sensitive time (MacDonald, 2007).

There are a number of disorders linked to swallowing and feeding difficulties in infants, associated with structural, neurological, cardiorespiratory and inflammatory issues (Miller, 2011). These include, but are not limited to, cleft lip and palate, vocal fold paralysis, cerebral palsy, botulism, prematurity, cardiac anomalies, and inflammation of the pharynx and larynx (Miller, 2011). Between three and 10 percent of all children experience some form of feeding disorder (Linscheid, 2006; Manikam & Perman, 2000). In three percent of all cases, hospitalisation is required in order to treat and manage the condition (Garro, Thurman, Kerwin, & Ducette, 2005; Kerwin, 1999). Hospitalisation may be required due to the fact that feeding disorders impact an infant's ability to grow and develop appropriately, with links to other medical, developmental and nutritional issues (Miller, 2011).

Parents typically must demonstrate sufficient understanding and skills in

managing their child's feeding condition before hospital discharge (Weiss et al., 2008). However, parental perceptions of readiness often vary from health care professionals' perceptions (Bernstein et al., 2002). Parents have described taking their newborn home for the first time with a feeding disorder as stressful, and a cause of anxiety over whether they can adequately care for their child (Firth, Grimes, Poppleton, Hall, & Richold, 2000). Parents often feel underprepared and uninformed, unconfident, and unwilling to take their child home when they have been discharged from hospital (Bissell & Long, 2003). Heweston and Singh (2009) suggest that parents often feel greatly uninformed about the reasons for and management of tube feeding, and parents of tube-fed babies may be the most stressed in the cohort (Adams, Gordon, & Spangler, 1999). In addition, Mathisen et al.'s (2012) research suggests parents of newborns with feeding issues may experience difficulty with role negotiations with health professionals, whilst their child is in hospital. Mothers may also receive differing information from health professionals whilst in hospital, which may negatively impact on their understanding and levels of stress (Adams, Gordon, & Spangler, 1999; Hoddinott, & Pill, 2000)

Due to the often complex and multifaceted nature of swallowing and feeding conditions in infants and newborns, a range of health disciplines are typically involved (Miller, 2011). A neonatal feeding team usually comprises a physiotherapist, occupational therapist, child health nurse, paediatrician, gastroenterologist, ear, nose and throat specialist, lactation consultant, dietician, psychologist, and speech pathologist (Cameron, 2011). Speech pathologists, experts in feeding and swallowing disorders, are important members of the multidisciplinary team and have a role in assessment, treatment and ongoing support of these children and their families. However, Dodrill, McMahon, Donovan and Cleghorn (2008) suggest that the

management of an infant's feeding condition, whilst in hospital can vary greatly, with speech pathologists often having limited involvement in their management.

Furthermore, Ziev (1999) suggests that there are a limited number of speech pathologists practicing in the area of infant feeding, as it is a highly specialised area.

The published literature on the role of speech pathology in the discharge and preparation of parents for taking their newborn home, whilst experiencing a feeding disorder, is highly limited. A literature search (carried out in May, 2012) of CINAHL, SpeechBITE, PsychInfo and MEDLINE databases, amongst others, with the search terms 'parent\* perception', 'discharge', 'feed\* OR swallow\* OR dysphagia', 'newborn OR baby OR infant OR neonatal', and 'speech patholog\* OR speech language patholog\*' failed to find any studies regarding parental perceptions of the role of speech pathology leading up to, and at the time of, discharge for newborns with feeding difficulties. Despite evidence on parental stress in relation to newborns with feeding disorders, there appears to be very little research regarding the role of speech pathologists in easing the transition from hospital to home. This represents a significant gap in our professional knowledge.

Therefore, the aim of the research study was to gain a deeper understanding of parental experiences of discharge from hospital, transition from hospital to home with a baby with feeding issues, the role of speech pathology in that discharge and transition, and parental perceptions of their child's feeding outcomes with speech pathology intervention.

## **Method**

### **Methodology**

Qualitative inquiry was best suited to this research topic, as it focuses on an individual's social construction of their world (Liamputtong, 2009). More

specifically, this research study used an interpretative phenomenological methodology (Osbourne, 1994), allowing a detailed exploration of individuals' first-hand experiences (Creswell, 2007). The interpretative phenomenological approach suggests that the way in which a phenomenon is constructed depends upon both the context in which it is originally created, as well as the context in which it is then interpreted (Patton, 2002). In-depth, semi-structured interviews were used to facilitate the understanding of the phenomenon of parents' experiences of hospital discharge, the transition to home and the role of speech pathology. In-depth semi-structured interviews are effective when discussing complex and lesser researched topics (Corbin & Morse, 2003), as they are flexible enough to allow participants to focus on the topics that are particularly important to them (Rubin & Rubin, 1995). Finally, this method was consistent with the phenomenological methodology and offering the research process a degree of internal rigour.

### **Recruitment Sample**

Participants for this study were parents of newborns with feeding issues, who were recruited at Princess Margaret Hospital (PMH) in Western Australia. It was proposed that to be eligible to participate, parents must have had a baby up to three months of age, who had been admitted as an inpatient at Princess Margaret Hospital. Participants would be interviewed within two days of being discharged from hospital, and would be returning home for the first time. Parents would then be interviewed again up to one month after discharge. However, due to the small number of potential participants fitting these criteria and willing to participate in the interviews, the eligibility criteria were changed. These changes were made approximately one month into the data collection period. The revised inclusion criteria included parents of babies up to one year old, with no requirement to be transitioning from hospital to

home for the first time. In addition, parents were able to complete only one interview, if desired, at any time, up to one month post-discharge. Potential participants, who had been discharged more than two days ago, could complete one, post-discharge interview. Participants' newborn babies must have experienced feeding issues to be eligible to participate in the study. However, it was not a requirement that causes of hospitalisation were feeding issues.

The study aimed to recruit a sample which included a variety of feeding disorders, differing feeding methods for the child (e.g. breastfeeding, bottle feeding, nasogastric tube, percutaneous endoscopic gastronomy), and differing family circumstances. Due to the limited availability of participants, this degree of maximum variation sampling was not feasible. However, the participants of this study experienced a range of medical and social situations; for example, one participant's baby was one of twins, whilst another participant was a foster carer to her baby.

This study aimed to recruit six participants. Due to a limited number of available and willing participants, only four individuals participated. Todres (2005) suggests that four participants is a sufficient number for an exploratory study such as this, as a phenomenological approach requires rich, quality information, rather than a prescribed minimum sample size. Qualitative research aims to gain a greater understanding of the lived experiences of participants and the phenomenon being investigated, rather than making quantitative statements about the generalisability of the phenomenon (Todres, 2005).

Potential participants were identified by their speech pathologists at PMH, and were then invited to participate in the study. In cases where the potential participant's baby had already been discharged from hospital, the family's contact details were given to the researcher, who then made an invitation to participate via a phone call.

Prior to the commencement of the first interview, consenting parents were required to read an information sheet (Appendix A). After being informed of any potential risks and harms, participants were asked to sign a consent form (Appendix B). To understand the medical background of each child, hospital speech pathology staff provided the researcher with a summary of the baby's condition prior to the first interview. The research study received approval from both the Edith Cowan University Ethics Committee and the Princess Margaret Hospital Ethics Committee.

### **Conduct of the Research**

During the data collection period, six points of contact were made with four participants. Four interviews were completed face-to-face, whilst one participant requested correspondence by email. The interview topic guide can be seen in Appendix C. Due to the sensitivity of the research topic, thorough ethical considerations were made. Participants were informed of their ability to withdraw from participation at any time, and that removal of consent meant that no data they provided would be included in the research study. No participants withdrew consent from the study. However, one participant elected to not complete her post-discharge interview, citing time constraints.

Non-verbal cues were monitored during the interviews, to determine if the informants appeared distressed. It was planned that, should participants appear distressed, the researcher would offer to cease the interview. This was not required. These steps were completed to ensure the procedural rigour of the proposed research study. All information collected was of direct relevance to the study topic, kept in de-identified form and properly stored on the researcher's password protected computer.

The interviewer was provided with opportunities to observe speech pathology services being delivered on the wards at PMH, to facilitate a richer and more



encompassing understanding of participants' experiences. It should be noted that the aim of this research study was not to determine the nature of speech pathology services for this population, but to discover parents' perceptions of these services.

### **Analysis**

Interviews were audio recorded, as May (1989) suggests audio recordings ensure the precise and accurate transcription of the events of an interview, facilitating the extraction of meaningful data during analysis. They may also aid in ensuring the correct representation of the individual, through the researcher's ability to listen to interviews multiple times ensuring clear understanding of both the spoken words and nuances (Barriball, & While, 1994). Furthermore, the integrity of the interview data is more likely to be upheld, as the audio recording can be checked by external sources.

Interviews were transcribed verbatim by the researcher. Bird (2005) suggests that this is an important stage in qualitative research, as it ensures that the researcher is highly familiar with the data, and may, in fact, be considered the foundation of data interpretation (Lapadat & Lindsay, 1999).

The collected data was analysed through thematic analysis. This involved the identification and organisation of present themes, with interpretation and conclusions drawn as to how they address the research question (Boyatzis, 1998; Braun & Clarke, 2006). Interpretative phenomenology interprets written or spoken language to determine the meanings that create a phenomenon (Stout, 1982). Patterns and recurring issues were identified from all transcripts and sorted into themes and sub-themes, until no new themes emerged. Interview data was analysed both transversely and longitudinally. Bird (2005) suggests that thematic analysis is a reliable and effective approach for the interpretation of data relating to a wide variety of methodological approaches. It was proposed that this process would be facilitated by

the use of the computer-assisted qualitative data analysis programme, NVivo 9 (Auld et al., 2007). However, due to the decreased number of interview transcripts available for analysis, thematic analysis was completed on a Microsoft Word document.

Due to the subjective nature of the inquiry methodology, and to increase credibility and rigour, reflexivity records were kept. These outlined the researcher's conscious efforts to reduce personal biases and to acknowledge those possessed (Angen, 2000; Liamputtong, 2009; Ryan, Coughlan, & Cronin, 2009). The credibility and rigour of this study was further developed through the implementation of member checking (Liamputtong, 2009; Ryan, Coughlan, & Cronin, 2009). This completion of member checking was offered to all participants, with the exclusion of the participant who completed her interviews by email. Only one participant chose to complete member checking. Both interview transcripts were posted to the participant, with the offer to respond by mail, email or phone. The participant elected to respond by phone. Member checking was completed to ensure that the individual's beliefs and comments were represented correctly, so that research findings were truly representative of the views of the participants (Curtin & Fossey, 2007).

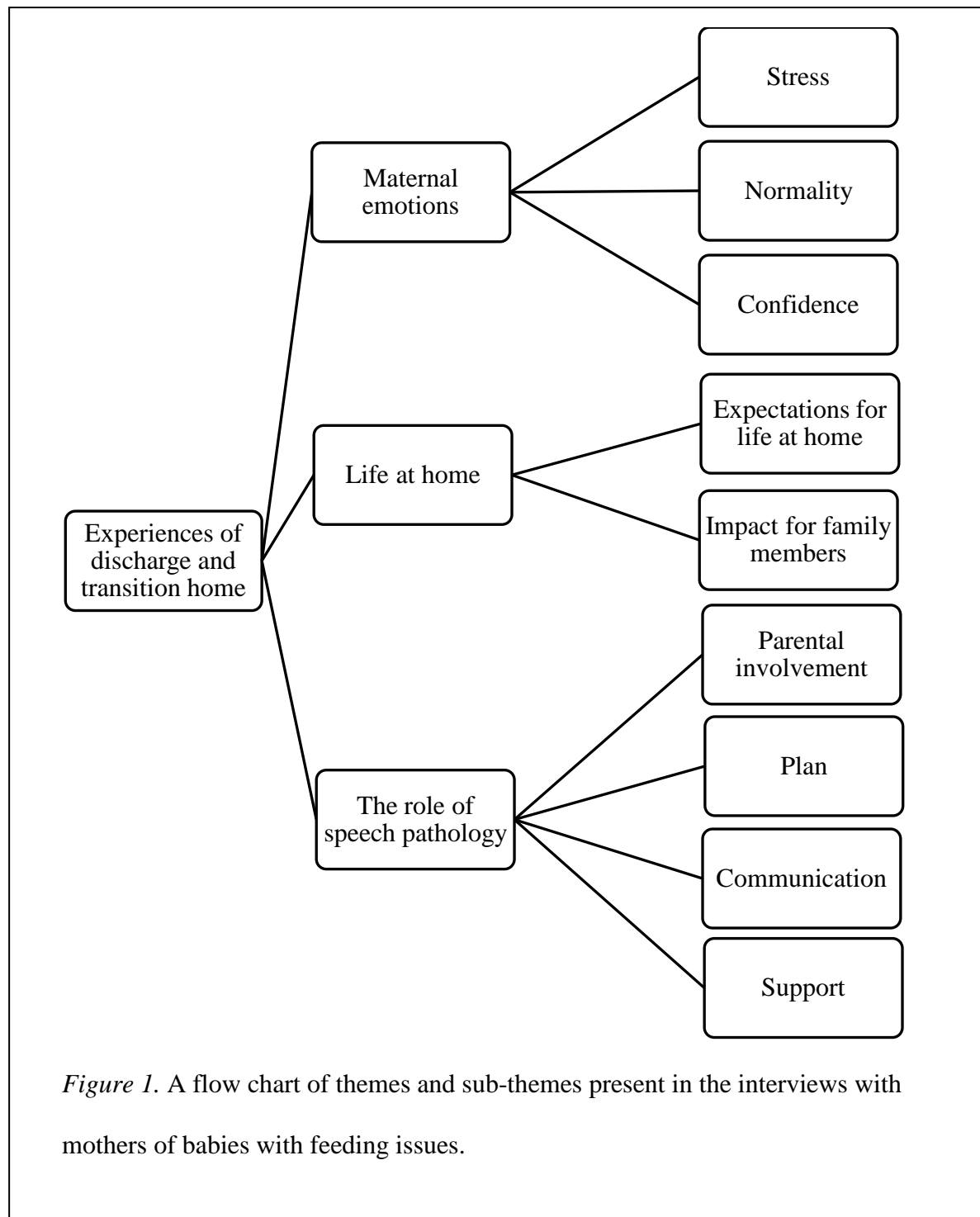
To achieve consistency and neutrality, an audit trail was used (Johnson & Waterfield, 2004). This involved the researcher keeping thorough notes of data, interpretation and changes to research plans, audio recordings, and interview transcripts (Tuckett, 2005). Documenting rationales for decisions made during the study was completed to ensure the confirmability of results and the overall credibility of the research (Lincoln & Guba, 1985).

In this study, researcher triangulation was implemented, which involved the interviewer and supervisor reviewing interview transcripts and identifying themes. Upon completion of all interview transcripts, comparisons between identified themes

were made and collated (Liamputtong, 2008). Triangulation across conditions was achieved through the variety of the participants' situations, and triangulation through the data collection on two different time occasions. The implementation of triangulation ensured the findings contain depth, breadth, complexity, richness and rigour (Denzin & Lincoln, 2005; McDonnell, Jones & Read, 2000). Further studies may be able to triangulate the findings from this proposed study with interview data from speech pathologists, observation and other sources of interest to create an even richer understanding of the phenomenon.

### **Results**

Through the six points of contact made with participants, two completed through email and four face-to-face, three main themes emerged. These were 'maternal emotions', 'the role of speech pathology', and 'home and family life'. A number of sub-themes were present within each of these, and are detailed below (see Figure 1).



To provide a greater understanding of the mothers interviewed, the Table 1 provides a brief overview of their circumstances. It should be noted that the names used are pseudonyms.

Table 1

*A summary of participants' social and medical circumstances*

<b>Mother</b>	<b>Marital Status</b>	<b>Baby's Siblings</b>	<b>Baby's medical issue</b>	<b>Hospital stay length</b>	<b>Primary feeding method</b>
Tia	Married	1 (twin)	Tetralogy of fallot	2 months (in and out)	Breastfeeding
Mel	Married	3 (foster children)	Foetal alcohol syndrome	1 week	Bottle-feeding
Renee	Married	No other children	Cardiomyopathy	1 month	Bottle-feeding
Charlotte	Married	2	Prematurity, Atrial septal defect	2 weeks	Nasogastric tube

### **Maternal Emotions**

Maternal emotions were a major topic of discussion during these interviews, both with participants who were the biological mothers of their baby and with the foster mother. The themes which arose were categorised into three sub-themes: 'stress', 'normality', and 'confidence'.

**Stress.** Stress was a major theme discussed by participants, and presented in a variety of forms. Participants expressed frustration, some reported nervousness and concern for their baby, with one reporting that they felt judged and disappointed. Regret and failure were recurring issues, especially for Mel, the foster carer of a baby with Foetal Alcohol Syndrome:

*... I've had a lot of babies in my care but, you kinda still feel like you're failing him even if you're trying everything...*

Mel also reported feeling judged by staff on the wards, giving her a sense of failure and responsibility for her baby's difficulties. She stated that whilst speech pathology staff were understanding and that "the finger hasn't ever been pointed" at her, other

ward staff had made her feel less supported:

*...and then when a couple of nurses got involved and they turned around and they said 'Oh, we've never had a problem feeding him. He's a good feeder.' It kind of puts all the emotions back in, 'cause you're, like, 'Well, what am I doing wrong?', 'cause I wouldn't be wasting all this time all week in hospital if he was a good feeder... and it's not like I don't have experience behind babies.*

She went on to discuss her concerns for life at home, because of her sense of responsibility and potential failure.

*... I don't like the feeling of being responsible if he loses weight again. And, I blame myself even though I know it's not me. Because I know he has issues and I know he does struggle, but it's still hard not to blame yourself when you're at home and you're their caregiver.*

Mel said that coping with her baby's feeding issues made her feel "nervous", "fearful", "panicked", and that the experience was "...a bit nerve-wracking."

Charlotte reported feeling "...frustrated in some ways as we have the same issues as always and no solutions", about the uncertainty of her baby's feeding abilities and progress. Tia explained that the main stress of her experience was not the physical and time strains on her personally, but rather emotional strain due to her concern for her newborn. About her son's feeding difficulties, she said:

*...for us it was an inconvenience... But for him, you know, it's uncomfortable.*

Disappointment was another recurring theme, with Tia commenting that "...disappointment is always 'round the corner..." She felt it unwise to try to predict how her baby would feed from one day to the next, due to his erratic feeding abilities, and

that "...you gotta take everything day by day, otherwise you're in for a big disappointment..."

**Normality.** The desire for normality was readily discussed by all participants. Tia expressed a strong desire for her baby to feed normally and not appear unwell or different:

*... you walk down the shops and he's got this nasogastric tube and people stop, and 'Why has he got...Is he on oxygen?' and you know, things like that and you're like 'No'. And people look at him like he's sick baby and we just didn't want that.*

This was a particularly difficult issue for Tia, as her baby was one of twins. Whilst all mothers reported comparing their babies' abilities to normally developing babies, Tia would directly compare her baby with feeding issues to her healthy baby of the same age. She stated:

*...Depressing, 'cause, you know, like, they're twins but he's so far behind, like, it's like they're two different babies... That's how we do treat it now.*

Renee, a first time mother, also reported making these comparisons to children who feed normally, commenting:

*... some other kids, they eat, like, everything.*

This demonstrates an overlap of themes, where the mothers' comparisons of their children to healthy babies reinforced their disappointment and sense of failure.

The use of tube feeding was also an important issue in terms of the desire for normality. Some mothers did report that a nasogastric tube gave them a sense of security and relieved the pressure for consistently effective oral feeds, stating:

*In other ways the tube is a relief, as I know that I have a way to feed him when he refuses food... (Charlotte)*

However, the more significant and recurring theme was a strong dislike for nasogastric tubes. The subject of tube feeding brought up strong emotions, with participants having very strong views on the topic. No mother reported indifference to tube feeding. The mothers stated:

*I just wanted the tube out so I was willing to try anything. (Tia)*

*I just wanted the nasogastric tube out. That's all I wanted. (Tia)*

*I hate the tube... (Charlotte)*

*...it is another thing to worry about, he pulls it out all the time and people stare at him when we go out. (Charlotte)*

Linked to this need for normality was participants' strong desire for their babies to be discharged from hospital and to return home. They reported that being in hospital was a highly stressful and emotional time, and that their main goal was for their child to be able to return home. Participants commented:

*I was desperate to get home. (Charlotte)*

*... we want to get back on with things back at home... (Mel)*

*... every time we go home it's a good feeling... (Tia)*

*...main concern was getting [my baby] home whatever it took. (Charlotte)*

*...we're quite fond of going home. (Tia)*

**Confidence.** Confidence, or lack thereof, was a theme readily discussed during interviews and was linked to going home – a place where they would be more confident. However, despite this strong assumption linking confidence with returning home, participants reported feeling underprepared and uninformed about their situations. Before discharge, Mel reported feeling prepared, saying:

*... I do feel comfortable knowing what to do now, if he leaves...*



She then explained that her baby's feeding abilities were to change, she would be unsure what to, other than to call speech pathology. She reported feeling nervous about this possible change. Charlotte reported feeling confident at the time of discharge, but did not anticipate the large gaps in her feeding knowledge once home:

*I was very confident at the time but as we settled back in at home many more questions arose.*

Tia stated that experience was a major factor for her feelings of confidence, saying that "... we've been through it, we can do it again." She also reported that her baby's resilience gave her hope for ongoing success with his feeding:

*He even surprised me, though.*

Parents expressed initial surprise at their babies' feeding issues, and reported and that they were not prepared to cope with these:

*... you think your baby's just going to open his mouth automatically...*

(Renee)

*I'd never had kids before. I'd never had to worry about what a baby can eat.*

(Tia)

Approximately one month after discharge, Tia reported feelings of accomplishment with the progress made, both through her baby's stay on the wards and at home, stating:

*We have had a long, hard, fight but it's been worth it...*

### **Life at Home**

This theme comprised two sub-themes, being 'expectations for life at home', and 'impact for family members'.

**Expectations for life at home.** When in hospital, participants were eager to return home with their babies. Mothers had varying expectations of this transition,

with Tia commenting it will be “a lot easier”, and “... a little bit difficult at first...”, but stating “I think it’s going to improve.” Renee expected very little change between being in hospital and at home, acknowledging that the feeding problems continued despite a change of context. Charlotte, who was keen to be discharged from hospital, reported her transition home was more difficult than anticipated, which frustrated her:

*From this feed they expected him to feed well at home, which he has not continued to do.*

Tia reported that being home involved stressors and issues she had not considered, particularly concerning caring for two babies at once. She said that being at home was “... hard. It’s horrible. Nah, I think, because they're both teething...” However, overall she found the transition to home a positive experience:

*... I thought it’d be a lot harder than what it was.*

Tia pushed for progress and success with feeding at home, and felt more confident at the time of the second interview, especially involving trying new foods with her baby, saying:

*... you’s [sic] got to get him to open his mouth and shove it in, otherwise he won’t try new stuff....*

Participants also reported feeling more in control at home:

*I can, like, control everything, her foods, her feeding, even, like, with her drugs I have no problem to give them on time. I’ve got a book on her, with, like, everything written down. (Renee)*

*...at the end of the day, you know, you’re the one that’s at home with the child. You’re the one that needs to push it... (Tia)*

Tia then went on to explain the benefit of this, saying:

*... I think that pushing him was the best thing that we ever did...*

**Impact for family members.** A major concern for the mothers interviewed whilst in hospital was the issue of caring for both their child in hospital and their other children at home. Whilst all interviewed mothers lived at home with their husbands, they still felt stressed by their responsibilities to all their children. Participants said:

*... I had been away from my other children (4 and 2) for close to 2 weeks and they were becoming very distressed. (Charlotte)*

*... it makes it hard when you have a baby in hospital who's relying on you and you've got three kids at home relying on you. (Mel)*

*... it takes a big toll out of us, because we have three other kids. (Mel)*

*Its' horrible being here, and the baby's at home. (Tia)*

Tia also reported concerns over health issues when returning home, saying:

*I'm a bit concerned because my other twin has got a cold.*

However, she commented on the suggestion by speech pathology that her baby learn appropriate feeding behaviours from his twin brother. Tia reported speech pathology advised:

*... 'let him watch his brother, 'cause he's going to copy what he does', and he did.*

Tia also expressed the value of support from family members during the transition home. She said:

*...we cope, you know, but my mum's here now so, so that's a bonus.*

*I get my sister to look after him...*

*I taught her how to do the nasogastric feeding and she's, you know, if I can't do it then my sister is quite good with them...it's good to have someone that can do that.*

Conversely, Charlotte felt she was not receiving enough support at home, and was

required to use the internet to gain this information:

*Luckily there are a lot of online forums and Facebook pages about tube feeding that I have been able to access for support.*

### **The Role of Speech Pathology**

This theme, which relates to the involvement and practice of speech pathology, comprises four subthemes. These subthemes are ‘plan’, ‘communication’, ‘parental involvement’ and ‘support’.

**Parental involvement.** Participants reported on the importance of their role in the decision making process. About the speech pathology staff, in both inpatient and outpatient settings, Tia stated “... they’ve got just the right amount of involvement.” Participants suggested that it is important to feel involved in intervention, to positively contribute to their baby’s situation. This is consistent with Tia’s comments regarding feeling as though she were a member of the management team:

*...to know that you’re kind of contributing to his feeding ... I think that’s a big part, as well.*

The fact that speech pathology staff encouraged mothers to give their opinions and have their wants valued during the decision-making progress was commented upon by all participants, and was a highly prominent sub-theme. It was important that participants felt they were being heard, but also had the specialist input from the speech pathologist. Tia expressed her strong gratitude and affinity for being treated like an informed member of the decision-making team:

*...if I had a problem or wanted to try something they’d say, ‘Okay. But, how about this as well, with it.’*

*... if I wanted something, or if I had an idea, you know, that wasn’t going to work, but I wanted to try it, they would go with it.*

*... they don't look at you like you're an idiot and that you don't know what you're doing.*

Not only did Tia feel involved, but she also demonstrated that, with time, she became more assertive and demonstrative, actually feeling as if she could direct what was happening:

*... he pulled his nasogastric tube and I said to the nurse 'just leave it'.*

This involvement and sense of control was important to the participants because, as they pointed out, they are the child's caregiver, and would be the ones responsible for their care once home. Tia stated, about speech pathology decisions and recommendations:

*... at the end of the day, they can only really guide you. You know, they can't force you to do anything...*

Tia also commented favourably that her speech pathologist allowed her to work at her own pace, and did not force or rush intervention:

*... they don't push you and they don't, like hassle...*

**Plan.** Participants suggested that another important role for speech pathology was to provide a realistic and informative plan of their child's likely feeding abilities, and of how speech pathology will be involved after discharge. Whilst in hospital, Tia reported that it was highly important for speech pathology to provide her with realistic outcomes for her son's feeding. She said that speech pathologists "... reassure you at the same time but they don't tell you to get your hopes up...", and stated that:

*... they don't live in a fantasy world.*

It was important for her that "... they tell you the worst outcome and the best outcome...", so that if her son's feeding did deteriorate, or not improve as predicted

by the speech pathologist, she would be prepared and able to better cope:

*... You are disappointed but you're not, you know, um, it doesn't break your heart. (Tia).*

As mentioned previously, some participants reported the existence of a back-up plan was reassuring. For example, Charlotte said that she was "... happy we have the NG tube as back up...", whilst Mel commented on her reassurance from the nasogastric tube, saying she "...was a bit more comfortable knowing that there was a backup..."

Participants, in particular Tia and Renee, reported feeling reassured by speech pathologists planning in response to the skill acquisition pace of the baby, and not forcing progress:

*... they just reckon, give him some time. After, we can work on it then. (Tia).*

The importance of speech pathology providing a plan, particularly for discharge and once their child was an outpatient, was discussed readily by the participants. Two of the mothers found this area to be severely neglected, as highlighted by their comments:

*On discharge I expected more of a plan. (Charlotte)*

*...no reason for my son's issues has been given and no plan to wean him from the NG has been given. (Charlotte)*

*... I'm not sure exactly what they want to do... (Renee)*

*...I am still a little unsure what role SP will have for us in the future. (Charlotte)*

*... I'm not sure and what they want to exactly see... (Renee)*

*... I am waiting for the review with the whole team to get a forward plan.*

(Charlotte)

The crucial nature of how speech pathology could best support these mothers with clear plans is explored further in the discussion.

**Communication.** Participants reported limited knowledge of the role and responsibilities of speech pathologists, with regard to feeding. Participants commented they were initially confused by the involvement of speech pathology services:

*... was quite shocked they were, um, to find out that you were under speech, 'cause I said to them that he doesn't talk yet. (Tia)*

*... I didn't know anything about the speech pathology... (Renee)*

*... when they come to the hospital, like, asking about [my baby], I was like 'Okay, who are they and I don't know anything about them'. (Renee)*

*... I didn't actually know that speech pathology was involved in, like, feeding as well. (Tia)*

Participants noted the need for speech pathology to explain their role, with Tia commenting "... they said who they were and things like that", and Renee commenting "... they explained it to me...". Charlotte felt that more information should have been given concerning both speech pathology and the feeding team as a whole:

*A printout of information about the role of each member of the feeding team and some information on what they would do in the future would have been useful.*

Participants also commented on their preference for written information, rather than solely verbal:

*... they write it down for you, as well, so you know you can take it home with you and it's not just all in your head, and kind of jumbled. (Tia)*

They also reported finding written information “really helpful” (Renee) and effective in making them feel “prepared” (Mel) for discharge and the transition home.

With regard to receiving discharge and management information, personal preference largely dictated when participants wished to receive the information and how much they wanted to receive. For example, Tia said that “...two or three days before he got discharged I learnt how to do the nasogastric tubing. So, it was kind of, very rushed.”, whilst Mel reported that, with regard to learning how to prepare thickened fluids, “... on the day of discharge would be fine ‘cause I can’t, yeah, really make it up until he gets home anyway.”

In terms of the amount of information provided regarding feeding management at home, responses were very individual. Renee, who spoke English as an additional language, said that “... I prefer step-by-step, because I’m not going to read all that information if I get them all together.” She then said that some information should be given before discharge to allow time for preparation of the home environment and for asking questions:

*... I knew what I have to do to start with, so with I ask my husband to prepare everything for me before we get home.*

Another recurring and predominant sub-theme was the need for the speech pathology service to be accessible and to have follow-up:

*...I’d just, you know, ask them questions. Pick their brains. (Tia)*

*... they might just ring up and see how he’s going. (Tia)*

*... it’s reassuring that they still know, and that they’re thinking about him... (Tia)*



Participants also reported that it was necessary for their peace of mind, that they had the contact details of the speech pathology department:

*...it would make life easier just knowing that there will be somebody there I can at least get some information from. (Mel)*

*... if I'm unsure about something I can ring them and ask. (Tia)*

*So now that I have contacts that would make it a lot easier. Yeah, like, I wouldn't feel alone. (Mel)*

Some participants felt that their speech pathologists lacked adequate involvement, and did not gain a full view of their babies' feeding abilities:

*It was unfortunate that the SP at PMH was only able to observe one feed... (Charlotte)*

*It would be good if they could watch him feed more regular... (Mel)*

*Both me and his Pediatrician [sic] are not convinced that his suck is completely safe... (Charlotte)*

However, other participants reported that they had been seen daily by their speech pathologist, which gave them confidence that they were receiving appropriate management, and helped the mothers feel better understood. Mel said:

*... they've seen the way he drinks when he's having a bad day.*

*... understanding that it's not just me who thinks there's something wrong with him, like, they've actually witnessed what I've been talking about.*

*... it has helped because they could see it wasn't just me trying to explain myself, they could actually see where I was coming from.*

All participants, including those who had daily contact with their speech pathologist, reported some feelings of being uninformed or lacking complete understanding of their child's condition. Comments on this included:

*... you'd just think 'Oh for God's sake! Why is he doing this?' (Tia)*

*I guess we just didn't think that, um, it would have that big an effect...*

*(Tia)*

*... then I was stressing out why she's not eating... (Renee)*

Participants reported that speech pathology staff were receptive to questions, yet still reported feeling partially uninformed on decisions and issues:

*...it does get a bit confusing when, um, that was the plan, and then the plan's now, kind of, changed. (Mel)*

*... not very well informed. They have tried to inform me, but it's just really confusing... (Mel)*

*... I don't know, like, why she's doing this. So, I want them to see her more and to check, like, what she's doing, why she's doing this... (Renee)*

Mel noted, however, that being informed and having an understanding of the baby's condition was only necessary if the information was immediately relevant, stating:

*...if he's still drinking really well tomorrow then, I guess they don't need to make me understand.*

Notably, Charlotte felt she lacked understanding throughout her and her baby's stay in hospital, as well as once she was home. Charlotte reported that her baby was admitted at PMH to have a videofluoroscopy, but was discharged before this was completed. She said:

*.... I am confused by this as it was one of the reasons we went to stay at PMH.*

She reported feeling uninformed about her child's condition, saying "His feeding is very erratic and we don't know why as yet", and then discussed her lack of understanding of the management of the nasogastric tube with which her baby was

discharged:

*Things I have not been told include the long term impact of having a tube, how long they will leave the tube in, if the tube will effect [sic] his speech, if the tube is in long term are there other options that are not so visual, how the tube will be impact [sic] on the introduction of solids. I have also not been given much information on how to gravity feed and ways to make tube feeding more easy in a busy household.*

Whilst most participants focused on the communication between themselves and their speech pathologist, Mel commented on the need for speech pathologists to better communicate with the nursing staff, saying:

*I think they should all communicate a bit more together, maybe. Which would make it easier on the parents...  
...the information isn't getting read and things backtrack and they do their own thing.  
I hear one thing from one lot of people and one thing from a different lot.  
...be fine when it's just me dealing with the speech pathology, but it's when other people get involved, which makes things a bit confusing.  
... you get told one thing and then you get told another. So, that makes it really hard...*

**Support.** Participants suggested that one of the most important roles for speech pathologists was to reassure and emotionally support mothers. They reported the emotional support gave them hope, helping them better cope with their child's feeding difficulties:

*... I think the support is the biggest thing. (Tia)*  
*... they've been there to help me through it all. (Mel)*

*... to just be there to support us through the whole thing... (Mel)*

*...they make life easier. (Tia)*

*... I've never been by myself. (Tia)*

Participants were also relieved by reassurance from speech pathology staff regarding their baby's feeding, with participants saying:

*... they would reassure you and say that, you know, it doesn't matter. (Tia)*

*... they said that, everything, don't worry, you know, you've done it before, you can do it again. (Tia)*

*... it was, like, more relaxed and then, yeah, I can leave her 'til she gets ready. (Renee)*

Tia found her speech pathologists support particularly reassuring when discussing the possibility of her baby having a percutaneous endoscopic gastrostomy (PEG):

*...one of the cardiologist doctors made a comment about maybe seeing him for a PEG, and I was kind of like 'nah, I don't think so', and they kind of said 'don't worry, he doesn't need one. He, he will feed one day. He's not going to be, you know, a baby that's never going to feed.' So, I think that they're, they're like, you know, they support you emotionally, as well. You know, like, it, it is hard. It's not a nice feeling having to feed your baby through a tube, and, you know, they kind of, yeah, they helped you through it...*

Participants reported that speech pathologists' determination and willingness to try alternate feeding approaches was highly reassuring to them, and gave them a "...little bit more hope..." When talking about the potential need for nasogastric tube feeding for her baby, Tia reported that the speech pathologist "...said that there are different ways that they can get around that, and they were really good about that".

## Discussion

The aim of this research study was to gain a deeper understanding of parental experiences of discharge from hospital, transition from hospital to home with a baby with feeding issues, the role of speech pathology in that discharge and transition, and parental perceptions of the child's feeding outcomes following speech pathology intervention. Through the completion of interviews with four mothers of babies with feeding issues, the voices of a largely under heard population are discovered and presented. This cohort is underrepresented in the literature, which is likely due to their potentially limited contact with speech pathologists following discharge (Dodrill, McMahon, Donovan, & Cleghorn, 2008). The results of this study suggest that discharge from hospital is neither the end of these individuals' stories, nor the end of the need for speech pathology support and involvement.

### **Discharge**

The results show that discharge from hospital was a vulnerable time for mothers of newborns with feeding issues. They suggest that mothers may have experienced a sense of failure and disappointment, and felt responsible for their babies' difficulties. It appears that these emotions stemmed from a strong desire for normality, with mothers longing for their children to have a healthy appearance. Consistent with the research of Fowlie and McHaffie (2004), the findings of this study suggest that mothers may have felt unprepared for managing a child with feeding issues, and without adequate speech pathology involvement, felt uninformed about the circumstances in which they found themselves. This adds weight to the current literature, which suggests that mothers of ill babies have great difficulty in understanding and coping with their situations (Delmore-Ko, Pancer, Hunsberger, & Pratt, 2000; Feldman & Nash, 1984).

A recurring theme of the research was that mothers reported feelings of

nervousness, stress and anxiety associated with hospital discharge, which is consistent with the findings of Bissell and Long (2003). Contradictory to their research, however, findings of this study suggest that despite these emotions, mothers had a strong desire to be discharged and begin the transition home. This appeared to resonate particularly for mothers with children at home. They reported difficulty coping with needs of both groups of children, and, as a result, appeared more likely to push for hospital discharge. These findings imply that, in spite of the physical and emotional strain of caring for a baby with feeding issues, the mothers' main desire was for their lives to achieve normality. This is consistent with the research of Judson (2004), which suggests mothers feel a sense of loss when their child is not able to feed as others do.

Findings of this study also suggest that mothers experienced some degree of underpreparedness for discharge. Whilst only one baby was in foster care, these feelings appeared most prevalent in the women who were biological mothers of their babies. Only one mother in this study had a tube-fed baby at the time of discharge, but it is noteworthy that she presented more stressed and uncertain at home than mothers of orally fed babies. This is supported by the findings of Adams, Gordon, and Spangler (1999), and is likely due to mothers feeling uninformed about tube management, and also confronted by the aesthetics of having a tube in place. Mothers used emotive language to express their experiences, including the terms 'struggle' and 'fight', suggesting the intense nature of their emotions (Cameron, 2007).

### **Transition Home**

This study found that, once mothers returned home, additional questions arose. Questions most frequently related to likely developmental progression of the baby, timelines for achieving normality, and speech pathology involvement with these

issues. Whilst findings imply that some individuals expected the transition home to be a smooth and wholly positive experience, mothers were confronted with unforeseen obstacles. For these individuals, leaving hospital did not necessarily equate to the normality they predicted, which may have contributed to a frustrating and uncertain transition. This is partially consistent with the findings of Sneath (2009), in that mothers experienced growing concern and uncertainty at home. However, Sneath's (2009) study suggests that parents did not expect the attainment of normality once home to the same extent expressed by the mothers in this study.

Confidence held regarding the raising and caring of the child at home appeared to rebuild itself after seeing positive changes and progress with feeding. These emotions may have been responsible for the findings that suggest mothers were more likely to strive for greater gains in their baby's feeding abilities and to push them to try new foods. This may have been responsible for the feelings of pride, self-worth and achievement, with determination and optimism for further development.

Another important aspect of gaining confidence during the transition home may be attributed to an increased sense of control over the environment. Once home, mothers were given a sense of not only being the primary care-giver, but also the primary decision-maker. The study indicates that speech pathologists largely succeed in involving mothers in decision-making whilst in hospital. Nonetheless, feelings of competence and control appeared to increase during the transition home. Adding to the findings of Fowlie and McHaffie (2004), results suggest these individuals were glad to be home, but frustration and anxiety increased over time if speech pathology contact was not maintained.

Whilst undertaking the transition home, findings of this study suggest that support from other family members was important. Results indicate mothers may

have experienced increased feelings of empowerment and control when they educated other family members regarding issues such tube feeding. This appeared to elicit greater feelings of confidence than were gained by reassurance from others alone.

Interview findings suggest that mothers may have felt compelled to access alternate support and information networks if they were receiving insufficient contact from their speech pathologist following discharge. The internet was cited as an important information and support source. This indicates the resourceful and determined nature of mothers, but also suggests the importance of constant and thorough speech pathology involvement throughout discharge and transition home.

### **The Role of Speech Pathology**

The findings of this study indicate that families place great importance on speech pathology services, and value the support given through effective communication of ideas. Results suggest that subtle actions by speech pathologists may have a positive impact on the discharge and transition process, and help ease the long term emotional strain of raising a baby with feeding issues.

This study suggests that it is important for mothers to feel involved and valued in the decision-making process, whilst receiving speech pathology services. Results indicate that involving mothers may help ensure they are up-to-date with current management plans and skill acquisition. This may allow mothers to feel informed about decisions and plans, facilitating a greater understanding of their child's abilities. This has consistency with the findings of Hoddinott and Pill (2000), who suggest that mothers prefer facilitation of the implementation of their own ideas. However, Hoddinott and Pill (2000) suggest that mothers may resent constant suggestions made by health professionals, which was not reported in this study.

Participants noted that they felt reassured by the knowledge of a back-up plan,



with regards to feeding methods. The existence of this plan appeared to alleviate pressure on mother to succeed with initial feeding strategies, especially once home.

The findings also suggest that constant, effective and tailored information was integral in keeping mothers informed. Consistent involvement in speech pathology management may facilitate the expansion of knowledge and information acquisition. Findings noted that some discharges occurred suddenly, with speech pathologists being unaware discharge was imminent. This may have lead to discharge information being rushed or partially omitted by speech pathology staff. Consistent involvement may ensure that, were discharge to occur unexpectedly, mothers already have a certain amount of understanding and feel in control of the baby. This is important, as Bernstein et al. (2002) suggest that perceptions of readiness for discharge may vary greatly between mother and speech pathologist.

The need for absolutely clarity when conveying information, relating to both communication with mothers and with other hospital staff, was highlighted in the findings of this study. Results suggest that a lack of understanding by the mother may be largely due to receiving conflicting information from hospital staff. This is consistent with the literature, which suggests that mothers receive inconsistent advice from health professionals concerning the management of a baby with feeding issues, especially when tube feeding is involved (Adams, Gordon, & Spangler, 1999; Hoddinott, & Pill, 2000). Results suggest that parents who received conflicting information were more likely to be stressed and feel uninformed. This is also consistent with the research findings of Adams, Gordon, and Spangler (1999) and Hoddinott, and Pill (2000).

Effective communication appears to begin with speech pathologists informing mothers of the roles and responsibilities of a speech pathologist, and providing a brief

overview of the aims of speech pathology. Preference for the timing of discharge information was highly individual, with the general consensus being two to three days prior to discharge. This allowed mothers to practice the recommendations provided, whilst maintaining current relevancy.

Mothers reported difficulty in comprehending speech pathology education. This was apparent for mothers both with and without English as their primary language. This is pertinent as the findings of Fowle and McHaffie (2004) suggest that individuals may experience stress when they lack understanding about their child's management. The results of this study suggest participants preferred to receive written information to support that conveyed orally. Whilst participants cited the ability to refer to this information later as a reason for this, a contributing factor may also be the ease of comprehension of written language over spoken language (Houts, Doak, Doak, & Loscalzo, 2006). Their research also suggests that the presentation of images with written information may be even more effective (Houts, Doak, Doak, & Loscalzo, 2006).

The results suggest that the accessibility of speech pathology staff was crucial to the mothers feeling supported, both on the wards and at home. Accessibility included a reassurance that the speech pathologists could be contacted readily, with the provision of speech pathology contact details. Mothers reported appreciating daily contact with speech pathologists on the wards, even if only in an informal manner. Once home they were aware that daily contact was not feasible, but expressed a desire for more frequent contact than was being received.

Results also suggest that it may be beneficial for speech pathologists to make contact with the mothers of babies with feeding issues within one to two days of discharge. Findings indicate that parents found this necessary to provide any

information omitted at discharge, answer new questions which may have arisen during the transition home, and to provide emotional support.

Emotional support from speech pathology staff appears to be a major contributing factor for the ability of mothers to cope and experience a largely positive discharge and transition home. Therefore, findings of this study suggest that the role of the speech pathologist may involve listening to the concerns of mothers, and providing information, reassurance, and hope. However, results suggest that it is important that speech pathologists also provide realistic prognoses to facilitate the ability of mothers to cope, especially if large gains in feeding abilities are not achieved.

### **Limitations**

It could be suggested that recruitment from one hospital is a limitation for this study, restricting the potential diversity of responses. However, PMH is the primary paediatric medical centre for Western Australia, where the majority of newborns with feeding issues and their families are seen. Therefore, this study provides parental perceptions after receiving the best possible and most typical service.

Another potential limitation involves the small sample size (i.e. four parents). This could be countered by the argument that it is the richness and depth of understanding which is required for this study, rather than a prescribed minimum sample size (Liamputtong, 2009). Completing two interviews, whenever possible, provided a valuable, longitudinal focus, permitting analysis across participants and time. Furthermore, the emergence of recurrent themes adds strength to findings of this study.

As discharge is a highly sensitive time, it is possible that a degree of sampling bias occurred. This is evidenced by the limited number of participants, despite more

than four families being discharged during the data collection period.

### **Future Research**

This is a highly exploratory study, motivated by previous literature suggesting discharge and transition home is time of stress, concern and confusion for parents (Hewetson & Singh, 2009). Speech pathology has limited understanding on the impact of discharge, and may benefit from further research in the area. Future studies could further explore the aetiology of stress for both biological and non-biological mothers.

Whilst participation was extended to both parents in this research study, only mothers elected to be interviewed. Therefore, little is known about the impact of discharge and transition home for fathers of newborns with feeding issues. A similar research design could focus upon the experiences of fathers, to help speech pathologists be responsive to their needs. Furthermore, whilst this topic diverges slightly from the scope of speech pathology, a longitudinal study exploring the long term impacts of feeding issues on families may add to the current literature. Findings from this may facilitate the holistic practice of speech pathologists.

### **Implications**

These interviews suggest that speech pathologists play a vital role in the physical and emotional management of mothers with newborns experiencing feeding difficulties. This role may extend from admission to hospital to the transition home and beyond. As mentioned previously, this appears to be a vulnerable, stressful and emotional time for mothers. However, results suggest that there are a number of ways in which speech pathologists can contribute to a positive and successful discharge and transition. In light of this research, it may be beneficial for speech pathologists to

implement the following recommendations when interacting with mothers of babies with feeding issues:

- Introduce self and provide overview of role
- Communicate in simple, clear language
- Provide written information
- Reassure contact availability and provide contact details
- Actively listen and respond to questions and concerns
- Acknowledge the additional strain of having a tube fed baby
- Provide support, reassurance, and realistic prognoses
- Involve mothers in the decision-making process
- Ensure mothers remain updated regarding management plans, including back-up plans
- Provide discharge information one to two days prior to the transition home
- Provide information regarding outpatient services, scheduling the first appointment date prior to discharge
- Contact family within three days of discharge

Whilst these recommendations are largely addressed in the Speech Pathology Australia Scope of Practice (2003), this research clearly demonstrates the importance and value of following these guidelines. The implementation of the suggestions documented both in this study and in the Scope of Practice of Speech Pathology (Speech Pathology Australia, 2003) may allow for a smooth discharge and transition home, providing mothers with the best possible practice.

### **Conclusion**

The study suggests that the role of speech pathology is vital in providing support to the mothers of newborn children experiencing feeding issues. There may be many stresses involved at this time, and the severity of the situation may be alleviated through caring, on-going professional support. A comprehensive understanding of the issues faced is imperative if speech pathologists are to adequately respond to the concerns of parents in these situations. This study may begin to sensitise speech pathologists to the issues and experiences of mothers of newborns with feeding difficulties. The recommendations presented may help speech pathologists to be more responsive to the needs of parents, providing a holistic service whilst facilitating positive discharge and transition for this vulnerable yet determined population.

### References

- Adams, R., Gordon, C., & Spangler, A. (1999). Maternal stress in caring for children with feeding disabilities: Implications for health care providers. *Journal of the American Dietetic Association*, 99(8), 962–966.
- Angen, M. (2000). Evaluating interpretive inquiry: Reviewing the validity debate and opening the dialogue. *Qualitative Health Research*, 10(3), 378-395.
- Auld, W., Diker, A., Bock, M., Boushey, C., Bruhn, C., Cluskey, M., ... Zaghloul, S. (2007). Development of a decision tree to determine appropriateness of nvivo in analyzing qualitative data sets. *Journal of Nutrition Education and Behavior*, 39(1), 37-47.
- Barriball, K., & While, A. (1994). Collecting data using a semi-structured interview: A discussion paper. *Journal of Advanced Nursing*, 19(2), 328-335.
- Bernstein, H., Spino, C., Baker, A., Slora, E., Touloukian, C., & McCormick, M. (2002). Postpartum discharge: Do varying perception of readiness impact health outcomes? *Ambulatory Paediatrics*, 2(1), 388-395.
- Bird, C. (2005). How I stopped dreading and learned to love transcription. *Qualitative Inquiry*, 11(2), 226-248.
- Bissell, G., & Long, T. (2003). From the neonatal unit to home: How do parents adapt to life at home with their baby? *Journal of Neonatal Nursing*, 9(1), 7–12.
- Boyatzis, R. (1998). *Transforming Qualitative Information: Thematic Analysis and Code Development*. Thousand Oaks, CA: Sage.
- Braun, V., & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Cameron, L. (2007). Patterns of metaphor use in reconciliation talk. *Discourse and Society*, 18(2), 197-222.

Cameron, H. (2011). *Feeding assessment and intervention for the 0 to 3 year old*.

ECU Paediatric Feeding lecture. (Available from Princess Margaret Hospital, Subiaco, Western Australia, 6008).

Corbin, J., & Morse, J. (2003). The unstructured interactive interview: Issues of reciprocity and risk when dealing with sensitive topics. *Qualitative Inquiry*, 9(3), 335-354.

Cresswell, J. (2007). *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. (2<sup>nd</sup> ed.). Thousand Oaks, CA: Sage Publications.

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

Delmore-Ko, P., Pancer, S., Hunsberger, P., & Pratt, M. (2000). Becoming a parent: The relation between prenatal expectations and postnatal experience. *Journal of Family Psychology*, 14(4), 625- 640.

Denzin, N., & Lincoln, K. (Eds.). (2005). *The Sage Handbook of Qualitative Research* (3<sup>rd</sup> ed.). Thousand Oaks, CA: Sage Publications.

DiLillo, D., DeGue, S., Kras, S. Di Loreto-Colgan, A., & Nash, C. (2006). Participant responses to retrospective surveys of child maltreatment: does mode of assessment matter? *Violence and Victims*, 21(4), 410–424.

Dodrill, P., McMahon, S., Donovan, T., & Cleghorn, G. (2008). Current management of transitional feeding issues in preterm neonates born in Queensland, Australia. *Early Human Development*, 84(10), 637-643.

Firth, H., Grimes, A., Poppleton, H., Hall, R., & Richold, P. (2000). Assessment of parents' concerns and evaluation of outcomes. *Journal of Public Health Medicine*, 22(1), 473, 478.



- Feldman, S., & Nash, S. (1984). The transition from expectancy to parenthood: Impact of the firstborn child on men and women. *Sex Roles, 11*(1), 61-78.
- Fowle, P., & McHaffie, H. (2004). Supporting parents in the neonatal unit. *British Medical Journal, 329*(1), 1336– 1338.
- Garro, A., Thurman, S., Kerwin, M., & Ducette, J. (2005). Parent/caregiver stress during pediatric hospitalization for chronic feeding problems. *Journal of Pediatric Nursing, 20*(4), 268- 275.
- Graungaard, A., & Skov, L. (2006). Why do we need a diagnosis? A qualitative study of parents' experiences, coping and needs, when the newborn child is severely disabled. *Child Care, Health and Development, 33*(3), 296–307.
- Heweston, R., & Singh, S. (2009). The lived experiences of mothers with children with chronic swallowing and/or feeding problems. *Dysphagia, 24*(3), 322-332.
- Hoddinott, P., & Pill, R. (2000). A qualitative study of women's views about how health professionals communicate about infant feeding. *Health Expectations, 3*(4), 224–233.
- Houts, P., Doak, C., Doak, L., & Loscalzo, M. (2006). The role of pictures in improving health communication a review of research on attention, comprehension, recall, and adherence. *Patient Education and Counseling, 61*(2), 173–190.
- Johnson, R., & Waterfield, J. (2004). Making words count: the value of qualitative research. *Physiotherapy Research International, 9*(3), 121-131.
- Judson, L. (2004). Protective care: Mothering a child dependent on parenteral nutrition. *Journal of Family Nursing, 10*(1), 93-120
- Kerwin, M. (1999). Empirically supported treatments in pediatric psychology:

- Severe feeding problems. *Journal of Pediatric Psychology*, 24(1), 193-214.
- Lapadat, J. & Lindsay, A. (1999). Transcription in research and practice: From standardization of technique to interpretive positioning. *Qualitative Inquiry*, 5(1), 64-86.
- Liamputtong, P. (2008). *Doing Cross-Cultural Research: Ethical and Methodological Perspectives*. Dordrecht, The Netherlands: Springer.
- Liamputtong, P. (2009) *Qualitative research methods*. (3rd ed.). Melbourne, Australia: Oxford University Press.
- Lincoln, Y., & Guba, S. (1985). *Naturalistic Inquiry*. Beverley Hills, CA: Sage Publications.
- Linscheid, T. (2006). Behavioral treatments for pediatric feeding disorders. *Behavior Modification*, 30(1), 6-23.
- MacDonald, M. (2007). Mothers of pre-term infants in neonate intensive care. *Early Child Development and Care*, 177(8), 821-838.
- Manikam, R., & Perman, J. (2000). Pediatric feeding disorders. *Journal of Clinical Gastroenterology*, 30(1), 34- 46.
- Mathisen, B., Carey, L., & O'Brien, A. (2012). Incorporating speech-language pathology within Australian neonatal intensive care units. *Journal of Paediatrics and Child Health*, 48(9), 823-827.
- May, K. (1989). Interview techniques in qualitative research: Concerns and challenges. In J. M. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue* (pp. 171-182). Gaithersburg, MD: Aspen.
- McDonnell, A., Jones, M., & Read, S. (2000). Practical considerations in case study research: the relationship between methodology and process. *Journal of Advanced Nursing*, 32(2), 383-390.

- Miller, C. (2011). Aspiration and swallowing disfunction in pediatric patients. *Infant, Child and Adolescent Nutrition*, 3(6), 336- 343.
- Osborne, J. (1994). Some similarities and differences among phenomenological and other methods of psychological qualitative research. *Canadian Psychology*, 35(2), 167-189.
- Pancer, S., Pratt, M., Hunsberger, B., & Gallant, M. (2000). Thinking ahead: Complexity of expectations and the transition to parenthood. *Journal of Personality*, 68(2), 253-279.
- Patton, M. (2002). *Qualitative Research and Evaluation Methods* (3<sup>rd</sup> ed.). Thousand Oaks, CA: Sage Publications.
- Rubin, H., & Rubin, I. (1995). *Qualitative Interviewing: The Art of Hearing Data*. Thousand Oaks, CA: Sage Publications.
- Ryan, F., Coughlan, M., & Cronin, P. (2009). Interviewing in qualitative research: The one-to-one interview. *International Journal of Therapy and Rehabilitation*, 16(6), 309–314.
- Sneath, N. (2009). Discharge teaching in the NICU: are parents prepared? An integrative review of parents' perceptions. *Neonatal Network: The Journal of Neonatal Nursing*, 28(4), 237-246.
- Speech Pathology Australia. (2003). *Scope of Practice in Speech Pathology*. Speech Pathology Australia, Melbourne.
- Stout, J. (1982). What is the meaning of a text?. *New Literary History*, 14(1), 1-12.
- Todres, L. (2005). Clarifying the life-world: Descriptive phenomenology. In I. Holloway (Ed.), *Qualitative research in health care*. Buckinghamshire: Open University Press.
- Tuckett, A. (2005). Part II. Rigour in qualitative research: complexities and

solutions. *Nurse Researcher*, 13 (1), 29-42.

Weiss, M., Johnson, N., Malin, S., Jerofke, T., Lang, C., & Sherburne, E. (2008).

Readiness for discharge in parents of hospitalized children. *Journal of Pediatric Nursing*, 23(4), 282-295.

Ziev, M. (1999). Earliest intervention: speech-language pathology services in the

neonatal intensive care unit. *American Speech Language Hearing Association*, 41(3), 32-36.

## Appendix A

### Participant Information Sheet

#### **Newborns with feeding issues: parental perceptions of the hospital discharge, transition home and the role of speech pathology**

Investigators:

Katie Ilich  
Dr Deborah Hersh  
*Edith Cowan University*

Corina Gill  
*Princess Margaret Hospital*

Princess Margaret Hospital Speech Pathologist, Corina Gill, has identified you as a potential participant for this research study. You are free to say 'no' to participating in this study. Choosing to or not to participate will have no direct impact on the services or quality of service you receive from Princess Margaret Hospital.

The aim of this research is to gain a deeper understanding of parental experiences of discharge from hospital and its impact on their ability to care for their baby with feeding issues. We will explore the role of speech pathology in that discharge and transition and parents' perception of their child's feeding outcomes with speech pathology intervention. This information should help speech pathology service be responsive to the needs of parents with these children at discharge from hospital. I would like to **interview** you **twice**. One or both parents may participate. The first interview will take place on the wards, or in a nearby room, at Princess Margaret Hospital, up to one day before your child's discharge from hospital. The second interview will take place at your home or another location that is convenient for you. This interview will be completed up to one month after the first interview. I anticipate each interview will take around **60 minutes**, but may be longer or shorter, if you prefer. These interviews will be audio recorded.

Please note that there are no significant anticipate risks, but you are still able to withdraw from the study at any time without any negative consequences. Your privacy while participating in this study will be maintained at all times. Your responses during the interviews will be de-identified, and an alias will be given when discussing your discussing your responses with people other than you, and for information storage purposes. Files will be kept in a locked filing cabinet at Edith Cowan University, and on the interviewer's password-protected personal computer. Your interview transcripts will be provided to you for you to read and check after the completion of each interview. Reading and revising the interview transcripts is optional. Your de-identified interview transcripts may be used in further research. If you have any questions regarding the research, please feel free to contact me, Katie Ilich, or my supervisor, Dr Deborah Hersh, on 6304 2563. We will be happy to provide you with more information.

This study has been cleared by the Edith Cowan University Ethics Committee and the Princess Margaret Hospital Ethics Committee. Whilst you are free to discuss your participation in this study with the project staff, if you would rather speak to an officer of the university not involved with the study, you may telephone 6304 2170. Thank you for your interest in this research project.

Katie Ilich

Signed

Date

**Appendix B**Participant Consent Form

**Newborns with feeding issues: parental perceptions of the hospital discharge,  
transition home and the role of speech pathology**

Investigators:

Katie Ilich  
Dr Deborah Hersh  
*Edith Cowan University*

Corina Gill  
*Princess Margaret Hospital*

1. I, \_\_\_\_\_  
(PLEASE PRINT FULL NAME) hereby consent to take part in the research project  
titled: *Newborns with feeding issues: parental perceptions of the hospital discharge,  
transition home and the role of speech pathology*.

2. I acknowledge that I have read the information sheet provided, and that I have  
had the project, so far as it affects me, fully explained to my satisfaction by the  
investigators. I freely consent to my participation in the project.

3. The details of the procedure proposed has also been explained to me,  
including the anticipated length of time it will take, and indication of any discomfort  
or possible risks that may be expected. I understand the procedures to be undertaken  
are as follows:

- One interview up to two days before my baby's discharge from hospital about  
my perception of readiness for discharge, expectations for my family's  
transition home, and my perception of my child's feeding outcomes with  
speech pathology intervention.
- A second interview up to one month after the first interview about my  
perception of readiness for discharge, experiences of my family's transition

home, and my perception of my child's feeding outcomes with speech pathology intervention.

4. Although I understand that the purpose of this research is to improve the quality of health care, I understand that this is a research project and my involvement may not be of any direct benefit to me.

5. I understand that I am free to withdraw at any stage and this will have no negative consequences.

Signed \_\_\_\_\_  
(Participant)

Date \_\_\_\_\_



## **Appendix C**

### Interview Topic Guide

#### **Newborns with feeding issues: parental perceptions of the hospital discharge, transition home and the role of speech pathology**

##### Interview One

1. Describe how you are feeling about your child being discharged from hospital
  - Describe how ready you feel
  - Tell me about the information you have received
2. Describe your feelings about the transition home
  - Describe how ready you feel
  - Describe how you plan to cope with the transition home
3. How has Speech pathology been involved with your child?
  - What do you think of the service received?
  - What should speech pathologists do?
  - What more could be done?
4. Describe your child's feeding abilities
  - How has Speech pathology influenced this?
  - Describe your perception of this change
  - What role has Speech pathology played?
5. What else would you like to add/discuss?

Interview Two

6. Describe your experience of your child's discharge from hospital
  - Describe how ready you felt
  - Tell me about the information you received
  - Describe any differences between the expectation and reality of discharge
  - What could have been done to help you feel more prepared?
7. Describe your feelings about the transition home
  - Describe how ready you felt
  - Describe how you coped with the transition home
  - Describe any differences between the expectation and reality of transitioning home
  - What could have been done to help you feel more prepared?
8. How has speech pathology been involved with your child?
  - What do you think of the service received?
  - What should speech pathologists do?
  - What more could be done?
  - Describe any differences between the expectation and reality of speech pathology involvement
9. Describe your child's current feeding abilities
  - How has speech pathology influenced this?
  - Describe your perception of this change
  - What role has speech pathology played since discharge?
  - Describe any differences between the expectation and reality of your child's feeding abilities
  - What could have been done to help you and your child more?
10. What else would you like to add/discuss?