
Mothers' Experiences of Surgery in Babies with Cleft Lip and/or Palate

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Dissertation submitted in partial fulfilment of the requirement for the degree of D.Clin.Psy at Cardiff University and the South Wales Doctoral Programme in Clinical Psychology.

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Abstract

Objectives: Cleft lip and/or palate (CLP) affects around 1 in 700 live births. Research has been conducted into the impact of the diagnosis but little research has looked at the effect of the initial surgical repair. This study aimed to discover more about the experience of surgery and its impact on mothers. The study also focused upon whether factors such as attachment, loss of control and expectations of appearance were relevant.

Design: A qualitative methodology was chosen in order to allow participants to express their experiences in their own terms, rather than being bound by the researcher's ideas or perceptions.

Method: Seven semi-structured interviews were conducted with mothers of babies with CLP who had had routine lip and/or palate surgery in the last three years. Mothers were recruited from the Cleft Lip and Palate Service based at the Morriston Hospital in Swansea.

Results: Interviews were analysed using Interpretative Phenomenological Analysis (IPA). The super-ordinate themes which emerged were concerned with the Context of CLP, Emotions, Coping, the Impact of Others, Information and Expectations and Considerations of Surgery.

Conclusions: Implications for clinical practice included provision of reference information, more opportunities to share experiences with other parents, as well as the need to provide time for parents to spend time together. Emphasis was also placed on professionals maintaining a friendly and approachable attitude, which was highly valued. The need to spend time with families to better understand their concerns for surgery, their needs for information and their strategies for coping were also emphasised.

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1. Introduction

This research focuses on the experiences of mothers during the time of the surgical repair of their babies' cleft lip and/or palate. In order to investigate this area, a thorough literature search was performed using the following databases: Swetwise, Scopus, Web of Science and OvidSP (which included Medline, EMBASE and PsychInfo). A number of terms and terminology were used to search these databases. These terms, as well as their use, combinations and number of hits, can be seen in Appendix I. Initially, restrictions on the searches were not made in regard to the dates of articles, however, on some occasions, dates of papers were restricted to the last 15 years if many articles were available. Articles were also restricted to the English language. Information was also gathered from relevant textbooks regarding cleft lip and palate as well as health psychology texts regarding issues to do with surgery. The following is therefore a critical representation of the relevant evidence found.

1.0.1. Abbreviations

For the purpose of this research, the abbreviation CLP will be used to signify cleft lip and/or palate, CP will be used for a cleft of the palate only and CL will be used for a cleft of the lip.

1.1. Cleft Lip and Palate

Clefts of the lip and palate affect around 1.7 per 1000 live births worldwide, however, ethnic variations do apply (Mossey et al., 2009) with around 1 in 700 babies born in the UK having a cleft ('Understanding Cleft Lip and Palate'; 2009). The term 'cleft' means split or separation. During development in utero, parts of a baby's face develop individually and eventually join, however, in the case of a baby with a cleft, this does not occur ('Understanding Cleft Lip and Palate', 2009). Clefts are the most common congenital craniofacial anomaly and vary in their type and severity.

1.1.1. Types of clefts

There are two main types of clefts; clefts of the lip and clefts of the palate. Clefts of the lip and palate can occur separately or together (Martin, 2004).

1.1.1.1. Cleft lip

Cleft lips are openings in the top lip between the mouth and the nose ('Understanding Cleft Lip and Palate', 2009). They can be complete clefts, where the gap extends into the nasal passage, or incomplete, which may result in just a notch in the lip itself (Martin, 2004). Clefts of the lip can also be described as unilateral or bilateral, occurring on one or both sides of the lip respectively ('Understanding Cleft Lip and Palate', 2009). Cleft lips can also extend to the bony area which supports the teeth (the alveolus).

1.1.1.2. Cleft palate

Cleft palates occur when there is an opening of the roof of the mouth ('Understanding Cleft Lip and Palate', 2009). The roof of the mouth is divided into the hard palate (which is located at the front of the mouth) and the soft palate (located towards the back of the mouth towards the throat). Clefts can affect the hard and soft palates separately or together and can be found in combination with the different types of cleft lips. Cleft palates tend to also affect the nose and gum, although in some circumstances, they can remain intact (Royal College of Surgeons of England, 2003).

If a baby is born with a cleft palate (or combined cleft lip and palate), there is an increased likelihood of particular additional abnormalities including cardiovascular and musculoskeletal difficulties (Hodgkinson et al., 2005).

1.1.2. Diagnosis of CLP

CLP can be identified at different time points; antenatally, if the foetal face is observed during the ultrasound scan, at birth or in the case of cleft palates, it may be later when the baby has difficulty feeding or with speech (Martin & Rose, 2004).

Certain types of cleft palates can be hidden in the lining of the mouth and may only be identified later in childhood when the child experiences speech difficulties (Martin, 2004).

1.1.3. Aetiology

The causes of CLP are relatively unknown, although it is believed to be a result of a combination of both genetic and environmental factors (Martin & Suri, 2004):

- *Heredity* - a baby's genetic makeup can make them more vulnerable to acquiring a CLP and therefore a family history of CLP may be relevant. However, most children of parents who have cleft lip and palates do not develop clefts themselves (Martin & Suri, 2004).
- *Environmental Factors* - maternal smoking, consumption of alcohol, antenatal nutrition, deficiency of folic acid and other vitamins, as well as the use of particular medications, all show evidence of being factors related to CLP development (Mossey et al., 2009).
- *Pierre Robin Syndrome* – there are over 400 syndromes thought to be associated with clefts, the most common of which is Pierre Robin Syndrome. This syndrome is rare (estimated at 1 in 8000-30,000) and like CLP in isolation, the causes are not known (Martin & Suri, 2004).

Identification of such syndromes is important, as the additional symptoms may require an adaptation to the typical treatment journey provided to those individuals with just a CLP. For example, with Pierre Robin Syndrome, repair of the palate may be undertaken at a later time than normal due to the additional breathing problems that may be present ('About Pierre Robin Sequence', 2009).

1.1.4. Typical treatment journey for individuals with CLP

In 1998 the Clinical Standards Advisory Group (CSAG) set up a review committee to review the treatment of CLP. This report led to a change in CLP service provision. It

was discovered that cleft care was not acceptable in many areas, with factors such as surgery not happening in a suitable timeframe and good outcomes not being achieved in terms of facial appearance after surgery (further details on the consequences of the CSAG report can be seen in the article by Bearn et al. 2001). Following this report cleft care was centred in 19 specialist centres around the UK and Ireland. Although regional differences in treatment do occur, stages of treatment tend to follow the CSAG (1998) recommendations. Following diagnosis (be that before or after birth) the family should be introduced to the CLP specialist service. This service includes professionals from a number of different disciplines to provide care for individuals and their families with CLP at all stages of a person's life. Issues such as feeding, repair and additional surgery, hearing difficulties, orthodontic treatment and speech therapy may also be part of the treatment journey over the individual's childhood and future life. These issues are discussed further in the following section. An overview of the typical treatment journey for a child born with cleft lip and palate from the South Wales South West Managed Clinical Network can be seen in Appendix II. It should be remembered however, that this treatment journey is a detailed representation of the South Wales CLP team care pathway. Although all care pathways for the CLP treatment journey should be based on the recommendations made by the CSAG review of services (1998) regional variations do occur. Possible variations in treatment should be considered when attempting to understand the CLP journey, however, the main aspects of the treatment journey will be similar across CLP teams across the UK.

1.1.5. Factors impacting individuals with CLP and their families

Cleft lip and/or palate can have consequences which affect both the individual and those close to them. These factors include the following:

Feeding Difficulties

A CLP can affect a child's feeding due to the effect that this has on a child's ability to suck. The problem is more severe with a CP, which results in the baby being unable to create enough pressure to produce the suction required to take in milk and can

also result in food escaping from the nasal passageway (Berkowitz, 2006). Babies with a CP may also swallow excess air whilst feeding, which can add to the overall difficulty with this activity. Swallowing can also be altered with a CL as well as the baby not being able to grip the nipple itself (Berkowitz, 2006). These problems do not mean that the child cannot feed but it does mean that more time and effort is required and the result may be inadequate food intake and subsequent insufficient weight gain (Berkowitz, 2006; Martin, 2004).

Appearance

A difference in appearance is perhaps the most obvious consequence of having a CLP. This difference depends upon the type of cleft and its severity as well as other possible effects of the cleft, such as dental difficulties. Individuals with a CP may have little outward evidence of any differences in terms of their appearance but repercussions from the condition (such as abnormal growth of maxilla due to scar tissue) may lead to difficulties being more apparent as the child grows (Berkowitz, 2006). Similarly, whilst a cleft lip has more implications for a person's appearance, it may be that, with repair, only a small scar remains. Resulting appearance therefore depends to a significant degree on the surgery to repair the cleft. Appearance is difficult to predict following surgery due to the child's growth contributing to the result in the future (Berkowitz, 2006).

Surgery

Repair surgery occurs at around 3 and 6 months of age. The use of surgery in CLP has a number of aims. The surgery is designed to gain anatomic closure (which aids breathing and feeding), to maximise growth of the maxilla, to aid production of normal speech and to attain good dental aesthetics (Berkowitz, 2006). Further surgery, relating to realignment of the jaw or bone grafts for orthodontic work, may happen later in the individual's life.

Hearing Difficulties

Difficulties with hearing result from an association between having a cleft palate and the condition known as otitis media with effusion or 'glue ear' (Martin, 2004). This has implications for speech development as hearing plays an important role in the development of language (Martin, 2004).

Need for Dentistry and Orthodontics

Clefts of the lip and palate can have an effect on the development of a child's teeth (Berkowitz, 2006). Both primary (baby) teeth and permanent teeth can be missing, malformed, badly positioned or can erupt from incorrect positions due to the cleft (Berkowitz, 2006). These difficulties can affect appearance, speech, chewing and swallowing and therefore have a far reaching impact. Clefts involving the alveolus mean that the bony plate from which teeth emerge is not present (Berkowitz, 2006). In order for teeth to be realigned in these areas, bone is required to anchor the teeth and therefore bone grafts may be required (Berkowitz, 2006). Additional surgery may be conducted to alter the alignment of the jaw if a cross bite is apparent, which can make chewing difficult (Berkowitz, 2006), as well as it being conducted for cosmetic reasons.

Difficulties in Speech and Language Development

Speech and language development can be affected by a number of aspects of having a CP, however, an isolated CL is unlikely to produce speech difficulties (Berkowitz, 2006). Initially the production of speech sounds relies on the ability to suck, chew, swallow and breathe (Berkowitz, 2006). They are created through the vibration of exhaled air in the voice box (Britton, 2004), which is then manipulated through the movement of the lips, tongue, vocal folds and the soft palate in co-ordination to produce the particular sounds that are required for language (Britton, 2004). As the separation of the oral and nasal cavities in a cleft of the palate does not occur, direction of the exhaled air in speech is unmanageable (Berkowitz, 2006). In most cases then, speech development depends on the closure of the palate using surgical repair (Berkowitz, 2006). The development of language is built on the

foundation of the ability to create speech and therefore they develop in parallel (Britton, 2004). Difficulties with language can result in problems in understanding or using language. Children with CLP tend to have delays in language development and again, this is related to various factors, including hearing loss, lower parental expectations and disrupted parent-child interaction (Britton, 2004).

1.2. Psychological Issues in CLP

All the factors mentioned, as well as having functional and practical implications, also have psychological consequences. Each can affect the way an individual and their family feel as well as affecting how others may react to them. A great deal of research has been conducted to discover the minutiae of the psychological impact of CLP. This section outlines this research and particular areas of investigation.

1.2.1. General wellbeing in CLP

The extent to which CLP can impact upon an individual's wellbeing is unclear, with seemingly contradictory results across studies. A review of studies focusing on the psychosocial factors involved in CLP showed little effect on individuals' wellbeing (Hunt et al., 2005). However, this paper considered 64 studies covering different ages and different methodologies, making it challenging to come to any firm conclusions. Conversely to this, a study which gained self-reports from children and young adults with CLP aged 8-21 years showed more behavioural problems, more depressive symptoms and less satisfaction with facial appearance and speech, than a control group (Hunt et al., 2006). There was no difference in terms of anxiety and self-esteem but past teasing appeared to be a predictor of future psychological functioning. However, the study, being cross sectional rather than longitudinal in design, means that intimations of causality may be difficult to determine. Similarly, there is no explanation as to how the control group was created or whether a matched paired design was used and therefore a comparison between the two groups may not be helpful. Feragen et al. (2009) conducted a study focusing on 10 year old children with CLP. Questionnaires and interviews were conducted with a

focus primarily on coping and resilience. Visibility of cleft did not seem to have an association with resilience. Those with CP showed more problems than those with CLP (a result paralleled in other studies, for example Millard & Richman, 2001). Again, teasing was identified as a factor associated with resilience but it is unclear whether this caused vulnerability or whether it was an effect of an already present vulnerability. There was also no clear definition of what teasing involved. This study also included children with additional diagnoses, which makes it more difficult to determine causal relationships.

Similar studies of well-being have been conducted with adults with CLP. A study by Marcusson et al. (2001) using self-report questionnaires to investigate quality of life in adults with repaired CLP and a control group found no significant difference between the groups.

Evidence of differences in future development for those with CLP is also mixed. A review of the literature and subsequent study by Collett & Speltz (2006) suggests that there is little evidence that children with CLP are at greater risk of social-emotional difficulties in the future, compared to those without CLP. They found that at certain time points, specific areas of development saw some difference between groups, but not significantly so. It may be that any differences between groups may not manifest themselves until later on in life (this study was conducted with children between the ages of 3 months and 7 years), with other studies showing adjustment difficulties in adolescents with CLP (Berger & Dalton, 2011). On the contrary, a study by Damiano et al. (2006) suggests that children with CLP are more likely to have concerns with appearance and speech compared to a group suffering from clubfoot. However, the impact of these concerns was not considered (i.e. the distress these concerns might have). Furthermore, the study was conducted through parental opinion of concerns and consequently their perception of difficulties may not correspond with the child's concerns or an objective view of their situation.

Other studies gathered responses from parents regarding their children's adjustment (e.g. Baker et al., 2009; Endriga & Kapp-Simon, 1999). Again, responses are mixed, with some studies showing little distress or negative impact related to CLP (Baker et

al., 2009) or little difference to the normal population (Berger & Dalton, 2009). A study by Speltz et al. (1993), however, shows that those with craniofacial abnormalities are at twice the risk of behavioural problems at school compared to a control group.

Difficulty comes when interpreting the myriad of studies due to the differences in design, population, method, focus, analysis and use of control groups. Most studies take a cross-sectional design which makes it difficult to ascertain causality.

1.2.1.1. Murray et al. (2010) study of socio-emotional functioning in school-aged children

As the above studies show, there is a great deal of contradiction in the literature on whether CLP has a significant impact on an individual's wellbeing. Difficulties in interpreting the literature are primarily due to weaknesses in the methodologies used. However, a study by Murray et al. (2010) used a longitudinal design, which focused on the socio-emotional difficulties of children with a CL (with or without palate). Due to its well thought out design and large sample, this study and its conclusions will be considered as being at the forefront of CLP research into issues of well-being. This study, therefore, will be considered in detail.

The study focused on the child's social relationships (particularly infant attachment) and symptoms of anxiety and depression. The effects of facial appearance and communication skills were also investigated.

Initially, 103 infants were recruited from birth and were assessed up to 18 months of age. Recruitment was conducted at four UK regional cleft centres. One hundred controls were recruited from local maternity hospitals. These control participants were matched by sex, birth weight and gestation. Babies suffering from a syndrome associated with CLP, heart problems or other health problems were excluded from the study.

At 18 months of age there was no evidence of poorer socio-emotional functioning in children with CLP. Around two thirds of the participants in both groups were securely attached and behavioural problems in both groups were comparable.

At seven years of age, families were re-contacted; 93 participants within the CLP were re-recruited, as were 77 controls. Within the CLP group, participants either had a CL or CLP. No differences between the groups were found in gender, infant attachment and current parenting environment, however, the control group was slightly younger. Participants were not matched against these variables. At this age, a comprehensive set of assessments were carried out both within the family and school environments. The attachment measure, however, which was used at 18 months of age, was not repeated, with the assumption that attachment would not have changed.

It was found that children with CLP had both an increase in communication difficulties compared to the control group and the poorest communication skills. These problems were the most consistent predictor of the overall difficulties experienced by children with CLP. Negative responses from others were associated with communication difficulties, which were significantly correlated with social problems, anxious-depressed behaviour and withdrawn-depressed behaviour.

Mothers did not report socio-emotional problems in the CLP group. Children within the CLP group who experienced poorer current parenting were vulnerable to experiencing difficulties at school. Better current parenting across both groups was associated with the child playing with others and receiving friendly approaches.

Cleft children were rated more likely to have internalising than externalising problems by teachers and were also more likely to be rated as having social problems, being withdrawn, anxious and depressed.

Children with CLP were more likely to spend time alone and spend less time in group play. Although the two groups were just as likely to make and receive approaches from others, children with CLP were more likely to give and receive negative

responses and to portray negative interactions but they did not report themselves as less competent than the control group.

In terms of attractiveness, children in the cleft group were rated more often as less attractive than the control group. However, there were no effects of attractiveness using these ratings.

In summary, more difficulties were found in the CLP group but significant problems were only present in the minority. Communication problems largely accounted for these difficulties, with insecure attachment and poor parenting also having an impact.

The Murray et al. (2010) study provides one of the few longitudinal studies within the literature focusing on investigating potential psychological difficulties with CLP. It used a large sample, allowing the majority of appropriate statistical investigations to be made. Its use of a wide range of assessments completed by the children, mothers and teachers meant that reliance on one result or measure in isolation was not necessary and therefore greater validity was achieved.

Despite these advantages, there are difficulties with the study. Unfortunately, no individuals with cleft palate only were included, with the sub groups of cleft lip and cleft lip and palate being too small to investigate group effects. Although the attachment measure was conducted at 18 months of age, it was not repeated and therefore the assumption was made that the result was still valid at seven years of age. It is therefore difficult to ascertain the usefulness of the conclusions concerning attachment. Likewise, although matching was conducted at 18 months of age, this was not the case at seven years, which impacts the reliability of conducting comparisons between groups. Lastly, although a large number of statistics were conducted, the presentation of these results was confusing and no adjustments were made for the effect of using additional statistics, which may have led to finding more significant effects.

Specific conclusions made by this study should be considered with caution due to its methodological weaknesses, but it would be fair to suggest communication to be an

area of particular concern for those with CLP. However, it provides an optimistic view of CLP by highlighting that having a CLP does not mean inevitable difficulties.

1.2.2 Attachment

Another area which has been the focus of psychological research relating to CLP is the theory of attachment. This suggests that the bonding of a child to its primary care giver (usually defined as the mother) in early childhood can have significant repercussions throughout life (Rees, 2007; Dykas & Cassidy, 2011). This initial relationship provides individuals with a template to understand the value of relationships throughout their life (Rees, 2007). The aim of a secure attachment is to allow a child to have a secure base from which to explore the world and to learn that relationships can be valuable, reliable and safe (Rees, 2007; Dykas & Cassidy, 2011). A person's attachment is thought to continue to develop throughout life but initial attachment experiences can act as a foundation to all future development (Rees, 2007). Therefore, a secure attachment in childhood can aid attachment and relationships in the future. Early attachment is a reciprocal process, relying on the reactions between a primary care giver and the baby. It occurs through a mother's attunement to her baby, including aspects such as: movement, touch, facial expression and vocalisations. The interaction process in attachment is activated by various conditions such as: stress, fear, unfamiliarity and hunger (Bowlby 1977; Hoeksma et al., 1996). This interaction aids the baby's ability to recognise and self-regulate their emotions as well as other bodily sensations such as hunger and thirst.

Attachment has been highlighted as a potential issue in CLP for a number of reasons. It is thought that a difference in a child's appearance may affect the bonding relationship. Attachment relies on the mother's ability to tune into her baby's needs. If the baby's ability to form facial expressions (such as smiling) is affected, then the relationship may be affected (Ainsworth & Bowlby, 1991; Rees, 2007).

The mother's reaction to the CLP diagnosis and all the factors involved in the CLP journey may also affect the relationship. The effects of maternal fatigue, stress and

anxiety (all of which could be heightened with a CLP diagnosis) can lead to mothers being less able to react to the subtleties of their baby's reactions (Rees, 2007). There have also been suggestions that separation of mother and baby can also affect attachment, with initial studies highlighting hospitalisation as a specific way in which this might occur (Ainsworth & Bowlby, 1991; Bretherton, 1992). Although hospitalisation no longer means an extended period of separation between children and their families, considerable experiences at an early age could influence the attachment formation. It is thought that childhood attachment tends to be apparent at around six months of age (Ainsworth & Bowlby, 1991) and therefore experiences around this time could be significant. In terms of the CLP journey then, issues such as feeding and surgical repair could be disruptive. Similarly, at this age, the child's developmental stage is of particular relevance, as the baby's development is largely dependent on their interaction with others, primarily the parents due to their extensive contact with the baby. Elements of development, such as the development of communication, identification of emotions and physical symptoms (such as feelings of hunger) help the baby to start to understand the world. These elements develop through interaction with others and therefore any disruption to that interaction can affect development more generally. For this reason, the baby's development and their attachment to their primary care giver are extricably linked. If a difference in the appearance of a baby, such as in CLP, can affect that interaction, a knock on effect to development and attachment may be seen.

A study by Clements and Barnett (2002) looked at attachment in a variety of birth defects including CLP. Although it was found that CLP could interfere with emotional and verbal responsiveness, parental care giving behaviours were more likely to predict attachment styles over the medical condition concerned. Parenting quality also seemed to be better for those children with more severe facial disfigurements. Despite providing an insight into attachment considerations, the small numbers make it difficult to come to any firm conclusions as to the link between CLP and attachment difficulties (and its potential consequences). Similarly a study by Murray et al. (2008) showed no significant difference in attachment between those with or

without CLP but on comparing the timing of the repair (either neonatally or between three and four months of age), those with a later repair showed worse scores relating to mental development at 18 months of age. This was thought to be linked to mother-infant interactions at two months of age. This could be suggestive of differences in interaction between mothers and infants, if the infant has a CLP (although the reason for this is unclear). Although this study shows that CLP has little effect on attachment, it still emphasises the importance of this early interaction and the potential consequences of disruption to it.

Despite the potential for attachment difficulties, most evidence seems to suggest that there are no significant differences in attachment between those with CLP and control groups (Coy et al., 2002; Speltz et al., 1997; Hoeksma et al., 1996; Maris et al., 2000; Endriga & Speltz, 1997). In contrast, a study by Maris et al. (2000) suggested that those with CP have a lower rate of attachment security at 12 months compared to those with CL. Again, despite this, attachment security seemed to show no difference at two years of age. Once again, the literature seems to be inconclusive.

1.2.3. Appearance in CLP

Although appearance can have an impact on attachment relationships, differences can also affect an individual's psychosocial development, being central to impression formation, as well as being associated with attractiveness, which in itself, will affect a person's development of social relationships (Taylor, 1997). Studies have shown that stigma associated with appearance has been reported by individuals with CLP and their families, as well as the acknowledgement of issues relating to perceptions of facial attractiveness and social acceptability (Strauss et al., 2007; Turner et al., 1998). Although the understanding of the impact of visible differences is complicated (due to it being influenced by many factors such as the degree to which the disfigurement is visible, which body parts are affected and so on), certain difficulties have been highlighted as prevalent (Harcourt & Rumsey, 2008). These include: negative emotions (particularly self-consciousness, shame, lowered self-esteem, depression, and anxiety), difficulties with others (staring and questioning) and

behavioural consequences of that (for example, avoidance of new people or social situations) (Harcourt & Rumsey, 2008; Moss & Rosser, 2008). All these difficulties can be exacerbated by a person's stage of life, their age and even their gender (with females seemingly reporting appearance concerns to a greater extent than males) (Moss & Rosser, 2008; Rumsey & Harcourt, 2007). If such difficulties are present, a process of psychological adjustment may be required to come to terms with visible difference. Work involving the attainment of social skills can help individuals develop their social networks and therefore, their social support (Moss & Rosser, 2008). Issues of self-concept and a person's sense of self can then be modified through social feedback (Moss & Rosser, 2008).

Despite these potential difficulties, many people with significant and challenging visual differences (for example, following physical trauma and injury) cope well, even expressing personal growth because of their difference from the 'norm' (Harcourt & Rumsey, 2008).

A Norwegian study by Feragen and Borge (2010) focused on the body image of children who had a CLP. Six hundred and sixty one children aged 10 to 16 years were asked to fill out a questionnaire and interviews were also conducted relating to their cleft. They found that children with CLP did not report significantly negative social experiences or dissatisfaction with their appearance. Visibility of the cleft was not related to appearance dissatisfaction. Peer harassment however was related to appearance dissatisfaction, with girls aged 16 years being most dissatisfied with their appearance. These results seem encouraging, but there are a few difficulties in interpreting these findings. As a control group was not used, it is difficult to ascertain a comparison with a normal population. Similarly, it is difficult to determine any causal relationships due to the study being of cross sectional design. Another study (Feragen et al., 2010) showed that an individual's subjective belief about the severity of their visible difference helped to explain depressive symptoms more so than objective measures of the disfigurement, something that has been mirrored in other studies (Harcourt & Rumsey, 2008). How a person perceives and feels about their appearance may therefore have more relation to subsequent difficulties than

the severity or visible nature of the difference. This is an important consideration in CLP, where differences in appearance may seem slight but could have a significant impact on the individual or their families.

Another important consideration is the expectation of the change in appearance both at birth and following surgery. A discrepancy between the expected appearance of the baby and the reality can lead to feelings of grief and loss (Beaumont, 2006; Riski, 1991). Adjustment is required from the anticipated 'perfect' baby and their baby with a visible difference (Bradbury & Hewison, 1994). A study concentrating on surgery in young people with CLP (Turner et al., 1998) reported that unrealistically high expectations of appearance after surgery led to dissatisfaction in parents, as well as parents generally reporting more disappointment with their child's facial appearance than the children themselves.

1.2.4. Needs of parents

As CLP can impact a person throughout their life, it has been researched across the lifespan. Particularly in childhood the needs and concerns of the family are integral to understanding the CLP journey. Studies focusing on the impact of the diagnosis on parents, as well as their needs and worries and general experience of having a child with CLP, have been investigated.

The diagnosis of CLP can be an emotional time for parents as the condition generally occurs without any family history of CLP (Martin & Suri, 2004). The birth of a baby with CLP can be shocking and even traumatic if unexpected (Young et al., 2001), with emotions as diverse as happiness, despair, guilt and anxiety (Baker et al., 2009). Studies seem to suggest that an antenatal diagnosis is seen more positively, as it allows parents to feel more prepared before birth and those who did not have an antenatal diagnosis would have preferred one (Davalbhakta & Hall, 2000; Matthews, 2002). Davalbhakta & Hall (2000), using a retrospective postal survey, found that the majority of parents who only received counselling postnatally found that it was confusing, particularly if this counselling was conducted during the first few days after birth. In a qualitative study conducted by Johansson & Ringsberg

(2004), which concentrated on the parental experience of having a child with CLP, two main categories emerged. The first was the unexpected nature of having a baby with CLP and the second was 'reactions' concerning adaptation to having the baby but also others' reactions to the baby. This study emphasised the lack of knowledge parents had about CLP prior to learning that their baby had the condition, as well as the impact that other people's reactions can have on them.

In a retrospective questionnaire study conducted by Young et al. (2001), parents expressed the importance of knowing basic information in the first few days of their babies' lives, particularly knowledge concerning feeding and recognising illness in their babies. Other topics to do with CLP (such as aetiology and repair) were not important at this early stage. Chuacharoen et al. (2009), in a similar study, looked at the felt needs of parents in the first three months of their baby's life. In that time, the main concerns were information on feeding, surgery, speech problems and finances, although the importance of each of these differed at different time points. This study was conducted in Thailand and therefore the financial concerns, as well as the other conclusions drawn, may not be as relevant to families within the UK.

1.2.4.1. Impact of feeding difficulties on parents

As the above studies show, one of the most significant concerns of parents was feeding. Feeding can be difficult, frustrating and exhausting for parents who may have to spend a great deal of time trying to feed their baby without much food actually being consumed and therefore, a failure to thrive in their early life (Bannister, 2004). Owens (2008) conducted retrospective interviews with twenty parents about their experiences of feeding. The families involved included children with different types of cleft. The study highlighted difficulties concerning a lack of support from professionals when attempting to feed, guilt when a mother is unable to breastfeed, the importance of family support in order to cope with difficult feeding and the lack of choice over whether to breastfeed or not.

1.2.4.2. *Measuring parental experience*

Studies have also looked at ways to measure parental experiences more objectively, in order to provide a quick and reliable method of highlighting parental distress. Ruoh-Lih Lei et al. (2010) developed a stress scale specifically designed for use with parents of children with CLP which seems, in this initial Taiwanese study, to have evidence of content and construct validity. Mazer et al. (2008) have developed the ICCAP (Impact of a Child with Congenital Anomalies on Parents) scale, which focuses on the domains of contact with caregivers, social network, partner relationship, state of mind, child acceptance and fears and anxieties. This particular study investigating the scale indicates early reliability and validity, however, its focus was with parents of congenital anomalies other than CLP. Further research would be required to discover its potential use with the CLP population but it might prove to be a quick and easy way to highlight potential areas of difficulty for parents.

1.2.5. *Coping and adjustment*

On identifying the needs of parents, elements of coping and adjustment have been investigated in order to best understand how a family adapts to having a child with CLP. Expectations of having a healthy baby need to be assimilated as well as an understanding of the various elements of CLP, such as surgery. Social support has been highlighted as being useful in the process of coping, as well as perceived support from professionals involved in the child's care (Johansson & Ringsberg, 2004; Baker et al., 2009). Support from friends and family has been linked with lower distress, better adjustment and less negative family impact (Baker et al., 2009). This is thought to be due to social support providing greater feelings of belonging, self-esteem, a positive outlook and a greater sense of value (Baker et al., 2009). In terms of coping strategies, use of approach coping was associated with more positive adjustment compared to avoidant coping (Baker et al., 2009). Approach coping was described by Baker et al. (2009) as seeking support, problem solving, logical analysis and positive appraisal. Social support was also highlighted as a coping strategy used by parents by Schuster et al. (2003), as well as intensification of partnership, self-respect and fulfilment, with a positive approach being particularly

important. The significance of support from other parents has also been highlighted (Riski, 1991; Johansson & Ringsberg, 2004).

Riski (1991) highlighted two important considerations in terms of parental coping. Firstly, needs of parents tend to be greater at times of transition (such as birth, surgery and school) and therefore, support and coping should be emphasised at these times. Secondly, parents can be highly diverse in their experience and needs, as well as their abilities to cope and therefore, a standardised approach to supporting families may not be sufficient or appropriate.

The extent to which parental expectations impact on the perception of the baby has been considered as perhaps supplying a framework on which to better understand parental adaptation. Beaumont (2006) used personal construct theory (which is based on the making and testing of hypotheses in order to understand the world) to understand the reactions to diagnosis. She found that this initial study was suggestive of the process being similar to the stages observed in bereavement, as a way of adjusting to the unexpected nature of CLP. This study, however, was a pilot study involving just two mothers and therefore, further research is needed to examine the usefulness of this framework.

1.2.5.1. Resilience

A growing area of research in terms of coping is the concept of resilience. Resilience can be defined as 'the ability to withstand and rebound from crisis and adversity' (Walsh, 1996, p.261). This concept has been studied from the perspective of the individual as well as from the family unit. The aim of resilience literature is to develop those areas, within the individual or the family, which strengthen resilience, in order to improve coping (and even promote growth and development) when difficult events occur (Walsh, 1996; 2003). Literature on resilience debates the interaction between nature and nurture, the balance between resilience as a biological entity or one which is learnt (Walsh, 2003). Family resilience is not thought of as merely the use of family members as a resource for resilience. Instead, adverse events have an impact on the whole family and therefore can affect

the family's functioning, which in turn can affect elements which aid resilience. Resilience factors within a family can include having a positive outlook, spirituality, flexibility, problem solving, cohesion, communication and shared recreation (Black & Lobo, 2008; Walsh, 1996). In terms of the crisis itself, how the family understand and give meaning to it can also affect their resilience to it (Walsh, 1996), as can the type of crises. Differences in resilience may be apparent for a short term crisis compared to one which has multiple stressors and is more persistent. Long term medical conditions then provide unique challenges to a family. The Family-Systems-Illness Model (developed by Rolland, 1994) provides a framework for those who are facing a chronic illness (also outlined in Rolland & Walsh, 2006). It focuses on the psychosocial type of illness (awareness of its onset, course, outcome, incapacitation and level of uncertainty), the time phases of the illness and family system variables (such as family scripts to do with illness and coping, normalisation of challenges, meaning made from the illness, beliefs about the cause of illness and so on). It is thought that this model offers a collaborative practice between professionals and families to aid coping and adaptation. This model has been applied to a number of illnesses, including families facing genetic conditions and cancer (Street et al., 2000; Rolland, 2005) however the empirical evidence for the model's application is limited. However, this model may be relevant within CLP, both when facing the diagnosis but also with significant times within the treatment journey, such as the surgery. Resilience has begun to be studied within CLP, but it tends to be focused on the resilience of the individuals with CLP themselves (for example, Feragen et al., 2009; Feragen et al., 2010), rather than their families. Further research is required on the resilience of the family when the individual with CLP is very young, and also whether the Family-Systems-Illness Model is a viable framework for aiding resilience for this condition.

1.3. The Experience of Surgery

Cleft lip and palate surgery has its own specific concerns which impact on those involved. However, surgery more generally impacts those experiencing it, as do

factors which accompany the process, such as hospitalisation. Studies have looked at the impact of surgery and of being a patient in hospital. Little research has been conducted on the experience of surgery on babies generally and babies with CLP more specifically. Some insights into the possible impact of CLP surgery on parents can be gathered from studies focusing on the needs and concerns of parents of children with CLP, but these concerns tend to be primarily focused on initial thoughts following diagnosis and therefore, do not provide a clear understanding of what aspects of the surgical process impact most on families. This section will highlight some of the concerns gleaned from such studies, as well as providing some information on surgery more generally.

1.3.1. Cleft lip and palate surgery

Surgery to repair the CLP tends to happen within the baby's first year of life. Surgical techniques have developed to include principles of plastic surgery to create results which more accurately appear as normal (Henley, 2004). Variations in technique, surgeon preference and timing, mean that every cleft centre will approach surgery in a slightly different way (Henley, 2004). Lip surgery tends to be performed at around three months of age, although this could vary depending on the child's weight and general health (Berkowitz, 2006). The surgical procedure involves joining the two edges of the lip together, with no extra skin being required. Depending on the extent of the cleft, lip surgery may include improving the shape and appearance of the nose (Henley, 2004). If the baby has a CP alongside the CL, initial closure of the palate will also be undertaken (Royal College of Surgeons of England, 2003). Cleft palate surgery usually takes place at six months of age and involves the realignment of the muscles and lining of the palate. Palate surgery tends to be conducted at this age in order to aid speech development, however, it can mean that difficulties arise in the growth of the palate and the jaw. Studies focusing on the timeliness of surgery have been conducted (e.g. Cassell et al., 2009) and attempts are being made to pinpoint the optimal time, but present knowledge suggests repair in the first few months of life is most beneficial. In both cases, babies are put under a general anaesthetic. Alongside these practical aspects of surgery, the experience of

it and how the process impacts on the parents and families involved, needs to be considered.

1.3.1.1. Media views of CLP surgery

Many medical conditions are promoted within the media in order to raise both awareness and funds for charities associated with them. Cleft lip and/or palate is no exception, with a number of charities promoting the condition to raise funds for research as well as for the repair of CLP in children in countries around the world. Charities such as 'Smile train', 'Bridging the gap' and 'Operation Smile' therefore use the media to promote the work they do and raise money to help those with CLP. The media representation of CLP is therefore designed to show the dramatic results that can occur from repair surgery. Clefts are shown before and after surgery to indicate the considerable effects of repair. Although repair is a huge part of treating the condition, difficulties associated with CLP can be far reaching. Difficulties associated with a CLP may not be resolved with the initial repair surgery alone and therefore additional procedures may be required. Visible differences have an impact throughout life and at each developmental stage and transition, right into adulthood, this may be an issue (Harcourt & Rumsey, 2008). The individual and their family have to cope with this additional issue at every life stage, and it may make these transitions more complicated. The work these charities do is invaluable to those with CLP, both in the UK and around the world, but it may provide families with an unrealistic view of the surgical element of CLP.

1.3.2. Reactions to CLP surgery

An early study by Spriestersbach (1961), where 175 sets of parents were interviewed, showed that both mothers and fathers placed repair of the cleft as an important concern on discovering the diagnosis. Surgery was seen as the solution to the cleft, as parents showed prospective feelings of 'everything being well' following surgery. Although an old study (and surgical practices have changed a great deal since then), it does suggest that surgery can be perceived as a significant concern but at the same time, as the answer to the problem of CLP. In a study by

Chuacharoen et al. (2009), surgery was also a main concern of parents, a concern which became more important as surgery got closer. Their main concerns were when it would happen, how long it took, recovery time, side effects, the care involved, whether additional tissue was required for the repair, techniques used, outcomes of surgery and pain. This study provides an insight into some of the concerns facing parents and unlike other studies, was not carried out retrospectively. However, it was carried out in Thailand, so the extent to which cultural factors may have influenced the concerns felt is unclear. A retrospective study focusing on parental experience also identified that parents showed anxiety around surgery, particularly with the anaesthetic, risks of infection, the possibility that surgery would not be successful and what their child would look like following the repair (Johansson & Ringsberg, 2004). Similarly, a parental focus group study by Stone et al. (2010) showed that surgery was a major factor influencing quality of life in the early stages of the CLP journey. Elements of surgery that were noted as important included: communication with professionals, empathy, expectations of surgery, postsurgical care and discharge management, with the preparation for surgery, as well as the discharge, being more significant than the time of the surgery itself.

Although these studies give an insight into some of the concerns relating to surgery, none of them focused primarily on the surgical process and experience. A study by Weatherley-White et al. (2005) looked specifically at surgery and parental expectations of it. Parental beliefs about the cause of the cleft were also investigated. Although this study provides some insight into parental beliefs about surgery, its setting means that it is difficult to generalise its conclusions to a UK population. The authors interviewed 52 families in rural India regarding repair surgery for CLP. Most had high expectations of the outcomes of surgery, believing that it would make their child's life better (this was explained primarily through the change in appearance). Issues such as marriage prospects (for girls) being affected by the cleft and the financial burden that would result if the child didn't marry, were seen as particular concerns and therefore appearance was especially crucial for these reasons. Families believed that the cleft was God's will or the result of sin in a former life; some children were restricted to being outside the family. Appearance

therefore, seemed to be the biggest issue for families. Most were not worried about the surgery although they seemed to have little understanding of what it may involve. Although this study provides a fascinating perspective on people's experiences of surgery, these findings are difficult to interpret for a number of reasons. The cultural setting and language may have affected the responses received. Many of the interviews were conducted with just the father or male relatives, perhaps reflecting the cultural family norms. Translators were used to carry out the interviews and responses were translated 'as verbalised' but nuances of experience may have been lost in this process. Responses may also have been censored by the families in order not to offend the medical teams involved in their child's care. The combination of obtaining an accurate portrayal of the parental experience and the cultural setting of the study, mean that being able to generalise the results to UK experiences is difficult. It is interesting however that such a study has not been conducted in a Western community.

1.3.3. Hospitalisation

One of the consequences of having any surgical procedure is that of hospitalisation, which in itself can have an impact on those involved. Hospitalisation in CLP is relatively short (a few days), however, little literature is available regarding its impact on families. Similarly, little literature is available on the hospitalisation of babies in both CLP and other medical conditions. For this reason, hospitalisation will be considered in a more general sense.

A stay in hospital could be viewed as a way of better understanding symptoms or providing a resolution to a medical condition (Johnston, 1997). However, instead, the overriding feeling appears to be that of stress (Johnston, 1997). Studies focusing on day surgery suggest that this stress reaction is influenced by previously identified feelings of insufficient preparation and problems with postoperative pain once home (Hug et al., 2005). Sources of stress within a hospital setting include the prospect of investigations or treatments and the uncertainty that may accompany them as well as being away from home (Johnston, 1997). Other factors such as the environment (Gilmartin & Wright, 2008), an unfamiliarity with the surroundings, dependency on

hospital staff and poor communication with staff also appear to cause stress (Johnston, 1997). Those having surgery show higher levels of stress than those receiving other forms of treatment, with stress being primarily related to loss of independence, unfamiliarity with surroundings and threat of serious illness. Other feelings such as empowerment, apprehensions and abandonment (felt during periods of waiting) have also been experienced even in day cases (Gilmartin & Wright, 2008). Hospitalisation may also leave an individual feeling isolated, that they have little influence and having confusion in relation to how they should act. Less research has been conducted on how hospitalisation affects others close to the patient (Johnston, 1997).

1.3.3.1. Isolation

The act of being in hospital can make an individual feel isolated, with little or restricted access to social support. This support helps to protect against both physiological and emotional stress responses and therefore is vital in helping the individual cope with the already anxiety provoking situation they find themselves in (Salmon, 2000). Similarly support from care staff can also reduce stress responses; however, evidence suggests that nurses can underestimate patients' concerns, for example, with pain (Salmon, 2000). Social support has also been shown to be linked with recovery, with a faster recovery being associated with a greater number of visits. Despite this, the effect of social support may have individual differences, where the patient ends up supporting the family rather than the contrary (Salmon, 2000).

1.3.3.2. Loss of autonomy

A person's sense of control may be affected in a number of ways relating to hospitalisation. Restrictions on both mobility and thinking through the medical procedures carried out and the medication being used may leave individuals feeling a lack of control (Salmon, 2000; Johnston, 1997). Similarly, the attitudes and requirements of the staff may also affect the patient's ideas of how they should act. Patients being seen as 'good' and 'bad' may affect both how they are approached by

staff and also how they believe they should act and behave. 'Good' patients may be seen as passive and accepting of the things asked of them whereas 'bad' patients may be more questioning and involved. In this way a 'bad' patient seems to be trying to exert some control over their environment but in doing so is seen in a negative or problematic light (Salmon, 2000).

Within a hospital environment, the culture means that staff are seen as having authority. This provides patients with the understanding that staff are in charge and patients have little or no control over what they can and cannot do within that setting. This may mean that patients are reluctant to ask questions or query any part of their stay. Studies show that patients usually want to know about their condition (even if the information is difficult or could be misinterpreted), with Reynolds et al. (1981) showing that over 90% of patients want to know about their diagnosis and treatment (cited in Johnston, 1997). Many patients felt that they haven't been given enough information and this may well have been due, in part, to the ethos of the hospital environment (Johnston, 1997).

1.3.4. Responses to surgery and hospitalisation

Evidence has been gathered looking at the emotional reactions (particularly that of anxiety) of being in hospital. The difficulties with many of these studies are the scales used to measure the stress felt. Some scales were developed in a hospital setting, whereas others were developed for other settings and populations (Johnston, 1997). This may lead to difficulties when there is a cross over between symptoms of an emotional condition (such as depression) and the consequential effects of a medical procedure (such as effects of anaesthesia). Caution must therefore be made on the conclusions drawn from this information source.

In comparison with the general population, high levels of anxiety have been found in surgical patients, with levels remaining high after surgery (Johnston, 1997). This may suggest that the discomforts and uncertainties of surgery may be a large part of the stress experienced, rather than the surgery itself.

Individual differences are also important to consider within the context of being in hospital. Those prone to anxiety tend to have higher anxiety reactions when in hospital and may also have different coping strategies (Johnston, 1997; Kincey, 1989).

1.3.5. Children in hospital

When a child is in hospital, further concerns may need to be considered. Although adults in hospital may not feel able to relate their wants and needs due to the culture and environment they find themselves in, children may not actually be able to express their needs. Initially it was deemed as appropriate for children to be separated entirely from parents during prolonged periods of hospitalisation (Schmidt, 1997). As a result, children experienced separation effects including stages of protest, withdrawal, detachment and then indifference on the parents' return. This is now seen as inappropriate and therefore, parents are encouraged to stay with their children whilst in hospital and initiatives have been put in place to facilitate this, such as: longer visiting hours, shorter stays in hospital and opportunities for parents to stay. Other considerations such as the setup of wards and buildings have also been considered, in attempts to improve a child's experience of the hospital environment (Schmidt, 1997).

Certain situations in hospital may prompt a greater need for parental presence, such as specific procedures or, for example, the administration of an anaesthetic. However, similarly to social support, parental presence may not always be useful or helpful (Schmidt, 1997). Parents who are considerably distressed can make the child more anxious (Salmon, 2000). In this case, hospital staff may be instrumental in providing support for parents, however, this relationship can be problematic in itself. Parents' concerns can be at odds with the care staff, with parents wanting to see their children as being stronger and more cheerful than they actually are. In one study investigating those with CLP, it was found that after hospitalisation (in children below the age of one year, where time in hospital was less than a week), children showed greater avoidance toward their mother in the short term compared with a matched control group (Koomen & Hoeksma, 1993).

Aside from the affect that surgery and hospitalisation has on the individual themselves, the impact on families and caregivers should also be considered. Even short periods of hospitalisation can be stressful for caregivers (Commodari, 2010), with parents showing raised anxiety, regardless of their child's age (Valdes Sanchez & Florez Lozano, 1993). In a study looking at the parents of children having cardiac surgery, stress levels remained moderate to high throughout hospitalisation, regardless of the severity of the illness (Franck et al., 2010). Parents from deprived areas and those born outside the UK were found to have higher stress levels (Franck et al., 2010). In a similar study, Utens et al. (2000) found elevated levels of distress in parents of children awaiting cardiac surgery (which included sleeplessness, social dysfunctioning and anxiety), as well as having less effective styles of coping during this time. The importance of support for parents and helping them in identifying more effective ways of coping was emphasised in both these studies.

1.3.6. Perioperative care

The evidence shown in the previous sections suggests that the experience of surgery and hospitalisation can have an impact both on individuals and, in the case of children, parents. However, little research has been conducted into the effect of a baby's initial CLP surgeries on the parents. This presents a gap in the literature regarding hospitalisation. Another area which seems lacking within the CLP literature is that of perioperative care. Evidence for perioperative care is available for a number of surgical procedures carried out on babies, such as congenital heart surgery (Uchita & Havada, 2008) and brachial plexus injuries (Saricaoglu et al., 2005). These studies tend to be technical in nature, relating to the procedural aspects of care, rather than the psychological perioperative care which might be required for the family involved. In a more psychologically orientated study conducted by Kain et al. (2007) a randomised controlled trial looked at the effectiveness of a behavioural perioperative preparation for children undergoing surgery and their families. It was discovered that this preparation led to better postoperative outcome measures, as well as reduced anxiety in the preoperative period. It seems that perioperative care has an important place in surgery, and can

provide positive outcomes for both the families involved and the medical teams. However, little literature seems to be available for CLP surgeries. Similarly, a gap is apparent in terms of the impact of surgery and the potential psychological impact of this on parents. Evidence shows that surgery can be a concern for parents (such as Spriestersbach, 1961 and Chuacharoen et al., 2009), but little more is known about the experience of surgery and its effects. Further research into the surgical experience within CLP could provide a starting point for thinking more specifically about perioperative care. As well as the effect of surgery, the potential psychological influences that can impact on parents and families of babies with CLP may also be involved in the overall experience of the surgical procedures carried out. Although there is little evidence to suggest that attachment is affected by CLP, the interactions between the baby and the primary care giver (usually the mother) are important at the age of surgery and therefore, should be explored more thoroughly within this time frame. Little research however, has looked explicitly at this area and therefore the inclusion and interaction of these factors is unclear. This research aims to clarify the understanding of the surgical journey for families and its consequential impact. By interviewing mothers, the hope is to begin to understand the experience of surgery, with particular focus on the interactions and relationship between mother and baby and the ways in which the experience can be optimised for both the individual and their families.

1.4. Aims and Objectives of the Current Research

This project aims to discover more about the impact that surgery, on a baby with CLP, has on their mothers and their needs at this time. It aims to discover more about the experience of the surgery for mothers and the aspects of care that were useful and those which could be improved upon.

The project will take the perspective of factors such as attachment, loss of control and expectations of appearance, which may be relevant when considering the impact of surgery.

1.5. Context of the Current Research

Following the 1998 CSAG review of CLP services, the Cleft Lip and Palate Association (CLAPA) carried out a postal survey of parental experiences to assess these changes (CLAPA, 2007). From this report, areas of improvements were highlighted. These included: areas relating to diagnosis, knowledge of staff within maternity wards, delays in meeting cleft team, delays with diagnosis, visits to the cleft clinic feeling intimidating, lack of information on the change in their child's appearance following surgery, not being offered overnight accommodation for initial surgeries, pain control following surgery and the lack of encouragement in breastfeeding. This report highlighted particular issues involving surgery. Although the majority of those surveyed were satisfied with the information provided to them, some felt that it was too simplistic, which meant that they felt ill prepared for surgery. The survey also highlighted the distress that parents felt during surgery, with parents feeling ill supported during that time.

Following this report a number of audits were carried out by the South Wales Cleft Lip and Palate Service based at the Morriston Hospital in Swansea. These prompted discussions on the experience of surgery for parents. These audits discovered that parents expressed that "nothing can prepare you for the moment you see your child after the operation". The audit therefore highlighted a potential gap in the team's knowledge of the parental experience of surgery. This coupled with similar gaps in the available literature concerning CLP surgery, parental experience of CLP, hospitalisation and preparation for surgery, all led to the proposal of a piece of research focusing on this area. The team felt that further exploration of the parental experience could provide valuable insight into whether anything further could be put in place to help parents cope more effectively with this difficult time in their child's life.

The similarity of care pathways across the UK for children with CLP allows this research to potentially be of relevance to other British CLP teams and therefore provides more relevance to the study of the experience of surgical repair in CLP for parents, as this aspect of the CLP journey is similar throughout the UK.

The South Wales Cleft Lip and Palate Service provide a specialist cleft lip and palate team for the whole of the South Wales region. The team consists of: surgeons, anaesthetists, paediatricians, orthodontists, psychologists, speech and language therapists, specialist nurses, an assistant psychologist and a dedicated administration team. Every baby diagnosed with a CLP is referred to the service and support is provided to both the child and family throughout the child's life. This research was conducted in collaboration with this service.

2. Methodology

2.1. Design

The aims of this study focus on understanding individuals' experiences. For this reason, a qualitative approach was selected. Individual interviews took place with mothers of children with a CLP to explore their experiences of the surgical process of routine reconstruction. This section will outline the rationale for the use of the qualitative method, as well as describing the philosophical stance of Interpretative Phenomenological Analysis (IPA).

2.1.1. *Rationale for using a qualitative methodology*

Qualitative research in psychology can be defined as 'involving the collection and analysis of non-numerical data through a psychological lens' (Coyle, 2007, p. 11). It provides rich information on how individuals make sense of their world.

Unlike quantitative research, which takes the positivist stance of collecting data in order to obtain generalizable results to explain specific phenomena, qualitative methods take a more idiographic viewpoint (Coyle, 2007). In this way, the detail of phenomena is captured rather than an overall view of a population's experience. The research question for this study is suitable for this approach, as it aims to explore an experience rather than explain it.

Although research into the area of CLP is extensive, little research has focused specifically on the impact of surgery on families. The area of study is therefore, relatively unknown. A qualitative methodology will allow participants to express their experiences in their own terms, rather than being bound by the researcher's ideas or perceptions (Coyle, 2007). This is particularly important in an under-researched area, as it allows information to be gathered on the issues that are important to those experiencing the phenomena, rather than the researcher making the assumption of knowing what to measure (Willig, 2008; Smith et al., 2009).

2.1.2. Rationale for using IPA

IPA focuses on understanding an experience in order to capture its quality and texture (Willig, 2008). It offers a perception of how individuals make sense of their world and experiences, rather than trying to explain or define a phenomenon (Smith & Eatough, 2007). The aim of this study is therefore, not to explain the process of surgery for babies with CLP, but to explore individual perceptions of it, in order to provide a greater understanding of the experience.

2.2. Interpretative Phenomenological Analysis

2.2.1. Background and philosophy of IPA

IPA is a relatively modern qualitative methodology developed within a psychological background, derived from the idea that psychology could and should be both experimental and experiential (Smith et al., 2009). IPA derives from phenomenological, interpretative and idiographic perspectives (Smith et al., 2009).

Phenomenology

Phenomenology is interested in the experience of individuals at a particular point in time and within a particular context, rather than in explanations (Willig, 2008; Smith et al., 2009). An individual's account of an experience thereby becomes the phenomenon (Willig, 2008; Smith et al., 2009). Phenomenological thinking is concerned with the identification of the essential qualities of experience, with the aim that this will resonate with others who have similar experiences (Willig, 2008; Smith et al., 2009).

Interpretation

IPA acknowledges that the researcher's role includes an element of interpretation in order to understand the experience that has been presented by an individual (Willig, 2008; Coyle, 2007). Both the context of the experience being explored and that of

the researcher, needs to be acknowledged in order to begin to understand how the experience was initially perceived and how it will be understood by the researcher (Coyle, 2007; Willig, 2008; Smith et al., 2009). This requires the researcher engaging fully with the experience, whilst also acknowledging their own beliefs, attitudes and potential biases might be part of the interpretation. It is not concerned with eliminating these factors, but recognising that they will be part of the interpretative process.

Idiography

Idiography is concerned with the particular rather than the general (Smith et al., 2009). Where quantitative methods aim to explain a phenomenon by describing a general process, qualitative methods, in contrast, look at the particular in order to understand the individual experience (Willig, 2008; Smith et al., 2009). In this way, an individual can provide their unique relationship with an experience (Coyle 2007; Smith et al., 2009).

The experiences studied by IPA should be those where individuals reflect on the significance of the experience in order to make sense of it (Smith et al., 2009). The experience can then be understood in terms of the meanings individuals place on them (Smith & Eatough, 2007).

The systematic, exploratory process of IPA involves the researcher engaging closely with the reported experience of an individual, in order to both obtain an 'insiders' perspective but also to be able to see the experience from other perspectives, to achieve an holistic understanding (Smith & Eatough, 2007; Smith et al., 2009). In this way, the process is both empathic and questioning (Smith & Eatough, 2007; Smith et al., 2009). The aim is always to do justice to the complexity of human experience by appreciating the nuances and detail (Smith et al., 2009).

2.2.2. Ensuring quality in IPA

Quality in qualitative research has been debated for a number of years, with a great many perspectives on the best way to achieve it (Long & Godfrey, 2004). A great

deal has been published on the best way to ascertain quality in qualitative research, resulting in numerous sets of criteria to determine 'good' qualitative research from 'bad'. These criteria have developed from a number of disciplines including Nursing, Psychology and Medicine (e.g. Walsh & Downe, 2006; Elliott et al., 1999; Meyrick, 2006; Rolfe, 2006; Kitto et al., 2008). While it is encouraging that qualitative research is seen as a mainstay of investigation, the myriad of different criteria means that there is still confusion as to which recommendations to use (Willig, 2008; Elliott et al., 1999). As this research is centred in psychological theory, it seems most relevant to use criteria that were developed from a psychological perspective. For that reason, the guidelines developed by Elliott, Fischer and Rennie (1999) will be used as the basis for ensuring quality in this project.

These guidelines provide seven standards which should be acknowledged to ensure quality.

2.2.2.1. Owning one's perspective

It is important for the researcher of an IPA study to disclose their position in relation to the subject area and the methodology. In this way, the researcher can recognise their values, assumptions and beliefs and how these may influence the analysis of the data. This acknowledgement allows the reader to draw their own conclusions as to the coherence of the research and have as clear a picture as possible of the potential influences on all stages of the project (Smith et al., 2009; Elliott et al., 1999). It also allows the analysis (which is, to a degree, dependent on the researcher's own biases and judgements) to remain a transparent process. For this reason, the researcher's position for this project is acknowledged below.

Family Health and Surgery

Since working as an assistant psychologist in a health psychology department, I have always had a curiosity for this area and therefore, this research sparked my interest despite having had no connection with those with cleft lips and/or palates, either professionally or personally prior to this research. However, in recent times,

surgery has been a big part of my personal life, with a member of my family undergoing surgery for a number of health conditions. Surgery therefore, has played a great deal on my mind for the past couple of years. I have thought about the impact of that process on myself as well as other members of my family and consequently I have gained my own perceptions of what surgery is like for a family member, what makes it easier to cope and conversely what makes it harder. From my own experiences, I believe in the details of surgery being told to more than one family member in order for the information to be taken in as coherently as possible. Meeting the individuals involved in the surgery, particularly the surgeon, for me, also seems important in order for those involved to feel more at ease. Knowing the people doing the surgery, in my experience, seems to allow the individual to have more faith in the procedure. I believe that the support of family members is paramount, not only for the individual having the surgery, but for those nearest to the individual. However, I do appreciate that I come from a close-knit family where support is consistent and constant and is perhaps accepted and assumed in difficult times. I hope that during this research, I will be able to remain open-minded and curious, in order to put my own feelings and opinions to one side. I do not wish my own ideas to cloud those which are being provided by the participants and therefore, I hope my acknowledgement of my perceptions of surgery will allow me to remain open-minded. I will continue to re-visit these thoughts throughout the research process in order to remain vigilant of my own views influencing the project.

Systemic and attachment models

During my training to be a clinical psychologist, I have become particularly interested in systemic thinking as a way of aiding the understanding of clients and their families. This has led me to be interested in relationships and their impact on all parts of an individual's emotional and, to some extent, physical life. I have therefore gained an interest in attachment and the particular relationship between primary care givers and babies. This project's particular focus, therefore, is very much involved in the idea of attachment. Although I am not going to shy away from the theory of attachment and its potential influence on this area of research, I

acknowledge that attachment, although relevant, may well not be a significant element of the analysis. Once again, this acknowledgement of my interest will aid me in endeavouring to remain open-minded and enquiring throughout the research process, rather than being shut off to new and perhaps, as yet, un-thought of ideas.

Models of service

I am also a firm believer in the importance of services, of any sort, being open to feedback and acknowledging the importance of evolving with the needs of those who access them. Although not the primary aim of this research, the results of this project could lead to services being more aware of the patients view, something which I believe is of paramount importance. However, as before, I do not want my hopes for recommendations or developments to influence what I hear or see within the data and therefore, this acknowledgement of my beliefs should help me to maintain impartiality as much as possible.

Culture and Society

Another important point that I will keep in mind during my research is the possible effect of cultural perspectives on CLP. If views of CLP derived from charitable organisations, for example, provide a basis for the general public's view of the condition, not only may they impact on the interviewee's perspective, but also my own during analysis. Again, by acknowledging this view, it will help me to be aware of my own biases and perspectives.

On a more general level, the emphasis of this project needs to be acknowledged. As a trainee clinical psychologist, naturally the psychological aspects of the surgical process are central to the orientation of this research. However, it is important for me, as the researcher, not to assume that this is the most relevant or important aspect of surgery for the participants. Although my background and knowledge means that my focus is on aspects such as attachment issues, coping and emotional reaction to surgery, these may not be the areas that participants feel are as poignant for them. During the interviews, it will therefore be important for me to

bear this in mind. I need to remember that prompts during the interview are merely that and should not be pushed onto the participant.

In order to maintain this transparency throughout the project, a research diary was kept in order for the thoughts, perceptions, influences and considerations of the researcher to be noted and acknowledged as they change and develop across the project. Extracts from this diary can be found in Appendix III.

2.2.2.2. Situating the sample

The researcher should describe the research participants in order to allow the reader to review the range of those being studied (Elliott et al, 1999). Demographic information, as well as information relating to family situation, was collected from participants and can be found in sections 2.4.4. and 3.1.

2.2.2.3. Grounding in examples

Examples of the original data (in this case excerpts of the interview transcripts) should be used to illustrate the understanding developed through the analytic process (Elliott, et al, 1999). It will be ensured that within the results section, multiple examples will be used for each theme developed.

2.2.2.4. Providing credibility checks

Credibility checks should be made on the themes developed through the analytic process. Elliott et al. (1999) suggested a number of methods in order to achieve this, such as comparing a number of qualitative perspectives. However, due to the limited time available, it was deemed more appropriate to use another method. Within this project, the analysis process generally and, more specifically, the development of themes will be shared with the research supervisors for this project. In this way, additional perspectives will be sought as to the process of the analysis and the interpretations made to develop the themes.

2.2.2.5. *Coherence*

An understanding of the data is developed which forms a narrative and structure (Elliott et al, 1999). This will be achieved by not only providing a verbal description of the themes development but also a map of the themes and how they fit together. This will be created to provide a visual version of the themes.

2.2.2.6. *Accomplishing general versus specific research tasks*

It is important to acknowledge the extent to which general or specific understandings can be made (Elliott et al, 1999). The limitations of being able to extend the results to other circumstances and contexts should be clearly recognised and stated. Acknowledgement of this can be seen in the discussion section of this report.

2.2.2.7. *Resonating with readers*

The report should be such that readers feel it provides an accurate portrayal of the subject matter (Elliott et al., 1999). In order to achieve this, the researcher will endeavour to always keep the participants' voices at the forefront, thereby attempting to allow readers to understand their perspectives as much as possible. The researcher will also continue to show the report to research supervisors in order to gain differing perspectives on the written representation of the project.

2.3. Ethical Consideration

2.3.1. *Ethical approval*

Before the study commenced, approval for the project to be undertaken was sought from the Research and Development department of the Cardiff and Vale University Local Health Board and the Abertawe Bro Morgannwg University Health Board. Ethical approval was sought from the South West Wales Research Ethics Committee. Final approval from all three of these sources was obtained in the months of August,

September and October 2010. Approval letters are enclosed in Appendices IV, V and VI.

2.3.2. Informed consent

In accordance with the Health Professions Council (HPC 2008; HPC 2009) and the British Psychological Society (BPS, 2009), informed consent was sought from all participants. An information sheet (Appendix VII) was sent to potential participants by the CLP service team. The researcher was not provided with the contact details of the potential participants until they agreed to discover more about the project. At this point the researcher, on ensuring that the potential participant fulfilled the inclusion criteria and none of the exclusion criteria, talked through the information sheet with the participants, which was repeated on commencement of the interview. On reading and understanding this information, participants were asked to sign a consent form to acknowledge their agreement to taking part. The consent form (Appendix VIII) asked participants to confirm that they had read and understood this information. It also clearly stated that participation was voluntary and withdrawal from the study at any time would not affect their or their children's medical care. It also stated that participants were free to ask questions at any time and that the interview would be audio recorded.

2.3.3. Confidentiality

The researcher is bound by both the British Psychological Society's and the Health Professions Council's codes of ethics (BPS, 2009; HPC, 2008; HPC, 2009). It was therefore essential to ensure that confidentiality was maintained unless a concern was raised surrounding risk of harm to the individual being interviewed or another person (such as their child). This was explicitly expressed in the information sheet and it was acknowledged that if any such issues were to arise, it would be discussed thoroughly with the participant.

In order to maintain confidentiality with regards to the interviews, the recordings, were stored securely and on transcription were anonymised. Participants were made

aware that research supervisors may see the anonymised transcriptions and that anonymised direct quotes from the interviews would be used in the final report.

2.4. Participants

2.4.1. Inclusion and exclusion criteria

The inclusion criteria for taking part in the project consisted of mothers of children who had had routine CLP surgery in the last three years.

One of the aims of the project was to better understand the impact of surgery on the attachment relationship between baby and primary care giver. Although not always the case, the mother tends to be the primary care giver and therefore, it was decided to restrict interviews to mothers.

The exclusion criteria included:

- Mothers whose children had had non-routine surgery.
- Mothers whose children had prominent co-morbid conditions or where a syndrome resulted in more complex symptoms and therefore treatment.
- Mothers of children who had had surgery in the last two months.
- Mothers who were identified by the CLP team as potentially finding the interview process distressing.

Non-routine surgery, co-morbid conditions and those who developed CLP because of another medical condition, were excluded due to the added considerations that would have been made during their medical care. The project's aim was to focus on the experience of surgery and therefore, it was decided that such complications would not provide a clear picture of surgery for the majority of mothers.

Those who had had surgery in the last two months were excluded on the recommendation of the CLP team, as were those who the team believed would find

the process distressing. These individuals were identified by the team at the time of recruitment.

2.4.2. Recruitment

Smith and Eatough (2007) recommend a sample size of six to eight participants for a qualitative postgraduate research project, with Smith, Flowers and Larkin (2009) suggesting between 4 to 10 participants for a professional doctorate project. For this reason, it was deemed as appropriate, in this case, to recruit between six and ten participants.

In order that the researcher did not have direct access to the potential participants' contact details, the recruitment procedure was carried out by members of the CLP team at the Morriston Hospital in Swansea. Potential participants were selected from the team database. Starting with families of children who had had surgery most recently, invitation letters (Appendix IX) were sent to those who fulfilled the inclusion criteria and had none of the exclusion criteria (as far as could be identified). The invitation letter allowed mothers who were interested in the project to contact the researcher directly by completing a reply slip and sending it in a stamped addressed envelope. On receiving the slip, the researcher contacted the potential participant by telephone and explained the purpose of the study and the procedure for the interview. The inclusion and exclusion criteria were then checked again with the potential participants and, if appropriate, an interview was organised.

Once an interview was organised, each participant was assigned a number. The participants' details were saved on a computer alongside their number in order to trace interviews back to the individuals if required. This information was password-protected to maintain confidentiality.

2.4.3. Response rate

In total, 40 invitation letters were sent out and of those eight responses were received. Due to time pressures (and having superseded the minimum number of participants required), no more invitations were sent out. The eighth participant

response was received at a late stage of the project and therefore, was not interviewed. She was contacted and thanked for her interest in the project and it was explained that she would not be interviewed due to time pressures. All of the potential participants who responded fulfilled the inclusion and had none of the exclusion criteria.

2.4.4. Participant demographics

The participants were Caucasian mothers with an age range of 19 to 37 years (mean age of 31 years). At the time of the interview, the babies were aged between 11 and 27 months, with the mean time since the last surgery being 10 months, with 18 months being the longest time since surgery. Three of the babies had been diagnosed with cleft lip and palate (and therefore had had two surgeries), three had a CP and one had a CL. The participants were based across South Wales, from West Wales to Gwent.

2.5. Procedure

2.5.1. Semi-structured interview schedule

IPA recommends the use of semi-structured interviews as the most common method for obtaining a description of an individual's experience (Willig, 2008; Smith et al., 2009). The design of the interview schedule is paramount to allow the participant the freedom to say what they believe to be important, whilst keeping the focus of the interview on the aims of the research (Willig, 2008; Smith et al., 2009). Interviews provide open-ended and non-directive questions which allow the participants to talk freely and at length in order to explore their experiences (Willig, 2008; Smith et al., 2009). The aim of the interview is not to lead the participant in their description or check their agreement with statements but to encourage participants to open up and describe their experiences in their own way, with their own words (Smith et al., 2009). The researcher's role is to encourage openness and elaboration where deemed appropriate (Smith et al., 2009).

Questions should not lead participants in their answers and should not contain predictive assumptions on the responses being given (Smith & Eatough, 2007). The structure should also be flexible, allowing the participant to take the interview in their own direction (Smith & Eatough, 2007). Following interviews, the structure can be adapted to reflect the direction of the previous ones.

The interview schedule (Appendix X) was produced by the researcher with these considerations in mind and, prior to interviews, the schedule was discussed with the research supervisors in order to establish the correct focus and type of questions being used. In this way, a schedule was developed that focused on aspects of surgery (such as awareness that surgery was required, time leading up to surgery, during the surgery itself and following the procedure) whilst maintaining open ended questions. The schedule was designed to create an interview of approximately an hour in length (having between six and ten questions). Prompts were also developed to aid the participant with the interview if required.

2.5.2. Interview process

All the interviews were conducted in the participants' homes at the participants' request. It was decided, if possible, that participants would be interviewed on their own (without their children) in order to gain a space in which they could focus entirely on what they wished to express. However, in some cases their children were present and in one case, the father of the baby sat in on the interview and made occasional comments. Where this occurred, it was clearly indicated within the transcript.

The interview was conducted flexibly. This meant that the schedule was not always followed absolutely but instead the participant was allowed to speak freely of their experience without interruption. Therefore, questions were not necessarily presented in the order described on the schedule. During the interview, the researcher made notes on questions to ask, thereby not disturbing the flow of the interview. Such questions included asking participants to elaborate on statements or words they used in order to ensure understanding, rather than making assumptions on the

proposed meaning (Smith et al., 2009). The researcher endeavoured to provide an inquisitive but non-interpretative air to the interview process.

Interviews were recorded using a voice recorder and following the interview, recordings were transferred to a computer and saved under the participants' numbers. These were password protected to retain confidentiality. Following the completion of the study, these recordings will be deleted.

2.6. Data Analysis

Following the interviews, the recordings were transcribed verbatim. During transcription, they were anonymised using pseudonyms to replace any names used. To ease the analysis, pseudonyms within one interview (the participant and their family's names) were given the same letter. Transcripts were formatted to have wide margins in order to aid the analysis process. Once transcribed, a number of stages were applied to begin to make sense of the participants' world. As this methodology takes an idiographic stance, aspects of individuals' experiences are identified initially (Smith et al., 2009). Commonalities shared with other participants are identified later in the process of analysis (Smith et al., 2009). The aim of the methodology is to gain an account of how the researcher understands the participant thinking about the phenomenon. The specific stages of IPA analysis are described below. Although these stages are shown separately, the process is not necessarily linear and stages may merge into one another. The IPA method followed here was based on that outlined by Smith, Flowers and Larkin (2009).

Stage One

On an individual basis, each transcript was read and re-read a number of times. This allowed the researcher to absorb and fully engage with the text. Unfocused reflections, observations and initial thoughts relating to the text were noted. These included any questions that came to mind, any comments on the language used, any associations perceived or any recollections of the interview itself. The aim of this

process was to ensure that 'the voice' of the transcript remains heard and is the focus of the analysis (Smith et al., 2009). During the first few readings, the interview recording was also listened to in order to retain and remember the voice of the participant. During subsequent readings, the participant's voice was imagined in order to ensure that it was being heard and focused on. This stage is not about reduction or creating a summary, it is about slowing down the process and really focusing on the dialogue (Smith et al., 2009).

Stage Two

Further notes on the interview, concerning anything of interest, were created, with the researcher remaining open-minded in order to see the text from differing perspectives. Although notes were not made on every part of the text, as some parts of the interview were richer than others, a comprehensive set of notes were developed. It was important, at this point, not to note ideas on what is expected to be seen but rather what is within the text itself. Again, the process is more about engagement rather than outcome i.e. the researcher should not be regarding the text with the aim of developing comments but merely encouraging engagement (Smith et al., 2009).

The comments made focused on certain elements of the text. Comments were created which provided a description of what had been said by the participant, staying very close to their original explicit meaning. These comments were concerned with aspects of the participant's life which matter to them and their meaning (Willig, 2008; Smith et al., 2009).

Additional comments focused on the language used within the interview. These included not only the use of specific words (and how this may relate to the individual's context), but also the use of particular phrases, such as metaphors, that give added meaning or emphasis for the participant (Willig, 2008; Smith et al., 2009). Notes relating to elements of the interview such as pauses, hesitations or moments of laughter were also created.

Comments were also made on a more abstract and interpretative level, in the form of questions, with the researcher attempting to provide ideas on the participants' meanings. These comments are an active reflection on the data and can rely, to some degree, on the researcher's own experience and prior knowledge, whether that be personal or professional (Smith et al., 2009).

There are no rules on the comments that can and should be made, but emphasis is placed on looking at the text from a number of perspectives (Smith et al., 2009). Comments were reflected on and refined further, however, they were always tethered in the participants' own words.

Techniques such as deconstruction and the underlining of text (Smith et al., 2009), also helped the researcher in the process.

All of these comments were made in the left margin of the transcripts.

Stage Three

This stage concentrated primarily on the comments that have been made, rather than the original transcript, as the comments should be closely related to the text (Smith et al., 2009). Focus on the comments made allowed a concise statement to be made of what was important. In this way themes developed, themes which reflected both the original words of the interview and the interpretation placed on it. These statements were written in the right margin of the transcripts. An example from a transcript and its subsequent analysis can be seen in Appendix XI.

Stage Four

Once the themes have been created, connections across the themes were developed. This was done by looking at the themes as they came up within the text, as well as looking at similar or related themes and how they might be grouped. The structure of the themes acknowledged the most important aspects of the interview. This process was achieved by studying the themes and clustering them as well as using numeration as a way of establishing the most relevant themes. In this way,

super-ordinate themes developed (themes which describe a group of other themes). These themes also emerged through the creation of a statement which better described a group as a whole.

Once groupings had been made, a table of the themes was created to show the overall structure.

Stage Five

Each interview was analysed in this way and attempts were made to look at each interview as if it is the first being seen. This allowed the researcher to remain open-minded and not allow potential influences from earlier interview analysis to influence the present piece of analysis. Doing this also helped to allow new comments and themes to emerge independently of the previous analyses.

Stage Six

The last stage involved looking for patterns across the interviews. This was achieved by taking the themes from each interview and looking for similarities and patterns. Themes were grouped in terms of meaning. Themes that highlighted or better described other themes were also identified. This led to themes being joined or amalgamated and relabelled. The researcher repeatedly referred back to the original transcripts during this process in order to keep the process circular. Adjustments were made based on this as well as on the prominence of themes across interviews. Each theme was annotated with the page number of the interview from which the theme developed, so the source of the theme is known.

Throughout this process, the researcher carried out a research diary (Appendix III) in which to note both the processes used but also the emotional aspects of the analytic process.

3. Results

This section explores the data generated during the interviews with the mothers of babies with CLP. In total, seven mothers were interviewed at their homes using a semi-structured interview. Interviews were transcribed verbatim and this data was then analysed using IPA. Although the interviews were initially analysed individually, this section will provide the themes which emerged when the analyses of all of the interviews were condensed into overall coherent themes. The super-ordinate themes and the master themes will be defined and direct quotes from the transcripts will be used to illustrate these definitions, allowing readers to examine the validity of the analysis and the creation of themes. The relationship between themes will also be explained.

3.1. Description of participants

A brief description of each participant is presented below to provide some background on the individuals. Potentially identifiable information has been omitted or changed and to preserve anonymity, participants were given pseudonyms.

1. *Anna and baby Abbie*

Anna is 34 years old and is married. Abbie is her first baby and was diagnosed with a cleft palate at birth following feeding problems. Anna has a support network of close family who live nearby. The interview was conducted at around 6 months post-surgery.

2. *Beth and baby Billy*

Beth is 32 years old and lives with her partner. Billy is their first child, who was diagnosed with a cleft lip antenatally with the confirmation of also having a cleft palate occurring at birth. Beth described great support from her close family. The interview was conducted at around 5 months post-surgery.

3. *Cathy and baby Callum*

Cathy is 30 years old and lives with her partner. Callum is their first child, although her partner has two children from a previous relationship who live with their mother. Callum was diagnosed with a cleft palate at birth. Cathy has the support of her parents who live close by. The interview was conducted at around 5 months post-surgery.

4. *Debbie and baby Dana*

Debbie is 34 years old and lives with her husband. Dana is their second child; their first child is 4 years old. Dana was diagnosed with a cleft palate within the first few months of life. The interview was conducted at around 18 months post-surgery.

5. *Elizabeth and baby Ellie*

Elizabeth is 19 years old and lives with her partner and her partner's mother. Ellie is their first child and was diagnosed with a cleft lip antenatally. Elizabeth's partner sat in on the interview and on occasions expressed his views. Within the transcript, the occasions on which this occurs is clearly stated. The interview was conducted at around 9 months post-surgery.

6. *Fiona and baby Faith*

Fiona is 30 years old and is married. Faith is her second child, with her elder child being 5 years old. Faith was diagnosed with a cleft lip antenatally, which was confirmed at birth along with a cleft palate. Fiona's husband spends long periods away from home due to his work but her mother lives nearby. The interview was conducted at around 18 months post-surgery.

7. *Gemma and baby Greg*

Gemma is 37 years old and lives with her fiancé. Greg is their second child, with their elder child being 4 years old. Greg was diagnosed with a cleft lip antenatally

and the cleft palate was confirmed at birth. The interview was conducted at around 9 months post-surgery.

3.2. Super-ordinate and Master Themes

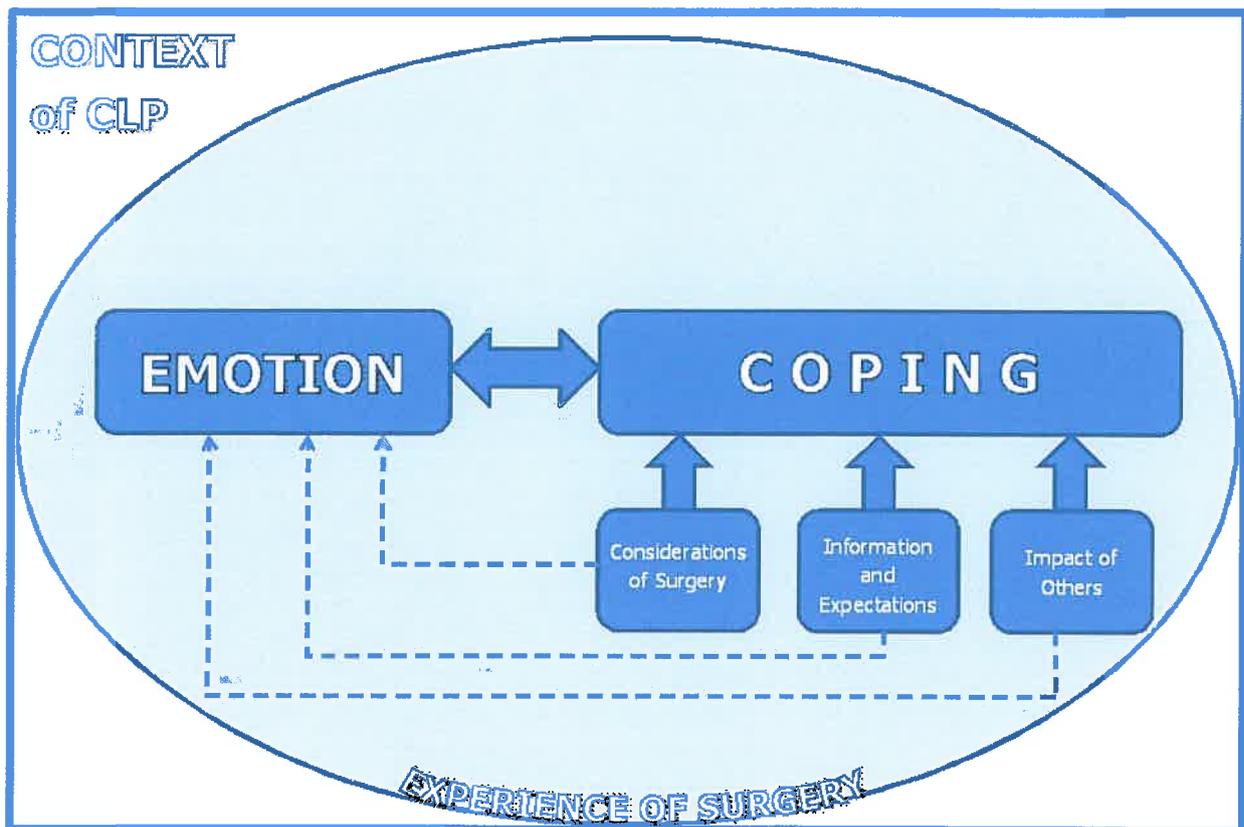
Table 1 (on the following page) outlines the super-ordinate and master themes. In some cases, the master themes have been broken down further in order to aid understanding and clarification. This breakdown will be illustrated within the different sections. A complete table of the super-ordinate themes, master themes and the breakdown of the master themes can be seen in Appendix XII.

Table 1. Super-ordinate and Master Themes

Super-ordinate Themes	Master Themes
<i>Context of CLP</i>	Diagnosis Birth Cause Feeding and Weight View of CLP as 'cosmetic'
<i>Emotions</i>	Diversity of Emotion Expression of Emotion Empathy for the Baby Impact and timeliness of emotion
<i>Coping</i>	Coping Strategies Need to focus on and be with the baby Coping Frame of Mind Personality and Attitudes
<i>Impact of Others</i>	Comparison with others Staff Attributes Reactions of Others Perception of Support Support from Others
<i>Information and Expectations</i>	Need for information and preparation Usefulness of Information Need for 'normality' Basis for Expectations
<i>Considerations of Surgery</i>	Choice Anticipation of Surgery Consequences of surgery

These themes will be described in turn, using quotes from the transcripts to illustrate them. Throughout this description, the relationship between themes will be expressed. This relationship is illustrated in a graphical format on the next page.

Figure 1: Graphical representation of the Super-ordinate Themes



A larger version of this figure can be seen in Appendix XIII.

3.2.1. Identification of quotations

For all the quotes shown, their location within the transcripts will appear in brackets following the quote itself. It will be expressed as:

(the name of the participant, the page number within the transcript, the line numbers).

3.3. Context of CLP

Although the focus of the interviews was the surgery itself, other aspects of the CLP journey were mentioned and emphasised as important. In many cases, these aspects 'set the scene' for the surgery itself. Therefore appreciating these factors

was important for understanding the experience of the surgery and providing it with a context. It felt important to acknowledge this context which emphasises that surgery is one part of the CLP journey and other elements of that journey also impact on a mother's experience. All the master themes below provide a background for the surgery and interact with the experience of it.

3.3.1. Diagnosis

Among the participants, diagnosis of the CLP occurred at different times from the antenatal scan to four months postnatally, due to failure to thrive. Diagnosis was significant for all the participants including the emotional impact of and the difficulty in not knowing about the condition and therefore not feeling prepared:

"you've been told all along is fine and normal and then you have what I consider a bomb shell really" (Anna, 3, 106-108)

"it was still a bit of a shock that he had a cleft palate and they didn't come back and explain anything about that, so you know, that was a bit disappointing really" (Beth, 8, 298-301)

"they told us that they could see something on the scan, they said the name and I didn't know what it was and then they just sent us upstairs so I didn't know then until I went up what it was" (Elizabeth, 1, 35-37)

"it didn't sink into me, it didn't sink into me that I was having a cleft baby until Faith was born" (Fiona, 1, 25-26)

For Gemma, the antenatal diagnosis had an impact on her pregnancy as whole:

"I mean it was on the 20 week scan that we had it, and gutted really, because you don't really think that anything's going to be wrong and all that. Really upset for a couple of weeks and on and off throughout the pregnancy" (Gemma, 1, 3-6)

Changes in expectations and the need to know more, are factors which recur when talking about the surgery itself.

3.3.2. Birth

Need for support from the staff at birth was expressed as important and it was felt that specific support regarding CLP was required as soon as possible. Mothers

expressed their awareness that, in the main, support was received relatively quickly, however, the first few hours after birth were emphasised as particularly important in feeling supported:

"they know the baby was going to be born with an issue and because they were so busy and they didn't have anybody specific to come to us you know" (Beth, 4, 164-167)

"I think if there was somebody to support us a bit more it would have helped because I didn't have you know, I wanted somebody there" (Beth, 5, 175-177)

For those who knew that their baby would have a CLP, there was anticipation on how the baby would look. Emotions were diverse:

"I must admit as soon as she was born I didn't even notice, I really didn't notice at all, she was my baby, she was beautiful and that was it" (Fiona, 1, 26-28)

"when I gave birth to him and seeing him and thinking yeah, it's a wide cleft lip and you can see that the palate is affected and yeah you are, you know, you are upset because you, you know it's more surgery, you know it's going to be longer issues" (Gemma, 3, 95-98)

3.3.3. Cause

The possible causes of CLP impacted on mothers in different ways. For some of those interviewed the cause was not mentioned whereas for others, it was initially anxiety provoking but wasn't a sustained worry:

"they told us about the different syndromes that could cause a cleft so you worry about those things, whether he has them" (Beth, 7, 275-277)

"Syndromes and all the rest of it and I thought Oh my word!" (Beth, 1, 32)

However, for others it was hugely significant. For Fiona, the unknown nature of the aetiology meant that she blamed herself and therefore, feelings of guilt and blame dogged her relationship with her baby, feelings which re-emerged during particularly difficult times such as the surgery:

"it was very hard to overcome being pregnant [with a baby with CLP], having no idea of how this happened, not really having information that could explain everything because ultimately you blame one another, you blame, well I've done something wrong" (Fiona, 1, 33-36)

"you think back to me again, I've done this, I've caused it because I didn't pick it up sooner, I automatically assumed everything would all be fine and it's my fault because obviously I did something wrong in pregnancy, so you're constantly in a rollercoaster" (Fiona, 9, 348-352)

3.3.4. Feeding and weight

Feeding was by far the biggest element of CLP to be discussed, other than the surgery itself. Issues with feeding continued to be significant throughout the period of time discussed within the interviews, whether it was due to difficulties in feeding, expectations of surgery improving feeding or need for feeding to occur before being able to leave hospital following surgery. Support and help with feeding was very important to mothers and if feeding was difficult, it tended to supersede all other issues within CLP including surgery:

"as brilliant as the midwives were in the hospital it would have helped if they had picked up on the fact a bit, I know it was only a day and a half but they are quite stressful days when you are trying to breast feed a baby that doesn't want milk, or can't take milk should I say" (Anna, 20, 788-792)

"they knew my concerns about feeding him and I really wanted to try and feed him myself and whether that meant expressing and giving it to him with the special squeeze bottles then I wanted to do that and they were aware of that and they didn't help me, they didn't do anything, they just shoved a bottle in his mouth" (Beth, 5, 178-182)

"We were back and forth to the health visitor to get her weighed, back and forth to the hospital so we had lots of people trying to keep an eye on her weight and she wasn't basically feeding, they wanted us to wake her up in the night, it was just horrific, it was just awful" (Debbie, 3, 89-93)

"I think, I hadn't got a clue how to do the squeeze bottles but you know, you know, you just go in and go, yeah, you're pumping air into him, but feeding was hard" (Gemma, 4, 124-127)

3.3.5. View of CLP as 'cosmetic'

Throughout the interviews, participants expressed their view of CLP and the meaning they attached to the condition. The most prevalent view was that of seeing CLP as a cosmetic issue, which was not regarded as a health problem. This view impacts greatly on the surgery itself. Seeing CLP as a cosmetic condition lends itself to the view that surgery is a 'solution' or a way of 'fixing' the difficulty, something which will be examined in section 3.7.4.

"it doesn't make him unhealthy, it's cosmetic, it doesn't make him unhealthy and they can fix it, and when you start to think that it got easier for us" (Beth, 2, 78-80)

"cleft babies are not stupid, they're not disabled in any, well they are in certain extents but they're normal people as well" (Fiona, 9, 345-347)

"I don't want him to be known as the baby who was born with the cleft lip and palate, we just want him to be known as Greg. And he just needs some extra medical stuff, he's got some extra difficulties which, you know, we'll get fixed" (Gemma, 7, 241-245)

"it's only a superficial thing, yes it's going to be long term things but at the end of the day you should be you know like any other person walking down the road" (Gemma, 21, 782-785)

3.4. Emotions

Emotions are at the centre of all the other themes expressed by the participants when speaking about surgery specifically and CLP more generally. All the themes ultimately are concerned with the mothers' emotional reactions to the surgery and either aspects of the process that improve or make the experience worse and how they feel about it. This theme highlights the variety of emotions experienced and the complexity of how these emotions interact, how they are expressed and the timeliness of the emotions.

3.4.1. Diversity of emotion

Emotion was expressed about all periods of the surgical process, from finding out that surgery would be required, to going home following surgery. Although instinctively, emotions such as anxiety would be expected, a wide variety of emotions were articulated, including excitement and relief. The emotions felt depended on a great deal of factors including: expectations of surgery, support from others, reactions of others, as well as other CLP-related concerns for the baby. The main emotions which emerged from the interviews are shown in the table overleaf.

Table 2: Breakdown of the Master Theme 'Diversity of Emotion'

Master Theme	Breakdown of Master Theme
<i>Diversity of Emotion</i>	Shock and Upset Anxiety Excitement and Happiness Exhaustion Relief Other emotions

Shock and Upset

The feelings of shock and being upset tended to arise as surgery approached, leaving the baby for surgery and when seeing the baby after surgery. These emotions were therefore caused by seeing or imagining the administration of the anaesthetic, as well as by expectations of how the baby would look after surgery:

"so we got there and you just hand them over, put them on a bed and then wave goodbye and I think that was when we both just got very upset and I had to go outside" (Anna, 11, 423-426)

"I sat outside and sobbed. And I was shaking, like physically shaking" (Beth, 3, 89-90)

"just the slightest little thing upset me and then anything and everything would just like upset me coz I was sort of feeling emotional" (Beth, 14, 533-535)

"Horrendous. It was just awful. I didn't expect it, I expected, I expected [the anaesthetic] to be hard, but I just didn't think it was going to be that bad" (Cathy, 8, 293-295)

"just going into the surgery that was just awful, really awful" (Debbie, 10, 360-361)

"Oh it was horrible, I was crying" (Elizabeth, 8, 274)

Anxiety

Anxiety was a common emotion expressed by the participants. Again, anxiety seemed to be borne out of numerous factors, including: expectations of surgery and concerns over the procedure, as well as the possible consequences of it. Anxiety

levels seemed to vary throughout the surgical process, with levels peaking as surgery got closer and receding once surgery was completed:

"obviously we were nervous and anxious about it but it wasn't till we actually got into the hospital that your nerve levels pick up" (Anna, 9, 331-333)

"you're really nervous and you're scared of what's going to happen and you know worried for him" (Beth, 11, 442-444)

"I felt awful on the way there, he was just like this happy little chappy, I thought aww, but I was quite nervous but apart from that it was fine" (Cathy, 8, 287-289)

"I was really worried then that she had to go into hospital as well, I'm not too good with hospitals either" (Elizabeth, 7, 227, 228)

"It's just like all those sorts of things and you're getting anxious and the driving, it's like that feeling when you go to the dentist and you've got butterflies in your tummy" (Gemma, 9, 325-328)

"I was anxious about surgery, yes you are on tenterhooks" (Gemma, 22, 809-810)

Excitement and Happiness

Although it could be assumed that surgery is, on the whole, a negative experience, participants did express more positive and, at times, light-hearted feelings, both before and after the surgery:

"when she first told me on the phone I was excited, sounds silly but excited that it was actually going to get done now" (Anna, 10, 366-367)

"So you're both really nervous but then again you've still got that excitement because you know that it's going to be over in a few hours" (Beth, 13, 521-523)

"But you're excited as well at the same time. It's hard to explain coz you're excited because it's going to be fixed" (Beth, 15, 586-587)

"I think I was just so happy to see him. My boyfriend cried when we went to pick him up but I cried dropping him off so (laughs) we both had a go" (Cathy, 11, 394-396)

However, with all the emotions acknowledged, the mixture of emotions were complicated. This quote from Anna expresses this with light hearted feelings right up until surgery, at which point it changed rapidly:

"so that was quite nice, and sort of having a laugh with us, and laughing as well and then we were fine until we handed her over" (Anna, 12, 445-447)

Exhaustion

Feelings of exhaustion were also common among participants. These feelings seemed to be the result of it being difficult to get to sleep (either through worry or being in a different environment) as well as the emotional impact causing them to feel emotionally exhausted:

"just came home and flaked out" (Anna, 16, 618)

"I think I got so fed up because I didn't sleep very well in the nights and it was just really horrific and I asked to be moved to a room if they could and they moved me to a room thankfully" (Debbie, 9, 309-312)

"I remember, you know, when you'll lying there, strange bed trying to sleep and you can't. And then trying to wake up really tired beforehand and knowing you're going to get more tired" (Gemma, 10, 351-354)

"Just remembering being knackered, I was hanging, absolutely hanging, you know, from not sleeping the night before, and you just like walk around like a zombie" (Gemma, 13, 491-494)

Relief

Feelings of relief tended to be experienced following surgery. This seemed to be linked with concerns about the possible risks associated with surgery, as well as the possible outcomes of the surgery:

"you've got the relief of it all and wow it's out of the way, she survived it and there were no problems" (Anna, 16, 609-610)

"Relief I think that he was okay, yeah, relief initially that he was okay" (Beth, 16, 614)

"I think I was just so relieved that he had come round and he was going to be okay and I just wanted to hold him" (Cathy, 11, 396-397)

"relief that the surgery, the first stage was over" (Gemma, 13, 461)

Cathy also describes feeling relieved on getting to the hospital and starting the process, rather than waiting for the process to begin:

"I think it was almost, it was quite a relief in a way to just get there and think okay so this is how it's going to be, it's actually happening and it's okay" (Cathy, 6, 223-225)

Other emotions

Individual participants acknowledged feeling differing emotions alongside those described above. It seems important to recognise these individual emotional responses as a way of identifying that there is no right or wrong way to feel within the experience of surgery.

Beth expressed her fear of surgery, particularly in regards to the anaesthetic:

"It's just scary I think, just the thought, especially for me, I've got a fear of being put to sleep" (Beth, 3, 84-85)

Cathy described how her emotional response to surgery was expressed with anger:

"as it got closer to the surgery I started getting really angry, not with him, but like I got really bad road rage (laughs) and I think I was probably quite snappy with my boyfriend and I'm generally quite a laid back person and I became quite militant and probably not very nice to be honest, so I think it came out in a bit of a weird way" (Cathy, 5, 167-172)

On taking her daughter Faith into surgery, Fiona describes a lack of emotion:

"It wasn't scary I think, I dunno what I did expect but I wasn't worried at that point, or distressed or, I think you're just going with the motion" (Fiona, 20, 802-804)

3.4.2. Expression of emotion

Although many emotions were experienced by the participants, there was a strong impression of it being important not to show that emotion and instead express those feelings when in private. In many cases, this was described as a way of being strong and presenting a positive front for the baby:

"obviously not showing Abbie that you're upset or nervous in any way coz it's not fair on her is it coz she wouldn't understand, so yeah behind closed doors a bit nervous but in front of Abbie fine" (Anna, 10, 371-374)

"you're strong for your baby and even though they're only six months, they can tell when your upset, they read off your vibes don't they so we hadn't realised how much of a show we were putting on really" (Anna, 16, 624-627)

"I managed not to cry until he'd gone to sleep and then I just absolutely burst into tears and didn't really know what I was doing, I just sort of went into a bit of a melt-down" (Cathy, 8, 295-297)

In the following quote, Gemma describes not wanting to take her son Greg for the anaesthetic:

"I guess [my husband is] less likely to burst into tears [.....] I'd rather not do it" (Gemma, 10, 364-366)

3.4.3. Empathy for the baby

Throughout the interviews, the participants showed a great empathy for their babies and concern over their emotional and physical well-being. Being aware of your baby's feelings, alongside putting on a brave face (as the last theme suggests), provides a sense of the mothers wanting to make the experience as relaxed for their children as possible. At times, the participants gave the impression of being an advocate for the babies' feelings, feelings which the babies themselves could not express:

"she wasn't sleeping properly she didn't sleep the first night we were there coz the noise anyway let alone after her op and feeling uncomfortable so you're more slightly uptight and on edge for your own baby really" (Anna, 15, 580-583)

"I felt sorry for her, coz I suppose I'm putting how I would feel in that, you know, she's only six months old at the end of the day, but we were thinking, god, it must be uncomfortable, and she obviously, they warned us she'd be in pain with her mouth [.....] you felt she must be very uncomfortable therefore you felt for her" (Anna, 17, 661-668)

"he can't tell you anything and I, you almost feel like you're feeling for him you know" (Beth, 12, 462-463)

"we were concentrating so much on trying to like keep him happy and just as relaxed as possible so we were trying to like laugh and joke with him and tickle him" (Cathy, 8, 282-285)

"you could tell that he was, that it was hurting him and you know, I suppose the first couple of days especially so it was just yeah trying to give him lots of cuddles and trying to take his mind off it as much as possible" (Cathy, 13, 473-476)

"this is going to be really painful for her and you don't actually want to do, but you do it because it needs to be done" (Fiona, 23, 904-906)

3.4.4. Impact and timeliness of emotion

Many of the emotions experienced by the participants changed in their intensity and extent at different times during the surgery. This theme describes the interaction between emotion and time, as well as describing its impact on behaviour. To illustrate this theme effectively, it has been broken down into sections, which are shown in the table below.

Table 3: Breakdown of the Master Theme 'Impact and Timeliness of Emotion'

Master Theme	Breakdown of Master Theme
<i>Impact and Timeliness of Emotion</i>	Controlling action Inevitability and Constancy of emotion Emotions changing over time

Controlling action

Participants expressed the feeling that, at times, they were being driven by their emotions, almost as if they were 'running on adrenaline'. This provides some idea of the impact and intensity of the emotions felt during this time. In one way, this seems to be a way of dealing with what is happening but it almost appears to occur on an unconscious level, driven by the emotional experience:

"I think you sort of, well, personally, we were both sort of running on, adrenaline" (Anna, 16, 623-624)

"yeah its very tiring, coz you're, yeah, you're just, automatic pilot I suppose" (Anna, 16, 630-631)

"It's a blur because you are running with emotion for that day" (Fiona, 22, 880-881)

"I think my emotions took over" (Fiona, 23, 907)

Inevitability and Constancy of emotion

Although in many cases participants were able to describe ways in which negative emotions could be relieved or avoided, there was also the view that certain emotional reactions were inevitable, as the very process of surgery could not be avoided and therefore, the emotional reaction would be present to some degree. Participants also suggested that despite using coping methods, the thoughts and feelings attached to the surgery were always there, a constant at the back of their minds:

"I think it was always, it was always going to be like that. I think, you know, there were people there if wanted to go and speak to them and ask any questions or. No, I think it couldn't have been any different to that really" (Beth, 14, 540-543)

"I don't think there's anyone who could have helped to be honest because there's no-one who can take away the fact the he's going to have to have the operation" (Cathy, 5, 179-181)

"And we knew that we weren't going to be able to see him, so yeah, we went to get some food and I was thinking about him all the time" (Cathy, 10, 344-346)

"at that point then sort of no amount of talking or distraction would have actually helped" (Debbie, 12, 432-434)

"also perhaps being warned that she might look a bit battered. Or maybe, I don't know whether you can prepare yourself for that mind" (Debbie, 20, 724-726)

Beth illustrates this when she describes experiencing the second surgery. She implies that despite knowing what would happen, it still was difficult:

"It's not easier to take him to the room where he's going to be put to sleep and it's not easier to be in the room when they're taking blood and different things" (Beth, 18, 722-725)

Emotions changing over time

This theme demonstrates that the emotion felt, was experienced as being a 'rollercoaster', with reactions continually going up and down and changing intensity. This seems to occur with different elements of the surgical process:

"obviously we were nervous and anxious about it but it wasn't till we actually got into the hospital that your nerve levels pick up coz obviously you know the operation is imminent then" (Anna, 9, 331-333)

I think once you get the date they're actually going in that's when you're, you start to worry about it again properly (Anna, 10, 357-359)

"It made me feel worse then coz when they took longer then you think there must be something wrong for them to go on longer" (Elizabeth, 5, 147-148)

Gemma describes how her anxieties over Greg and his difficulties have changed in terms of his CLP but haven't necessarily lessened, with her worries expanding to him going to school:

"I have my anxieties but over different things like his birthday is [in] August, I know it's a few years away but as [he] starts school in September he's going to be the youngest in his year" (Gemma, 20, 741-744)

This suggests that actually many areas of CLP are emotional, with surgery just being part of that, or it could emphasise the normality of worrying about a child, whether they have CLP or not.

3.5. Coping

The theme of coping is one that permeates through all the other themes which have emerged. The effectiveness of coping is affected by many areas of experience, including: the impact of others, the need for preparation, concerns of surgery, expectations for surgery and so on. In turn, the effectiveness of coping impacts on the emotions expressed. Within this named theme of 'coping', the focus is on personal coping, strategies and techniques, which come from the individual themselves. Although those interviewed expressed differing ways of coping, commonalities were present and this section illustrates the ways of coping that were most prominent.

3.5.1. Coping strategies

The master theme of 'coping strategies' focuses on specific techniques which were used in order to cope more effectively with the experience of surgery. Four main strategies emerged and these are shown in the table below.

Table 4: Breakdown of the Master Theme 'Coping Strategies'

Master Theme	Breakdown of Master Theme
<i>Coping Strategies</i>	Distraction Laughter Blocking Out Impact of the Environment

Distraction

One technique used as a way of coping was that of distraction. This was particularly used when the surgery was taking place as a way to avoid thinking about what was happening. The participants differed in methods of distraction, but the premise of 'taking their minds off' the surgery was the general purpose of all the activities used:

"I was able to talk to the other parents and play with the kids, that was my distraction then" (Anna, 16, 646-647)

"I think we were both just trying to talk about other things and just trying to, we went for coffee and different things" (Beth, 14, 532-533)

"if I'd just had to sit in a room and I'd had no distractions I think it would have been a lot harder, I think yeah, having distractions is helpful and makes the time go a bit quicker if nothing else I suppose" (Cathy, 10, 354-357)

"We went back to the room and put the telly on and watched some telly" (Elizabeth, 9, 307-308)

"I'm a very keen reader so I can read most things so I just lose myself in that for a bit" (Gemma, 12, 439-440)

Although specific forms of distraction were mentioned, more generally the ability to 'keep busy' was seen as useful, as illustrated here by Beth:

"we kept ourselves busy when he was in surgery so that went quite quickly, quicker than I thought" (Beth, 13, 510-512)

Laughter

Another way of coping and relieving some of the emotion which surgery brings, was the use of laughter:

"laughter makes things a lot easier for everyone" (Cathy, 8, 272)

"there seemed to be a lot of people milling around anyway who were going in, so that was quite nice, and sort of having a laugh with us, and laughing as well" (Anna, 12, 444-446)

Mothers expressed a view of it being a relief to laugh despite it seeming at odds with the situation itself:

"it didn't feel like you should be laughing because your baby had to go through something horrible" (Cathy, 7, 262-264)

The laughter often stemmed from the professions around the families and this was seen as positive and useful:

"they were laughing the nurses, saying that she is just very stubborn and if she can't do something first time she's not going to bother is she, so they were you know making a joke of it, but they were saying they were quite concerned at the same time" (Anna, 14, 541-544)

Blocking Out

Participants also described attempts to 'block out' thoughts surrounding surgery. Again, this was particularly prominent during the surgery but was also true of the period of time preceding surgery:

"you have to try and put it out of your head what you think they're doing to him because it's going to be painful you know, and you just think about those things so I had to try and not think about it" (Beth, 14, 528-530)

"I think I tried to completely put it out of my mind for quite a few months because there was quite a big gap from finding out to when it was actually going to happen so I think I kind of blanked it off" (Cathy, 5, 164-166)

"don't think about the what could and couldn't happen, run it over in my I head, I didn't do that" (Debbie, 7, 237-238)

This is expressed as a difficult thing to do. It appears as a struggle between having and not having the thoughts:

"not dwelling on it which is very difficult to do at that point" (Anna, 17, 654-655)

"it must be just the way I deal with it, block it out a little bit and so I just didn't really kind of go 'oh, my god it's the surgery tomorrow, ahh, isn't it really awful' but it was, you just kind of observing, taking in the surroundings" (Debbie, 8, 295-299)

Although on the whole 'blocking out' thoughts was seen as useful, Fiona describes how this coping strategy, when used in the longer term, can be problematic:

"Switched off. I switched off. And it comes back to kick me full hard every now and then it really does. If I switch off hopefully it doesn't have to bother me but something will kick it off" (Fiona, 25, 1007-1009)

Impact of the Environment

The environment in which the mothers found themselves also had an impact on how they coped. Although the hospital environment itself could not be changed, aspects of that environment, such as noise and temperature, seemed to make coping more difficult as well as being perceived as affecting the baby themselves:

"we don't think it was very good that you were with like kids literally screaming and playing football at the end of the bed and things, not really the best place for recuperating babies" (Anna, 15, 571-573)

"I would have found it quite hard, I think it would have been a lot more stressful if you were surrounded by other people all the time" (Cathy, 12, 435-437)

"I think I went in to get the nurses because the one child was making such a noise and then they took the child out then because it was just so noisy, it was just awful" (Debbie, 9, 334-337)

"it got to the point where I was desperate to get home because being in hospital is horrible" (Debbie, 14, 501-502)

"it was so hot the heating and the nurses couldn't turn it down and it was just so uncomfortably hot, I think that made it worse" (Gemma, 8, 298-230)

The ability to be away from the hospital environment was also expressed as a way of being able to cope better with the situation of surgery:

"so just a bit of fresh air, a change of scenery, a bit of a break" (Debbie, 15, 548-549)

"we went off the complete grounds, just for a walk and a coffee, just so you're not, you know, you're sat worrying all the time but if you sit on the ward or sit outside the surgery it's just going to be ten times worse" (Fiona, 21, 849-852)

3.5.2. Need to focus on and be with the baby

Being able to focus completely on the baby without having to be concerned with other things was seen as an important factor in the mothers' coping:

"you don't want to leave him but you have to eat and you have to you know, get a shower and things" (Beth, 17, 646-647)

"I think they even had nappies and things like that so you don't have to worry about anything you can just like focus on your child" (Cathy, 6, 220-222)

"So he was just good doing practical stuff which left me a lot freer to do more cuddling and I don't know" (Cathy, 10, 366-368)

Similarly, mothers showed a preference for being close to the baby. This goes alongside the idea of having the baby back following the surgery and therefore, may be linked with feelings of relief that everything has gone well and the baby is safe:

"so we didn't have to leave her from then on we were with her" (Anna, 13, 489)

"they let me hold him straight away, then I was just really pleased that I had him back" (Cathy, 11, 400-401)

"I just couldn't wait to see her" (Elizabeth, 11, 347)

"I felt a couple of times that I wanted to be closer to her coz like all the nurses were around her and stuff, but then when she was back in the room then, it was alright then" (Elizabeth, 15, 496-498)

3.5.3. Coping 'Frame of Mind'

Not only were specific techniques described as ways to help mothers cope with the process of surgery, but also ways of thinking about the process were conveyed as

being useful in coping. These ways of thinking about the process of surgery are outlined in the table below.

Table 5: Breakdown of the Master Theme 'Coping 'Frame of Mind''

Master Theme	Breakdown of Master Theme
<i>Coping 'Frame of Mind'</i>	Here and Now – 'One step at a time' 'Going through the motions' 'Getting it out of the way' As an active process

Here and Now – 'One step at a time'

One way in which participants expressed their way of thinking about surgery was the idea of staying in the here and now, and focusing on what was happening in the present. This idea of taking things 'one step at a time' meant, in some cases, that worry concerning surgery was held at bay (although not eliminated entirely) until the day of the surgery itself:

"you can put that to one side and not worry about that till about 5 months or so, and then you know we'll, just, deal with that when it happens" (Anna, 6, 209-211)

"it's kind of like, cross that bridge when you come to it, don't worry about it" (Debbie, 8, 260-261)

"surgery was way off my mind, I wasn't even contemplating surgery, it was what was going to happen there and then at that time" (Fiona, 3, 108-110)

"shove that to the side, deal with that another day I've got this now to do" (Fiona, 26, 1017-1018)

"I guess [worry] also about the surgery but that's tomorrow's problem" (Gemma, 9, 314-315)

'Going through the motions'

Unlike the use of particular strategies for coping, such as distraction, these 'coping frames of mind' were not necessarily consciously chosen as ways of coping. A

number of mothers felt, at various of stages of the surgical process, that they were 'going through the motions', rather than taking an active role in the present circumstances. This is linked to feelings of being saturated by the information given to them and blocking out what is going on around them in order to cope more effectively:

"as if it's kind of you're going along because you have to, you're going along with the motions but you're not actually thinking about it and analysing it too much" (Debbie, 7, 238-241)

"you're just sat there and you're going 'aha', you're just like a nodding dog and then you leave and someone goes was that good, yeah fine, what did they say, haven't got a clue, sorry!" (Fiona, 17, 675-678)

"again you don't actually think of what they're doing, you just follow the motion, you just do as they say" (Fiona, 17, 693-694)

"you just tend to go along with it but you know you're just out of your depth aren't you?" (Gemma, 6, 212-213)

"it all passes in a blur" (Gemma, 6, 226-227)

'Getting it out of the way'

Another way of coping with the surgery was expressed as wanting to 'get it out of the way'. This is linked to the mothers' views of surgery (see section 3.7.4.). If surgery is seen as a 'solution', a way of 'fixing' the CLP, then 'getting it out of the way' allows the mothers to put it behind them and begin to live a normal life:

"we could get this milestone out the way and move on" (Anna, 10, 368)

"we can just get on with our lives now without having something hanging over your head" (Anna, 16, 615-616)

"I think it was sort of a relief to know the date, [...] and then move on and just concentrate on him being able to get better and go forward" (Cathy, 6, 197-199)

"go and get it over and done with, it was kind of like going to the dentist, coz I hate the dentist, you know, it was like, you just want it over with" (Gemma, 16, 579-581)

As an active process

With all the coping strategies and ways of relieving the emotional burden of surgery, it was clear that none of them were completely successful in eradicating the negative emotions felt. Instead, these strategies had to be worked at and the coping mechanisms needed to be actively carried out. Beth expressed this most clearly by stating that she had to try harder to cope in these circumstances:

"I think I was trying to convince myself as well that that was, which I felt positive that that's what was happening, he was healthy and that's all they were doing, was just fixing his lip" (Beth, 12, 453-455)

"I think I had to work a bit harder because it was my son that I was trying to think about so I think I had to work a bit harder" (Beth, 12, 460-461)

"I had to be a bit more positive coz I dunno, I just think I worry more about him than I do about anyone ever in my life" (Beth, 12, 463-465)

3.5.4. Personality and attitudes

Coping also seemed to be based on the individual themselves, their backgrounds and their own beliefs, attitudes and personality. Previous experiences of coping, as well as how they saw themselves as people, had an impact on how they approached coping with surgery:

"I think we were quite positive. The pair of us, you know, quite positive" (Beth, 12, 449-450)

"I wouldn't say I know, I knew how I coped with things until then, because up until that point I've not really had that many horrible things happen to me, do you know what I mean? [.....] it's only on reflection now at looking back at how I coped with Dana [.....] that I realise my mechanism for coping, that's my mechanism, at the time I wouldn't be able to tell" (Debbie, 17, 625-632)

"I'm the sort of person who likes to have more information" (Gemma, 6, 207-208)

In some cases, however, personal styles of coping may not be particularly helpful. For example, Anna and Gemma expressed the following views of themselves:

"I am a bit of a worrier" (Anna, 10, 363)

"I worry a lot and I can be not the best sleeper when I worry" (Gemma, 10, 371-372)

These elements of their personality may not have been conducive to effective coping however just having an awareness of being 'a worrier' may have allowed them to compensate in different ways.

3.6. Impact of Others

Throughout the CLP journey as a whole, other people play a huge role, both in terms of the professionals involved with the individual's care and also the family and friends who act as support. These interviews suggest that these roles are just as important during the experience of surgery.

The name of this theme is indicative of the fact that other people may have either a positive or negative effect. The mothers interviewed expressed views of others as useful and supportive but also, at times, difficult to cope with. This theme demonstrates that pattern of interaction.

3.6.1. Comparison with others

These interviews suggest that, at times, the participants looked to others as a form of comparison. On the whole, this comparison was useful and for this reason, meeting other parents who had also gone through the process of surgery was generally seen as a useful practice. However, this wasn't always the case and comparison could also emphasise personal difficulties. This master theme is primarily concerned with the comparison between participants and other families with CLP who are going through or have gone through the same process of surgery. The breakdown of this theme can be seen in the table below.

Table 6: Breakdown of the Master Theme 'Comparison with others'

<i>Master Theme</i>	<i>Breakdown of Master Theme</i>
<i>Comparison with others</i>	Same – 'sharing experiences' Different – 'could be worse'

Same – 'sharing experiences'

In this case, comparison with others allowed participants to identify similarities with those who were going through the same experiences. In some cases, like in the following quotes, the shared experience in and of itself was seen as helpful:

"she seemed quite to be doing really well and spoke to other mums and how they're feeding and everyone had the same bottles and teats which was a simple thing that we all found quite funny" (Anna, 8, 294-297)

"you didn't have to explain, everyone knew" (Anna, 8, 300-301)

"It was also nice to be with other families and you know other babies going through the same thing really" (Beth, 20, 775-776)

"because I wouldn't have even thought about taking something like that in. So that was nice. And they shared a little bit of their experience of how they found it" (Fiona, 18, 743-746)

In other cases, it provided them with information about surgery which helped them to feel more prepared as well as being able to provide information for other families. This links to the Super-ordinate theme of 'Information and Expectations' as a way of feeling prepared, as well as being a form of coping.

"there was a young family from [place name] and their little boy, he's lovely, he only had a cleft palate so he was having surgery then for his cleft palate and it was the first time they had gone through it so I think they took a bit of comfort from us and asking us questions because he'd had his lip done already, you know we were trying to reassure them" (Beth, 20, 787-792)

"they were going for their second op, even though I was having my first, they were having their second and so that was nice, how they found it and their response was the same" (Fiona, 18, 729-731)

"they told me the good sides and the down sides so I already knew that I wasn't going to eat unless I had someone there to watch Faith, I already knew that I didn't have to bring my milk in because they supplied it" (Fiona, 18, 738-741)

Gemma found that comparison with others was particularly useful to her because it allowed her to see how those with CLP looked following surgery. The appearance of other children with CLP was therefore the overriding use of this type of comparison in her case:

"I quite liked the fact that there were other parents there with their children and you got to see what their babies looked like, you know, you're just nose-y" (Gemma, 4, 149-151)

"there were only three operations that day so it was one who had a bilateral cleft lip and then he was having the palate repaired so it was good to see him, it was like, wow, you know, seeing what it looks like three months down the line coz you know of course you pass that and it's like, okay what's it going to look, how obvious is it going to be and all that and then there was somebody who just had a palate so yeah so it is kind of good to see how the babies reacted after the palate surgery so you can sort of see" (Gemma, 14, 513-520)

"I often go on the face forward website, I've never posted but I look at the photos and you know, after the surgery, what's he going to look like in a year's time you know" (Gemma, 20, 763-766)

Fiona expressed the wish to have more opportunities to meet other families with which to share experiences:

"I was very surprised that there wasn't a lot of meetings that went together. So I arranged a meeting of my own and got in contact with CLAPA, they couldn't obviously give me the information so I gave them the flyer to post out and I think about four turned up to the coffee morning I put on" (Fiona, 6, 216-220)

In some cases, comparison with those going through the same experience was an important way of understanding what was 'normal' in these circumstances. This links with the need for reassurance and a need to know the norm (section 3.7.3.):

"his mouth looks normal because it didn't look normal before and you want him to look normal, for his sake, you know?" (Beth, 15, 580-581)

Different – 'could be worse'

While the above concentrated on comparison with others to determine similarities, this section illustrates comparison as a way of seeing the difference of others. This seems to be a useful way of gaining a perspective on what is happening. Many of the participants related their experiences to others as a way to appreciate that their own circumstances 'could be worse':

"In a very selfish way we realised how lucky we were that Abbie only had a cleft soft palate having never seen a baby with a cleft lip and things, we realised how much more trauma they're going through coz they've got two operations" (Anna, 8, 286-289)

"[Another baby's] got problems with her heart and everything and it puts everything in perspective because he's never been unhealthy" (Beth, 22, 843-845)

"But I think in a way it was a lot easier for us because he just had a cleft palate and not the cleft lip as well, so it's, I mean, I can imagine that if your baby had a cleft lip and you don't know that's going to happen it must be such a shock" (Cathy, 1, 9-12)

"Yeah, it did put life in perspective a little bit as well because her circumstances were very difficult and it kind of makes you realise how lucky you are you know, so that, it did put life, it does put life into perspective I think, and also like you said, seeing other kids with different levels of surgeries" (Debbie, 16, 574-578)

"I have worked with children with disabilities so I'm not sure whether that's had a help, but I'm like there's a lot of things that could be worse" (Gemma, 1, 11-13)

As these quotes show, this comparison can come from meeting others, but also from personal experiences, or merely by thinking through what others might be going through in other circumstances.

However, appreciating or seeing the difference in others is not always helpful. In the following quotes, participants express their concern over differences between their own child's experiences and others. Again, this may be an impact of trying to understand what the 'normal' experience is:

"that was a bit, well, a bit upsetting actually, coz the others all recovered quicker, even the one that had surgery after her" (Anna, 13, 517-519)

"And I know it's not a competition but you do worry when others are feeding and yours is the only one that isn't" (Anna, 14, 538-540)

"there was the other lady that was the lady that had her other boy, was it a boy or girl I can't remember now, so she was in with us in the HDU bit, and that was a bit demoralising because her little child started eating virtually straight away, but Dana wouldn't and they said 'oh don't worry about it, it usually takes normally a day or so' umm yeah! But Dana no. She just refused" (Debbie, 13, 473-479)

"After the surgery like there was a woman and her baby the same age as her and because she breast fed her baby took straight to the bottle, but with her she was on a bottle, she wouldn't feed" (Elizabeth, 6, 206-209)

3.6.2. Staff attributes

In terms of the cleft team and the medical professionals involved with the surgery itself, the participants tended to see them as a positive support:

"but the nurses in there were very nice, it was only four of us in that room coz it was the intensive care room for that night, and they were lovely" (Anna, 13, 503-505)

"they were brilliant, I felt relaxed that they were looking after her" (Anna, 13, 511-512)

"they were lovely. They were really sort of, they just sort of put us at ease straight away" (Beth, 10, 378-379)

"I think the cleft team from Swansea were amazing, they were really supportive" (Cathy, 3, 81-82)

"the nurses were really nice" (Cathy, 12, 422)

"the staff were lovely" (Gemma, 19, 698)

The reason for this has been broken down as shown in the table below.

Table 7: Breakdown of the Master Theme 'Staff Attributes'

Master Theme	Breakdown of Master Theme
<i>Staff Attributes</i>	Meeting and Knowing Staff Personality and Expertise

Meeting and Knowing

An important part of seeing the professionals involved in their children's care as a positive support, was having the opportunity to meet those involved and recognising them at future stages. Having a feeling of 'knowing' those involved was also deemed as important. Meeting staff was seen as almost a way of assessing them and establishing their ability and expertise (attributes that are discussed in the next section):

"the nurse who had been visiting us at home was there so that was a friendly face" (Anna, 5, 181-182)

"In a way I wish I'd met them earlier coz, you just feel more relaxed when you know whose, you've met the person who, in a way, has got your child's life in their hands so to know them makes you feel better [...] It just made you more relaxed having met them really" (Anna, 5, 188-193)

"She [the nurse] came out then to the hospital so that was nice because I'd spoken to her and seen her a few times" (Beth, 2, 61-62)

"And then we got to go up to Swansea just to meet the surgeon and some of the staff up there so we could then talk to the man who was going to do the operation and that was really reassuring as well" (Cathy, 3, 90-93)

"then we saw him again the second time so it just all helps you know that sort of thing" (Gemma, 18, 658-659)

Debbie felt, however, that meeting all the members of the cleft team in the initial stages of the CLP journey would not necessarily be helpful:

"there was a huge amount of people which I think, it didn't really bother me but I think it's probably very daunting for a lot of people and I'm not quite sure the purpose for them all being there" (Debbie, 5, 155-158)

Staff Personality and Expertise

In explaining the support received from professionals, participants highlighted their personal attributes such as being caring, approachable and available. This appreciation of the availability of support (knowing the support is there if required) is discussed further in section 3.6.4.

"the surgical team were so, they kind of played with her, it was only ten minutes, quarter of an hour just while we did some paper work. That was nice, coz they were all saying hello to Abbie" (Anna, 11, 437-439)

"I mean the staff in Morryston were amazing, they were amazing, they would come over and have a chat with you and just sort of ask if we wanted five minutes together as well or half an hour together to go get a coffee or some food and they'd watch him" (Beth, 19, 759-762)

"When he had his operation like the staff at the hospital they were fantastic as well, they were just the same like continuous, continuity of openness and like ask any questions" (Cathy, 5, 187-189)

"they were there all the time. And in the night then if we'd had a bit of trouble in the night then she'd come and get the food then and she'd say, aww, we'd try and give her the food now and we'd have a rest and stuff, they were really good they were" (Elizabeth, 12, 391-394)

"we'll keep an eye out for him and stuff like that and you'd come back to find them and they'll be cuddling Greg or something like that" (Gemma, 18, 662-664)

"the way that people respect, treat you and are friendly with you and make you feel that you are important, that Greg is the most important thing at the time goes a long way" (Gemma, 21, 803-806)

Fiona, however, did not always feel that she was supported by the staff. In the following quotes she illustrates feeling unimportant:

"I was a spare part when I was there, I was only there to make sure I was keeping an eye on [Faith]" (Fiona, 12, 480-481)

"I'm angry for every other cleft baby in the world because they seem to get lost, it's as if they're not important, and they're as important as any other illness or disability or anything like that" (Fiona, 18, 719-721)

This perhaps suggests that individual differences between mothers affect how much support they need.

Being aware of the team's expertise concerning CLP and their understanding of the condition and the surgery itself was also seen as important. This awareness of the professional's expertise allowed the participants to have confidence in their ability:

"All the staff in the hospital were very good. Even the ones on the ward that aren't actually specific to the cleft team, they were all very supportive and understanding, coz they know what you're going through" (Anna, 21, 850-853)

"the fact that he was really positive that he could do such a good job you know on fixing his lip, he was positive he could do such a good job" (Beth, 10, 386-388)

"I spoke to one of the nurses about the dangers of the anaesthetic and she explained that the anaesthetist that they have is like a special child anaesthetist that only deals with children and only dealt with cleft palate operations as well" (Cathy, 3, 84-88)

"he just obviously had a lot of experience and a lot of knowledge because that's all he dealt with" (Cathy, 3, 106-107)

"It was, yeah, because they know what they're doing and I didn't know, like if I'd had trouble feeding her they'd try for me" (Elizabeth, 16, 532-533)

"it's better to have that and be specialised then you know just for someone to be doing it a few times and not having the dedicated support. And the staff were fantastic, on the ward as well so that really helped" (Gemma, 18, 654-657)

The staff's approach of 'playing down' surgery and emphasising its routine nature was also deemed useful as was a calm and relaxed approach to the surgery:

"And it was quite nice because they were so, I wouldn't say blasé but so relaxed and like, what a silly question, of course she'll be alright was their attitude so that was quite nice" (Anna, 7, 273-275)

"I felt quite sure from the beginning that he'd be in really good hands and that it was, they sort of made it, not played it down, but it wasn't like they made it quite clear that it wasn't a major issue and that he wasn't going to be in any like danger or it wouldn't affect him too much" (Cathy, 1, 30-35)

"I think the fact that all the staff were quite laid back and would have a bit of a laugh and a joke with you which really relieved some of the tension that you feel" (Cathy, 7, 259-261)

"I think that helped a lot because his manner is very calm and you can't help but like him" (Gemma, 5, 155-156)

Despite participants seemingly preferring staff to show a calm persona and approach, it was noted that this may be an 'act' or a 'strategy' to help parents feel more relaxed. However, this did not necessarily mean that it was not effective:

"I know that's the way they do it to make you feel relaxed but it definitely worked on us!" (Anna, 7, 275-277)

"I'm sure it is part of the process I know to make you more relaxed but it definitely worked and they were all friendly, that's the key isn't it, that they're friendly" (Anna, 12, 440-442)

"it was nice that they were there just because it seemed to make it like a, quite a team and as though they actually, they didn't have to be there, or maybe they did, but it made it seem like they actually cared, if that makes any sense" (Cathy, 4, 143-146)

"he probably reads the notes five minutes before he walks into it all, but he can tell you everything that's in her notes" (Fiona, 19, 755-757)

Although the comments from participants were positive in the majority, there were occasions when support from professionals was not as beneficial. Beth described an occasion when she perceived that a negative appraisal of CLP by a medical professional went against her own beliefs about the condition:

"I sort of felt like she was making it a negative thing and I didn't like it. She made me feel like it was a negative thing and I hadn't felt like that" (Beth, 9, 356-358)

In Debbie's case, too much contact from the cleft team, instead of being helpful, was attributed to their belief that there was a problem:

"I thought maybe it's because she's so small and they've got concerns about it and they're anxious, so it actually increased my anxiety levels" (Debbie, 3, 109-111)

3.6.3. Reactions of others

In this section, the impact of others' reactions to the baby is emphasised. This highlights how the reactions of others can significantly affect the individual involved. The following quotes show how others' reactions to the baby and the condition can cause feelings of embarrassment and shame:

"I didn't like going out with Abbie knowing she'd need a feed coz I was embarrassed that I'd have to sit in a café for over an hour to feed her, when all my other friends would be over, done and dusted in twenty minutes" (Anna, 21, 841-844)

"I was very scared of people's reactions" (Fiona, 2, 46)

"people shy away from it, they'll turn their backs, and I didn't then take her out for a long time" (Fiona, 2, 58-60)

"he looked different and people are going to notice that and you're just like it's not their business" (Gemma, 3, 117-118)

"there were times when I did take him out of the push chair, you know, where people looking longer and it made me self-conscious because I'm not used to that" (Gemma, 5, 169-172)

For Fiona, the reaction of others affected her significantly, so much so that she felt the need to become isolated from others:

"And I was really shocked that they actually didn't say anything, they, one said 'oh why's it got a hole?' you'd explain it and they're fine. So I thought fine I'll take her out and I did and I got told, one day in the park, why didn't I take my freak child home and it crushed me" (Fiona, 2, 51-55)

Although these negative experiences were present, Beth offered a different perspective:

"I'd never experienced anybody being negative to us" (Beth, 9, 355-356)

With this mix of experience, it is important to stress that others do still react negatively and sometimes cruelly to CLP, but this is not an inevitable reaction. However, if negative reactions do occur, it can have a significant impact on the mothers of CLP children.

3.6.4. Perception of support

This section focuses on the perception of the availability of support provided by the CLP team. It does not focus on the content of that support (which is considered in section 3.7) but is, instead, concerned with how support is generally presented to the participants. This theme has been broken down as shown in the table below.

Table 8: Breakdown of the Master Theme 'Perception of support'

Master Theme	Breakdown of Master Theme
<i>Perception of support</i>	As being there if needed As being a choice As explicit

As being there if needed

Participants provided the impression of support as being 'there if needed', almost as if the knowledge of support being available was as important as any practical support that was provided:

"there were people there if wanted to go and speak to them and ask any questions" (Beth, 21, 541-542)

"we never had any problems really but they'd just ring up and have a little chat with you and it was, it was really nice" (Cathy, 4, 116-118)

"they were saying that after she'd had her operation she'd look different and then if I wasn't bonding with her so well I could go and see somebody about it and they'd explain then, yeah, so that was really good that was" (Elizabeth, 17, 569-572)

"you've got the cleft nurse and just knowing all that helped" (Gemma, 1, 22-23)

Gemma noted that it was comforting to know that support was available in the long term as well, not just for the surgery itself:

"I guess it's more like when Greg gets older you want them to have the support there if they need it and again if they get issues at school and how do we support him with that then again there is someone there that we can access" (Gemma, 5, 180-183)

As being a choice

Alongside the idea of knowing support was available if needed, participants also presented a want to choose whether support was used or not, rather than it being provided automatically. Participants seemed to believe it was their responsibility to get in touch with the CLP service if they required help in any way:

"we did have to say, okay we don't need as much help as you're giving us now, you can back off a bit, which they said to do when we were ready" (Anna, 20, 807-809)

"I would have approached them if I felt like I wanted to discuss anything or I wanted to talk to somebody, but I didn't feel like I ever wanted to" (Beth, 9, 361-363)

"we could ring up if we want but they weren't, I didn't think they come out, didn't come out to see us and I can't remember if they rang or not but it was for us to contact them" (Gemma, 15, 539-542)

As explicit

Participants also expressed how the availability of the support was made explicit by the team:

"if we wanted more we always knew they were there to support us as well and they always made that clear" (Beth, 4, 125-127)

"made it really clear that if we had any questions we could ask anytime" (Cathy, 3, 83-84)

"I think also they explained that the support doesn't just stop once you've had the operation" (Cathy, 4, 127-128)

"it was made clear like several times, they'd say if there's any questions you know feel free to ask them, and if you think of anything at a later date we had a number we could ring" (Cathy, 5, 156-158)

This feels important as the ideas of support being 'there if needed' and as being 'a choice', would perhaps not have been seen so favourably if the availability of the support was not given explicitly.

3.6.5. Support from others

Throughout the interviews, participants spoke about the importance of family members throughout the CLP journey including surgery. Participants saw family members as pivotal in helping them cope with the emotions connected to surgery. This theme has been broken down as shown in the table below.

Table 9: Breakdown of the Master Theme 'Support from others'

Master Theme	Breakdown of Master Theme
<i>Support from others</i>	Family and Friends Partners

Family and Friends

Support from family and friends, but particularly parents, was crucial to help mothers feel supported and better equipped to cope with surgery:

"I would say for me, it was family really and friends, having that support network at home" (Anna, 21, 839-840)

"all of our family [...] stayed positive, [...] there was never anything negative, all our families they were so positive and helpful and reassuring, especially your mums and dads and aunties and things like that" (Beth, 12, 469-474)

"we were really lucky that we had so much support, I don't think people could have done any more for us and I've got my family close by and things like that so I was really lucky in the amount of support that I had" (Cathy, 5, 181-184)

"mum and dad were really, really supportive, yeah, hugely. I knew I could always go to them if I needed to" (Cathy, 15, 456-457)

"it had to be someone completely I could trust and that fell to my mum to be here all the time" (Fiona, 4, 142-143)

Partners

All the participants had partners at the time of interviewing and during the time of surgery. Although for some participants this relationship was part of the overall

support they received from the wider family, for others it was essential in allowing them to share the experience with someone and to work as a team for their baby:

"We, we both feel we're a team, you know, we're a family now so we're there for each other and we support each other and we do things together" (Anna, 8, 307-310)

"I don't think it would have been as easy without a supportive partner. Coz obviously you talk to each other and help each other along" (Anna, 8, 314-316)

"we had each other to speak to" (Beth, 9, 363)

"Ben I think. Yeah, just each other, I think we helped each other, so yeah, you know, because we were both being positive we helped each other" (Beth, 19, 757-759)

"I'd rather share it" (Gemma, 10, 374)

3.7. Information and Expectations

This super-ordinate theme covers the information provision concerning surgery and the use of that information in terms of feeling prepared for surgery and having accurate expectations of that process. A major role of information provision is in helping the participants cope with the experience. By knowing the details of the surgical process, participants seemed less likely to have extreme reactions to events. This was emphasised by those participants who experienced both surgeries, with them feeling more at ease for the second surgery due to knowing what to expect. As Beth states:

"you've been through it once and you know what the routine is" (Beth, 19, 727)

"it seems a bit easier because you know what to expect" (Beth, 20, 794-795)

However, as the theme of 'emotions' shows, a feeling of being prepared does not rid participants of an emotional reaction altogether, but aids their ability to cope with them.

3.7.1. Need for information and preparation

Throughout the interviews, participants indicated a preference for gaining information either through their own discoveries or through talking to others, both professionals and those who had gone through the process previously:

"just not knowing anything about surgery on babies in that respect and obviously what they were going to do to her" (Anna, 5, 159-161)

"by knowing what you're facing in the long run is better than what you face in a very short time" (Fiona, 5, 201-202)

"it's like the unknown isn't it? If you know them it's much better" (Anna, 20, 814-815)

"you don't know initially what they would do, just the thought of what they might have to do to him" (Beth, 3, 93-94)

"we were lucky enough in that we'd been to visit the ward, so we did know like how it would look and that sort of thing, so we did know what to expect as far as that goes" (Cathy, 7, 232-234)

"if I hadn't known that I think I'd have been even more worried about his reaction, so yeah, definitely useful to know, and it's just nice to be included in things, so they're going to say okay this is what we're going to do, rather than just doing it, which I think would have made me feel quite panicky and like I didn't want to leave him" (Cathy, 9, 321-326)

On occasions, participants indicated how a lack of information or insufficient explanation of aspects of the surgery could lead to increased worry and trepidation as well as leading to participants jumping to conclusions. Within the following quotes, it seems as if the staff are perhaps unaware of the concerns of the participants because the procedure is routine to them, whereas the participants feel in the dark and therefore concerned:

"It made me feel worse then coz when they took longer then you think there must be something wrong for them to go on longer" (Elizabeth, 5, 147-148)

"they didn't say, they kept putting all these different masks on and they wasn't telling me what they were and they were from different oxygen things and stuff" (Elizabeth, 16, 541-544)

"her surgery went on longer than expected so we had to go and ask the question where is she, which was a bit worrying, we were like shouldn't you come and tell us, is everything okay" (Anna, 12, 463-466)

"But nobody actually said anything just kept on walking back and forth and it was just hideous" (Debbie, 12, 439-440)

"I didn't plan for that, I didn't really think about high dependency, I didn't think about her drinking afterwards and you're not told really or, I suppose you're told but you're not made fully aware that this is going to happen" (Fiona, 24, 960-964)

"because you don't know what to expect and you are you know if I think about it now and think back it is that packing, so you know its building up to that, you're packing and what do we take, how much do we take [.....] It's just like all those sorts of things" (Gemma, 9, 318-326)

Knowing what was going to happen therefore was an important factor for participants in terms of feeling prepared for surgery. They expressed a want not to be shocked or surprised by occurrences during surgery, but to know what to expect, especially when a procedure was occurring or participants were waiting for extended periods:

"they answered our questions and we felt more prepared then" (Anna, 8, 281-282)

"everything you needed was there for you, things we hadn't thought of" (Anna, 21, 853-854)

"I think you need to know what's going to happen" (Beth, 3, 107-108)

"The only thing I didn't like is when she was in surgery, no-one come up to see if she [.....] was alright or anything like that, we just had to wait and wait" (Elizabeth, 4, 136-138)

"I didn't even know where we were going or how, I didn't know if they were going to take her from the bed on their own or that we would have to walk her, I didn't know any of that, so of course when they said oh we're taking you down, yeah it was quite, oh right we're walking her, okay we just go with the motion" (Fiona, 21, 828-832)

"we knew he would be later down the line, so you are just, better prepared for it, you know what to expect" (Gemma, 16, 597-599)

"just having that information about the practicalities so it's one less thing to worry about" (Gemma, 18, 686-687)

Participants also indicated a need to be mentally prepared for the surgery, something that seemed to be a build-up to the surgery rather than a need for information:

"I think you prepare yourself mentally for that" (Beth, 19, 726)

"you just kind of psych yourself for that" (Gemma, 16, 604-605)

The need for information and feeling prepared, links both to emotional reactions to the surgery, the ability to cope and the impact of others, as a lot of information was provided by the professionals within the cleft team and in the hospital as well as other parents who had been through similar experiences.

3.7.2. Usefulness of information

This master theme concentrates on information provision by professionals and others. For the majority of participants, information provision was deemed as helpful however, suggestions were made for possible improvements to how that information was presented. Other factors regarding the information presented is also described here, including the timeliness of information and the feeling, on occasions, of being saturated with knowledge. The theme has been broken down as shown below.

Table 10: Breakdown of the Master Theme 'Usefulness of Information'

Master Theme	Breakdown of Master Theme
<i>Usefulness of information</i>	Type and communication of information Timeliness of Information Saturation of information

Type and communication of information

The way in which information was presented to participants was seen as important in understanding it in the most effective way possible. This included both the type of information and how it was presented. Having reference materials or having information from other parents were thought of as particularly useful methods of gaining information. However, individuals had differing views on what was most useful:

"it's useful to have information that you could then put aside and then read it maybe after the event if that makes sense because sometimes, sometimes before it you don't really want to have that much information" (Debbie, 6, 201-204)

"I would have loved more of worst case scenarios, and a real big breakdown of what could go wrong or what issues you're facing not just as a baby" (Fiona, 5, 187-190)

"I would have preferred to have gone to like, you've got your parent groups when you're giving birth to learn how you know all the tools, equipped and that. Something like that, group meetings" (Fiona, 5, 193-196)

"just a little brochure, done this, done that, done it, nothing technical or over thing, just basic so that you knew yourself that when you got home if you picked it up again you'd go, oh yeah, that's why they've done that and because again you don't actually think of what they're doing" (Fiona, 17, 689-694)

"you don't always want too much information" (Gemma, 6, 208-209)

Despite these individual preferences, a number of participants indicated their satisfaction with the information they had been supplied with:

"I don't think I even looked it up on the internet. I didn't do any, any research apart from what they, they told us, and I didn't know, they just so completely answered all our questions" (Cathy, 4, 133-135)

"They just explained everything as we could understand, it wasn't in their terms, you know, it was so that we could understand every detail" (Beth, 10, 383-385)

"we never felt like, oh god what's happening to our son, they're putting him away and we don't know what's happening, every step was explained" (Cathy, 6, 190-192)

Timeliness of Information

The time at which information was presented to participants was deemed as important in being able to process it effectively:

"a million and one questions to be answered really that, they are answered before she has surgery but you kind of want to know at the time don't you, straightaway" (Anna, 5, 161-167)

"I think we would have liked a bit more information up front. Seemed to be a bit, they weren't answering any questions at the very early stages when really you need to get it straight in your head at that point to put your mind at rest, they were kind of leaving that till later" (Anna, 21, 821-825)

"You just want answers to everything straightaway and obviously they can't give them, so they gave as much as they could and it was really, really helpful" (Beth, 11, 431-433)

"at the time I don't think I would have been capable of looking at [an information leaflet]" (Debbie, 19, 687-688)

Again, timing of information seems to be a personal preference. However, Beth illustrates in the following quote that even when she believed that she required the information at a different time, looking back it was not necessarily the case:

"I think I should have waited and not done [research] on the day we were told, coz I think I was a bit raw at the time" (Beth, 2, 43-45)

Saturation of information

At times, participants indicated that the amount of information being presented to them was overwhelming and, at times, it was felt that there was difficulty taking everything in sufficiently. This idea connects to the coping frames of mind of 'getting it out of the way' and 'going through the motions', where individuals felt the experience passed in a blur:

"I suppose it was just taking it all in really at the time it's just, it's a bit like a fog I suppose you just kind of, you're in the moment but can't, you're not really there" (Debbie, 1, 35-38)

"a little bit overwhelming I think because as I said, you go into this room and there's just a vast number of people in there" (Debbie, 7, 225-227)

"I don't think any of that sinks in, nothing sinks in really" (Fiona, 1, 37-38)

"you've just got different people talking to you, so you're just going, okay, yeah I think I get it, alright then, next, right, go in there and take some blood, okay, no problem [...] To be truthful I can't tell you exactly what they were telling me" (Fiona, 16, 656-660)

"I guess good to have the information, not sure if you take it all in" (Gemma, 6, 206)

3.7.3. Need for 'normality'

One aspect which helped participants feel prepared was knowing what was 'normal' in terms of their child's condition and their own experiences. A breakdown of this master theme can be seen on the following page.

Table 11: Breakdown of the Master Theme 'Need for 'normality''

Master Theme	Breakdown of Master Theme
<i>Need for 'normality'</i>	'Normality' Reassurance

'Normality'

Participants expressed a need for 'normality'. This was both in terms of being a 'normal' family, without the added complications of the CLP, but also in terms of what was deemed 'normal' in terms of the various stages of surgery, particularly in recovery:

"sometimes you just don't want to be reminded that there's a problem. You just, its normal to you, your everyday routine and life is fine, your baby's fine, but to have someone phoning or visiting all the time, that is over and above the norm just keeps reminding you that yeah, there's an issue, you know, there's something wrong with your baby and it's not quite as normal as other babies" (Anna, 22, 886-892)

"his mouth looks normal because it didn't look normal before and you want him to look normal, for his sake, you know?" (Beth, 15, 580-582)

"especially just after the surgery it was really helpful just to know is this how, you know, is he progressing as he should be sort of thing" (Cathy, 14, 492-494)

"a person who knows what they're doing feeding her and saying yep she's fine, you know, this is normal she's still going to have the gagging, you know. And I think that, I know it's going to take time out of people's day and it's meaning someone having to be there longer and so forth but for a ten minute feed for her parent to be put at ease, and say this is normal" (Fiona, 13, 524-530)

Both Cathy and Fiona remarked that they were unsure on how to act within a hospital environment with a child who was being operated on. This also indicates a need to know what is 'normal' in terms of their own behaviour within the unfamiliar environment of the hospital:

"it [felt] like you shouldn't be laughing because your baby had to go through something horrible" (Cathy, 7, 262-264)

"I think it's because you don't really know how you should be behaving either, and not that there's any particular I suppose way in which you should behave" (Cathy, 8, 276-278)

"well you didn't know what you were supposed to do at that point, you didn't know if you were supposed to stay in case something did go wrong, or if you could go and come back" (Fiona, 22, 859-861)

Reassurance

In order to understand what 'normality' actually is in terms of surgery, participants suggested that reassurance from others was the way to communicate this:

"at which point he said off the record that it looks great and he can't envisage any problems brilliant. So, that was nice to know" (Anna, 18, 728-730)

"it was a relief like you know that everything's fine with him" (Beth, 8, 327-328)

"And explained that the risk was actually really really low and that there'd be someone just monitoring just that, so that sort of put my mind at ease about that" (Cathy, 3, 88-90)

"I think possibly a little bit of reassurance from them sort of saying you know don't worry about you know, that probably would have helped a little bit as well" (Debbie, 10, 371-373)

"When the surgeon kept coming round to see her after she had had it done, he was saying that everything was fine and it was all looking good and stuff so that made it a bit better" (Elizabeth, 15, 521-523)

3.7.4. Basis of expectations

Although the participants' expectations of surgery were influenced to a large degree by the information received, they were also based on the individuals own experiences of hospitals and surgery but also their views of the surgical process in CLP. This breakdown of the theme is shown below.

Table 12: Breakdown of the Master Theme 'Basis of Expectations'

Master Theme	Breakdown of Master Theme
<i>Basis of expectations</i>	Previous experience View and perceptions of surgery

Previous experience

The participants' previous experiences of being in hospital themselves as well as aspects of surgery, such as anaesthetic, had an impact on their expectations of what the experience would be like and therefore, impacted on how they felt about the surgery:

"I've got a fear of being put to sleep, I can't have that, you know, I've had a wisdom tooth out and things and they've said we'll put you asleep, I've said no, I need to stay awake, and I'd rather be awake for anything than get put to sleep and just the thought of him having to have that" (Beth, 3, 84-89)

"I've never had an operation, I've been quite lucky medically so it just seemed a bit daunting" (Cathy, 2, 53-55)

"I didn't really know what to expect to be honest coz you get, I've, touch wood, never had any experience of hospitals before Dana, coz I've just been fit" (Debbie, 10, 356-358)

"I was really worried then that she had to go into hospital as well, I'm not too good with hospitals either" (Elizabeth, 7, 227-228)

View and perceptions of surgery

The participants' views of surgery were influential on how they approached the process and how they coped with it. In some cases, these views were gained from the professionals involved but it also felt as if they were used almost as a method of reassurance to help participants cope with the surgery. One such view of surgery was seeing it as 'routine', a 'solution' or a 'fix' to CLP:

"they've told us it's a very routine operation" (Anna, 6, 227)

"we'd spoken to people and it just seemed far more routine than you first think coz you just think surgery – ahh, not nice, but yeah far more prepared" (Anna, 9, 328-331)

"he's going to have it fixed" (Beth, 11, 445-446)

"it's going to be over in a few hours and that he's going to start to get better and you know his mouth would be fixed on the outside" (Beth, 13, 523-524)

"not played it down, but it wasn't like they made it quite clear that [surgery] wasn't a major issue" (Cathy, 1, 32-33)

"he was very much saying that for him that's a really easy operation to do so we felt quite reassured after that" (Cathy, 3, 97-99)

"you just think well at least it's a straightforward operation" (Gemma, 17, 615-616)

Participants also tended to view surgery as being for the child's own good and the 'best thing' for them:

"it was for his own good" (Cathy, 2, 74)

"And it needed to be done, it needed to be repaired" (Debbie, 17, 609-610)

"you know it's got to be done" (Fiona, 10, 393)

"it's something that needed to be done" (Gemma, 11, 394-395)

"You know it's the next stage, it has to be done but you just want it over with" (Gemma, 16, 570-571)

Although these views of surgery acted as a way of rationalising and coping with the process, for Fiona, these views made the experience more difficult. Fiona also viewed surgery as a 'solution' but instead, the difficulties derived from the CLP did not reduce. This expectation of surgery as a solution was, for Fiona, an unrealistic understanding of the process:

"you set your mind set that surgery was needed and I very much believed and I still believe now that if something is needed to be done, it needs to be done no matter what the consequences, you've got to have it done. Surgery I know has to be done, I know it's part of her plan, I know it's part of what she's going to have to go through and I knew back then so I knew that surgery was something that had to be done and I just went along with it, but it has to be done, that's what we're doing. I didn't think outside the box" (Fiona, 24, 946-953)

"And all of that has been a knock on from surgery where I'd assumed that everything would go back to normal and it hasn't" (Fiona, 8, 323-325)

3.8. Considerations of Surgery

This theme is concerned with specific aspects of the surgical process. It includes elements of the surgery that are particularly prominent for participants as well as issues surrounding the possible or perceived consequences of the process. Considerations of surgery had an impact on both aspects of the participants'

emotional experience and therefore is also relevant in their coping mechanisms as well.

3.8.1. Choice

Having a choice with the surgery was an interesting concept for participants. The majority of those interviewed saw surgery as something that needed to be done and was in the best interest for the child, ideas that were discussed in the 'Information and Expectations' theme. For this reason, these individuals felt as if the decision to have the surgery had not been explicitly theirs. However, they were not concerned by this, as they felt that the surgery needed to be done:

"I don't think we ever thought there was another option I guess" (Beth, 14, 559-560)

"you know they've got the cleft palate and they were talking about the impact it has on feeding and the impact it has on speech and why it's got to be done, but it was very much a 'this has got to be done'. So it wasn't a, didn't feel it was a, kind of a two way conversation it was just kind of them telling me that it's going to be done and this is why and this is roughly when we do it" (Debbie, 18, 649-655)

"the fact that it needed to be done, you haven't got an option, it needed to be done and that's it" (Gemma, 20, 768-770)

However, Anna felt differently. Although she also saw the decision as an easy one in terms of believing that surgery needed to be completed, she did feel that it was her decision to make as parent to the child. She felt that it was presented to her as a foregone conclusion and would have preferred to come to a collaborative agreement:

"it was kinda taken for granted that that's the path we were going to take" (Anna, 2, 72-73)

"not once were we asked do you want your child to have surgery" (Anna, 19, 755-756)

"it wasn't really discussed, it wasn't an option, it was going to happen, you felt that, you did feel that decision had been taken out of our hands, so yeah I think they could have worded that a bit better to be honest, because obviously you do want the best for your child but you do want to be, well, you want to have time to think about it and obviously come to the correct decision yourself in a way" (Anna, 19, 773-779)

This suggests that even if individuals hold similar beliefs about the need for surgery, how this decision is presented to them, needs to be considered.

3.8.2. Anticipation of surgery

Participants had general feelings of anticipation leading up to the surgery, anticipation which was, on occasions, thought as worse than the incident itself:

"I think actually once we actually got there, it was better, sometimes you know waiting for something is the worst bit isn't it, and it was almost like waiting for an injection or something and you're thinking oh god this is going to be horrible" (Cathy, 6, 212-215)

"I think the worst bit about the surgery bit was that waiting for her to come out really, the kind of the anticipation of it and the build-up" (Debbie, 17, 616-617)

Anticipation of surgery also included imagining what the outcome would be for their children. This covered a number of areas such as appearance, feeding and generally believing that the baby would be 'back to normal' following surgery:

"the implications of how Abbie, it would affect Abbie's speech rather than anything else when she's older and that's why they advise the surgery" (Anna, 2, 70-72)

"I thought maybe he'd have to have tubes and various things but no he could be fed straight away, so that was a bit of a shock that that could happen but we were pleased you know that obviously more or less be back to normal" (Beth, 10, 405-408)

"you try and imagine how he would look before, you try and think like how would he look and I did on one or two occasions, I put my hand over the one side of his mouth and think, right, okay so if that's what he'd look on the other side that's what he'd look like, but you can't really picture, you can't really picture it properly" (Beth, 15, 589-594)

"he's going to be able to eat properly and talk properly when that time comes and umm so yeah so I think I did try to look ahead quite a lot" (Cathy, 6, 205-207)

"I had it in my head that this was going to be, you know her lip was going to be fixed at three months which would give her facial features and so forth, her palate would be done so it would fix, close everything up so you know she shouldn't have milk coming back down her nose, and the sucking and the muscles in her mouth should start then working" (Fiona, 8, 296-301)

"About how she'd look after, I was worried about that, just in case she'd look completely different" (Elizabeth, 3, 92-93)

This theme links into how the participants' expectations of surgery develop (section 3.7.4) and whether they felt prepared for what was going to happen (section 3.7.1).

3.8.3. Concerns of surgery

Alongside the anticipation of surgery, were concerns over specific parts of the surgery, with the most common being that of safety, mostly with the anaesthetic:

"rightly or wrongly was an anaesthetic and the risk with a six month old, surely that's going to be really high. Coz they always say there's a risk with anaesthetic, so I think that was our main concern we were both worried about the anaesthetic and her being so small" (Anna, 4, 155-159)

"you know things can go wrong you know, you hear that things can go wrong" (Beth, 3, 99-100)

"I think I was mostly worried about the surgery. And just the risk of the anaesthetic really" (Cathy, 2, 52-53)

"I spoke to one of the nurses about the dangers of the anaesthetic" (Cathy, 3, 84-85)

Connected to this were worries over surgery in terms of the size of the baby and thoughts on how the surgery was going to be performed:

"just not knowing anything about surgery on babies in that respect and obviously what they were going to do to her, I mean, we couldn't really see how they were going to get in her mouth to stitch it up, so how do they get in there? Weird, do they have to cut her here (pointing at the sides of her lips) to get in" (Anna, 5, 159-164)

"just the thought of surgery really, because you don't know initially what they would do, just the thought of what they might have to do to him" (Beth, 3, 92-94)

"it felt very wrong to leave him there, and he looked so small" (Cathy, 9, 307-308)

"she was so small and it was just, it was just, obviously looked tiny and just going into the surgery that was just awful, really awful" (Debbie, 10, 359-361)

"you are anxious that they're going to be like three months old and having surgery" (Gemma, 3, 87-89)

3.8.4. Consequences of surgery

When speaking about the period following surgery, the consequences of the surgical procedure were commented on concerning the baby but also the impact of the surgery on the mothers' relationship with the baby. This master theme has been broken down into sections which are shown in the table overleaf.

Table 13: Breakdown of the Master Theme 'Consequences of Surgery'

Master Theme	Breakdown of Master Theme
<i>Consequences of Surgery</i>	Changes in the baby Relationship with the baby

Changes in the baby

Perhaps obviously, participants spoke about their observations on the changes in their babies following surgery. Both short term and long term changes were commented on. The main focus of both was that of appearance but other short term changes, such as bruising, were spoken of and it seems that the amount of information supplied to participants about these particular effects of surgery were important in how the participants viewed these changes:

"in fact we both commented we thought she looked better than we thought she would" (Anna, 17, 670-671)

"then to see his face and there's blood there and because it looked sore and there's stitches everywhere" (Beth, 16, 615-616)

"he actually looked better than I expected him to" (Cathy, 11, 408)

"That was a bit of a shock as well because she was a little bit, um, she looked a bit, what's the word, she looked a little bit battered I suppose" (Debbie, 12, 443-445)

"when we seen her as well it wasn't that bad because where they'd done the lip it was hardly any blood or nothing on there, it wasn't that bad, she wasn't covered in blood or nothing, which may have looked a bit frightening" (Elizabeth, 4, 117-121)

"I can remember seeing her face was really puffy, had changed anyway but, the puffiness, the blood was still on her face" (Fiona, 22, 890-892)

"there wasn't much bruising, he had like a little blood on his lip and all that, but his face was a bit puffy" (Gemma, 13, 466-467)

Long term changes focused primarily on the baby's overall appearance. For some participants, these changes were significant but seen positively and were adapted to:

"he looked so much more like Ben, he looked like Ben anyway" (Beth, 15, 596-597)

"do people honestly not notice that he's had a cleft lip because when you tell people sometimes they're shocked and they say oh I'd never know that" (Beth, 21, 820-822)

"It looked good because it was different" (Elizabeth, 11, 354)

"It was like seeing Greg mark two, you know, pre-op, post-op" (Gemma, 12, 450-451)

"You've just known him as this you know, as this one baby with a gap [.....] this is like Greg as he should have been born but it just wasn't because of what happened when he was in the womb" (Gemma, 12, 451-457)

For Fiona however, this change was devastating and something she felt ill-prepared for:

"she's not the same. And she never will be the same again" (Fiona, 10, 373-374)

"I miss Faith, I really do miss the characteristics that I got so used to [...] your baby completely changes, it was a new baby" (Fiona, 10, 376-379)

"the change in the facial features is devastating because you are given a complete new baby" (Fiona, 10, 394-395)

It should be highlighted here that changes in appearance are more relevant for those families whose child has a cleft lip and therefore, these changes were only significant for four of the participants.

Relationship with the baby

Participants spoke of changes in their relationships with their babies following the surgical process. In this case, opinions were diverse, with some participants believing that it had had no effect on their relationship whilst others felt that they had lost their baby and bonding needed to be achieved all over again. What this demonstrates is that comments regarding perceived changes to the mother-baby relationship were not restricted to those who had experienced a change in the baby's appearance:

"I think if anything it's made us closer coz you feel you've been through something more together, not you know not that you're not close to start with, but we, my husband and I both commented that we felt that we'd bonded closer as a family coz we'd had to go through something together" (Anna, 23, 911-915)

"I think in a way I'd been slightly holding back emotionally from him just because I was so worried that something might happen to him. I think this is all like sub-conscious, I didn't even realise that it was happening, but after this acupuncture, my relationship with him, I did feel like I was a lot more open to him in that maybe then I just don't need to worry about anything happening to him" (Cathy, 14, 505-511)

"in my head and my heart that it wasn't my baby, I was convinced, she wasn't mine" (Fiona, 22, 892-893)

"I've got photos of Faith from the way she looked before [...] I do it so I can remember what she was like because she went from that to that [pointing to photos] and it absolutely [distressed] me. So I leave them so I can remember what she was like when she was born" (Fiona, 23, 920-926)

"I think what changed the relationship was when the feeding got easier" (Gemma, 19, 710-711)

3.9. Summary of Results

Overall, these interviews have provided an insight into mothers' experiences of surgery. Surgery sits within the context of CLP as a whole, with other aspects of the condition, such as diagnosis and feeding, setting the scene for how participants experienced surgery. The process gave rise to a diverse set of emotions which were always present, although in differing intensities, with some feelings being inevitable to the process. These emotional responses were dependent on how prepared the participants felt, the information they were given, the impact of those surrounding them and the particular concerns over the surgical procedure. Coping strategies and mechanisms were therefore vital in aiding participants to balance their emotions in order to provide support for their babies. These interviews emphasise the importance of individual differences in coping with surgery, both in terms of personality and previous experiences of surgery. The need to consider these differences and appreciate that different people will cope with similar information and experiences in significantly diverse ways, were highlighted. Indications of the helpful nature of the professionals involved were encouraging. Nevertheless possible suggestions for alterations in information provision and presentation, as well as additional points to consider within the cleft team, were mentioned.

4. Discussion

This chapter will review the six super-ordinate emergent themes derived from the interviews with mothers of babies with CLP. These findings will be considered in terms of the broader literature. In this way, the discussion of the results will lead to service implications and future directions for research in this area. The methodological strengths and limitations of this study will also be considered, alongside the researcher's personal reflections on the study.

4.1. Discussion of Results and Service Implications

Each of the six super-ordinate themes will be focused on in turn. The theme will be summarised and reviewed in terms of the literature and the service implications leading on from that will be discussed.

4.1.1. Context of CLP

This theme focused on the background experience of CLP, which provided a context for the experience of surgery. Elements of the CLP journey, such as diagnosis and feeding difficulties were particularly prominent and, in some cases, meant that surgery was of little concern in the face of these other challenges. It emphasises that surgery is one part of the larger experience of CLP as a whole and although the surgery brings with it specific concerns and considerations, as the other themes show, an individual's experience of it cannot be fully understood without gaining an insight into their experience of CLP thus far. Feeding difficulties were particularly relevant within this theme; difficulties which are present in the literature (Owens, 2008; Bannister, 2004). In cases where these difficulties were present, surgery was not focused on unless it was seen in the context of improving the problems with feeding. It is not in the scope of this study to focus on these added elements of the early stages of the CLP journey but it is important to recognise the prominence of these factors and the interaction of them with the surgery itself. Studies such as those conducted by Spriestersbach (1961) and Chuacharoen et al. (2009),

emphasised this interaction by indicating the main concerns of parents as changing as time goes on. Chuacharoen et al. (2009) emphasised that surgery became more of a concern as it came closer and this it reiterated within this study. Initially surgery was a background consideration, but as time moved on so did the focus of concerns. It is essential to remember that the emotional impact of the other CLP considerations will have an impact on the experience of surgery. So, emotions of, for example, frustration over feeding or guilt and blame over the cause of the CLP, will be part of and will interact with the emotions connected to surgery.

Specific views of CLP also impacted on what the surgery meant to mothers. A view of CLP as 'cosmetic', allowed mothers to see the surgery as 'routine' and, perhaps, relatively simple (this view of surgery is discussed further in the theme of 'Information and Expectations'). It is unclear where this view of CLP derives from, but it could be that the CLP service opts for this view as a way of helping parents cope. It may also be a result of the media's view of CLP.

This interaction between elements of CLP and the surgery experience itself may be of relevance in terms of the support professionals provide for families. When surgery is introduced to parents, an understanding and awareness of their early experiences, which may require specific support, such as feeding, could be useful during the surgery itself. So, if feeding has been problematic up to surgery, then specific support might be needed during the surgical procedure to help parents understand how the surgery will improve feeding difficulties and to help them initiate feeding after the procedure. Time is required with the families then to discuss any difficulties with additional elements of CLP which may impact on the process of surgery.

4.1.2. Emotions

This study indicated that the emotions connected to surgery were both abundant and diverse, with both negative and positive emotions being present. Anxiety seemed to be the most prevalent emotion, something which is echoed in the literature concerning hospitalisation and surgery in the general sense (e.g. Johnston, 1997; Commodari, 2010; Valdes Sanchez & Florez Lozano, 1993). This emotional

reaction has been shown in both the individual going through surgery and the parents of children going through surgery. Within this study, mothers experienced increased stress due to their child going through surgery but they also demonstrated a particular empathy for the baby, perhaps as a way of providing a voice for the child. In this way, the emotional reaction may be two-fold.

Although issues such as isolation and loss of autonomy are apparent in the literature regarding hospitalisation (Johnston, 1997), this was not apparent here. This may have been due to the period of hospitalisation being short and mothers having the opportunity to be with their babies for the majority of the surgical period.

Emotions were also found to change in their intensities across the time period of surgery, as well as some feelings being inevitable and constant. This is echoed in the literature which focuses on the concerns of parents, with concerns changing with time (Spriestersbach, 1961; Chuacharoen et al., 2009). This may suggest that the same thing could therefore be true of the emotional reaction to those concerns. What this present study provides is a detailed insight into the complexity of the emotions felt, something that does not necessarily come across when examining the available literature. What also is not explicit within the literature is the perceived need for mothers to be able to express emotions in private, away from others. However young the baby, it seems that mothers feel the need to hide emotion when in the presence of the baby, for fear that the child, in some way, picks up on their anxiety. Therefore, this element of emotional experience may need to be appreciated further when professionals are working with mothers during the surgical period.

In terms of implications of this for a cleft service, the study emphasises the need to be aware of the diversity of emotional reactions and the validity of this. Cleft services should be aware of the individuality of emotional experience when it comes to surgery and the need for mothers to have the opportunity to express that in private, away from the baby. The ease of creating this opportunity within a hospital setting is unclear, but proposing the idea to parents of spending some time to

themselves, may allow them to feel able to do this. Normalisation of the emotional experiences of surgery, such as the 'ups and downs' and the inevitability of some feelings, may also be beneficial to parents to aid their coping.

4.1.3. Coping

Coping was a super-ordinate theme which interacted with all the other themes which emerged. Ways of coping and elements of the experience that affected coping were evident in all the themes and therefore, this is perhaps the most important component of the research. The ability to cope with the experience of surgery is paramount and every other aspect of the experience impacts on the ability to be able to cope. This, perhaps, reflects the findings of Riski (1991), who acknowledged that coping needs to be emphasised at times of transition, such as surgery. It appears to be a complex relationship between the ever-changing emotional experience and coping mechanisms with which to balance that.

This theme showed that strategies such as distraction and 'blocking out' can be useful for the short period of time during surgery and ways of thinking, such as concentrating on the 'here and now' and 'going through the motions' also were useful tools. Elements of personal attitudes were also influential, with a positive attitude being particularly helpful, which echoes the findings of Baker et al. (2009). Although mothers did not see being away from their baby as detrimental, they did show a preference for being close to the baby.

Individuals had their own ways of dealing with emotion, although commonalities in the coping strategies emerged. What this research may provide is an insight into some techniques which tend to be beneficial and which can then be adapted to suit individual preferences.

This research provides an awareness that 'coping' is a complicated process which is a part of all of the other areas of the surgery experience. Due to individual aspects of coping, an understanding of the individual and their families would perhaps aid the coping process. Understanding the type of person an individual is i.e. are they a

'worrier', what concerns them about the surgery and what social support they have, will all provide knowledge as to how they can be helped to cope with the emotional experience of surgery. It therefore indicates the importance of spending time with individuals and their families, to better understand them and their circumstances. In doing so, individual ways of coping can be understood and, if required, suggested.

Time is a limited resource within clinical settings and therefore the capacity for spending time understanding individuals' ways of coping is perhaps an unrealistic one. However, this study may emphasise the importance of coping and therefore may spark conversations which focus on the individuality of it. In this way, those who are having difficulty coping may be identified and areas of coping which are lacking, such as social support, can be compensated for through added professional contact.

4.1.4. *Impact of others*

As with the literature regarding support from others (for example Baker at al., 2009; Schuster at al., 2003; Riski, 1991), this study showed the huge part that social support plays in aiding individuals to cope with the difficult experience of surgery. Support from family was paramount, with particular emphasis being placed on the importance of the parental relationship as a way of sharing not only the experience itself, but also the responsibility of care for the baby. Support from professionals was also vital for mothers. Elements such as the expertise and caring attitude of staff, feeling that staff were known to families and being treated as important by professionals, were all part of being able to trust the professionals who would be caring for their child. A friendly approach, as well as the use of reassurance, was also deemed as an important aspect of professional support. In this way, the support of others formed part of coping as a whole as well as being the main vehicle for information provision, something which feeds into the need for preparation, which again acts as a way of coping.

Comparison with others who were going through the same experiences was also seen as useful, as it allowed both camaraderie as well as the opportunity to gain

information from those who had 'been there'. It also provided scope for gaining perspectives on what they, as individuals, were going through compared to others and provided a level of 'normality' in this unknown experience. The importance of the support of other parents was found by both Riski (1991) and Johansson & Ringsberg (2004), but what was not recognised was the possible detrimental impact of such comparisons. The present study showed that comparison with others could be a difficult experience as well as a positive one. In this case, professionals may be essential in providing a view of the 'norm' of surgery in order to reassure mothers; elements of support which are emphasised within the theme of 'Information and Expectations'.

Others' reactions to the baby and the condition are, again, shown to be diverse, with some instances being positive and accepting, and others being difficult and, at times, cruel. Again, the individual experience is vital here. Understanding the individual's experience would provide an insight into difficulties in coping or particular beliefs about what the surgery will accomplish. Again, the need to spend time with individuals to assess these aspects of their overall experience of CLP, may provide professionals with an understanding which could ultimately allow them to aid coping.

Perception of support was also prominent in terms of seeing the support as explicitly being there, if required, and being a choice. On the whole, mothers in this study felt secure in the knowledge that support was available but felt it was their choice as to whether they utilised it. It is important for professionals to emphasise the support available and the ways in which it could be accessed. However, some felt it was difficult to contact the cleft team. This could be due to mothers feeling they have little control in how to act within a medical setting, leading to uncertainty about whether they should ask questions or not. This reaction to a medical environment was suggested by Johnston (1997), but whatever the reason for these feelings, it again stresses the relevance of individual differences and needs. It suggests that there is a need for team members to spend time getting to know individual needs in

terms of support, in the hope of identifying those who may need more intensive support from the professional team.

This study highlights the importance of others in providing support and it particularly placed the professionals involved as an integral part of that support network. Professionals need to continue with their already approachable, friendly and caring outlooks to patients and their families, as it is shown to be highly valued. The importance placed on sharing experiences with those who have gone through similar circumstances suggests that providing an opportunity for parents to meet others could be beneficial. However, due to the possible detrimental effect of such a comparison, the choice of such interactions would need to be made by the individual themselves and their families. As before, professionals having the opportunity to understand the individuals involved may help to identify their specific support needs and whether they prefer a more 'hands on' or 'hands off' approach.

4.1.5. Information and expectations

Information about the surgery allowed mothers to feel prepared, which acts as another way to help them cope and alleviate some of the emotions felt in the process. Participants expressed a need to find out about the procedure and the practicalities surrounding it and in the instances where a lack of information was evident, an increase in worry or jumping to conclusions was shown, as indicated in the literature surrounding hospitalisation (Johnston, 1997). Similarly, Reynolds et al. (1981) cited in Johnston (1997) showed many patients want to know about their diagnosis and treatment, something which seems to be reiterated in the need for knowledge of the surgical process for mothers in this study.

In terms of the information provided, again, individual preferences were indicated. Where some wanted to know worst case scenarios, others felt that this was not necessary. Similarly, where some felt the need to do their own research, others felt they were given sufficient and comprehensive information. This could mean a difficult balancing act for professionals in knowing how much information to provide, particularly as a want for 'worst case scenarios', even when requested, may not be

beneficial. Similarly, the timeliness of information provision was commented on, with different information being more relevant at different stages of the process. Again, this adds to possible confusion surrounding how much and what type of information to provide. It highlights, again, the need to understand individual needs for information. In the same way, emphasis was placed on knowing what was happening on a step-by-step basis, when procedures such as the anaesthetic, were taking place or when surgery ran over the time given. Information needs to prepare mothers for the future but also needs to be provided in the present.

The use of reference material was highlighted as being a particularly useful presentation of information in allowing mothers to have something to refer back to, in circumstances when verbal information may be overwhelming or not presented at the right time for that individual.

The need to know what was 'normal' within the experience of surgery was important in reducing uncertainty. It also aided situations when comparison with others was seen in a negative way. This knowledge of 'normality' might come from other parents or professionals. In both cases, reassurance seemed to be an important mechanism in expressing this. Due to the importance of the professionals' expertise and knowledge in terms of support, it might be that this reassurance needs to be provided by those who do have this expertise in order for the mothers to have confidence in the information being presented to them. In this way, the themes of 'coping', 'impact of others' as well as the present theme all seem to fit with and complement each other.

Again, individual experience is relevant for this theme. The mothers' previous experiences of being in hospital, as well as their own beliefs of the surgery itself were significant in how their expectations of surgery manifested and how prepared they felt. Views of surgery as 'routine' and a 'solution' were on the whole useful but could be difficult to cope with after surgery if difficulties were not perceived as being solved. Therefore, careful consideration needs to be placed on how surgery is presented, as media views may play their part in encouraging the idea of surgery as

a 'fix' or 'solution'. For this reason, careful consideration of mothers' expectations for surgery and exactly what it may and may not achieve, may be useful in preventing a potentially unrealistic view of how much the surgical process can bring change for the better.

These results also resonate with the resilience literature. Mothers' past experiences of illness and being in hospital, as well as their own understanding of the CLP surgery, seemed to have an impact on coping, elements which are also stressed as possible influences on resilience (Black & Lobo, 2008; Walsh, 1996). Despite the lack of research into resilience and CLP, this may suggest the potential usefulness of this concept when thinking about and working with families with CLP.

Services can take a great deal from the experiences relating to information provision. On the whole, services provide useful information to mothers concerning surgery, but it is important to consider individual differences in preference as to how much information is wanted. The introduction of more written information may help to ease the overwhelming effect of some verbal information and therefore should be provided, particularly in the busy pre-surgery team appointment. Reassurance about what is 'normal' should be emphasised. Consideration should also be made of how the idea of surgery is presented. It could be important to present surgery as the first step in helping to overcome the difficulties associated with CLP rather than a 'fix' or a 'solution' for it, in order for mothers to feel realistically prepared for the consequences of surgery.

4.1.6. Considerations of surgery

This theme highlighted the particular concerns which mothers have about surgery. It primarily included aspects of risk about the surgery, such as the anaesthetic. The stage of life of the baby and the fact they were so small at the time of surgery were also commented on. Other factors, such as the perceived consequences of surgery and the actual consequences, were also important. Such concerns have been shown to be significant in previous studies (e.g. Stone et al., 2010; Johansson & Ringberg, 2004). Choice concerning surgery was also commented on; this is a challenging

aspect as even those mothers who felt they were not given a choice regarding surgery, commented that they would have chosen that route as the best option for their baby. In this way, it is not about the decision itself (as those interviewed all felt it was the correct decision to have surgery), but more about the locus of control for the decision. Awareness of the impact of not feeling in control is important, therefore, when the treatment process is being outlined to parents.

Changes in appearance following surgery were also prominent with, again, individual differences affecting the impact of these changes. This study indicates that this change of appearance can have a hugely detrimental effect on mothers and the subsequent relationships between them and their babies. On the contrary, however, other mothers saw the positives in the changes and felt no adverse effects. In some cases, it was even felt that the surgery had amplified the mother-child relationship, making it stronger. This reflects the diversely mixed literature regarding attachment within CLP (e.g. Murray et al., 2008; Clement & Barnett, 2002; Maris et al., 2000). Some of the negative feelings expressed in terms of changes in appearance are mirrored in the literature focusing on visible difference and individual reactions to their appearance, such as depression, anxiety and lower self-esteem (Harcourt & Rumsey, 2008). This study does not, perhaps, clarify the issues surrounding attachment but it does suggest that individual differences play a huge role in determining who may or may not be affected by such difficulties. Aspects such as personality factors, background history, family support, difficulties prior to surgery and reactions from others, all have their place in this complicated issue. What it does suggest, in this particular case, is that changes in appearance following surgery are closely linked to relationship changes between mother and baby.

This theme should highlight the need for services to provide parents with an awareness of the potential short and long term effects of surgery. It is important to make families aware of the possibility of seeing the baby differently following surgery, but stress that this is merely possible and not inevitable, with some seeing this difference in a positive light. This study should provide professionals with an

increased awareness that distress in relation to appearance change may be extreme and should be an element of surgical aftercare.

4.2. Summary of Recommendations

Overall, this study highlighted the role of coping mechanisms within the experience of repair surgery in CLP and that the support shown by both the cleft team and ward staff, was vital in helping mothers cope with the stressful and potentially anxiety-provoking experience of surgery. Despite this, elements of the study gave rise to possible recommendations for services in order to aid mothers further during this time. With all of these recommendations, it should be noted that although these appear to be useful recommendations for services, they are based on mothers' experiences. In this study the experiences of the service itself have not been gained. For this reason the recommendations made here may already be in place. However, these points may be used to confirm practice and emphasise the need for consideration of these elements of service provision. These recommendations should also be recognised within the context of the research itself. They are derived from a qualitative study conducted at one CLP team base, and therefore should not be seen as rigid rules to be applied to every CLP team. Instead they could be a useful resource for potential areas of consideration within the initial surgeries process. Differences between services, such as any variations within the clinical pathway for those with CLP, needs to be contemplated when considering the relevance of these recommendations and their application to a service setting.

The recommendations are summarised below:

- An introduction of a parent group or method for individuals to contact each other in order to enable mothers who have gone through surgery to share their experiences. Uptake of this would need to be the choice of the individuals involved.

- Continuation of an approach of friendliness, availability and care from professionals when working with mothers during the time of surgery.
- To spend time with families to discover their individual worries, the context of their surgery experience, their particular support needs and ways which might help them cope. This report could provide an insight into the particular concerns which may be present, as well as possibilities for facilitating coping.
- Use of more reference information. This would compensate for times when mothers felt overwhelmed with information. It is also important to keep mothers informed in the present, knowing what is happening step-by-step, for example, when surgery overruns.
- Providing a view of surgery as a first step to overcoming CLP difficulties rather than a 'fix' or a 'solution'. There needs to be an ability to hold a sense of ordinariness of the surgery, without minimising the extraordinariness of it for each family.
- The need to be aware that appearance changes can (but don't have to) have a significant impact on parents. Mothers should be aware of this potential consequence of surgery and professionals need to be particularly aware of those mothers who show distress or a change in approach to the baby following repair surgery. In this way, those mothers who are significantly affected can be helped as early as possible.
- Provision of opportunities for parents to be together and allow them time to express their emotions in private.

These recommendations could be relevant to all members of the CLP team, however, certain aspects, such as spending time with parents to understand the individual elements of their experience and making parents aware of the potentially significant emotional impact of appearance change following surgery, may be of more relevance to the psychologist within the team.

4.3. Methodological Strengths and Limitations

As with any study, this piece of research has both strengths and limitations which need to be appreciated in order to examine the usefulness of the conclusions which have been drawn. This study was carefully designed with regards to the original aims and objectives, with a qualitative methodology being deemed as most relevant and appropriate to those aims. The quality of the qualitative data and analysis generated within the project was outlined in detail in the Method section and, therefore, will not be discussed further here. However, it is important to reiterate the way in which the qualitative method enabled the generation of such rich and detailed data.

4.3.1. *The use of qualitative method*

The qualitative methodology of IPA was chosen for this study. This method allowed the detail and richness of experience to be gleaned from the participants to allow their voices to be heard. It allowed an insight into the nuances and the complexities of the mothers' experiences, something which a quantitative method may have missed. It also allowed the mothers' experiences to lead the findings rather than assumptions being made about what would emerge. Therefore, the qualitative methodology is an important strength of the research. However, with that strength, comes the difficulty of being able to generalise from this study and apply it to others going through similar experiences. The nature of qualitative methodologies means that a relatively small number of participants are used and therefore the ability to apply the findings to others is debatable. Similarly, as the research took place solely at one specialist cleft centre, the ability to expand the findings to other centres is unclear. Despite this, it provides an insight into individual experiences of repair surgery, something which has not been focused on before and, in this way, it might provide a basis for future research in this area.

4.3.2. Recruitment and participants

Although sufficient numbers of participants were recruited for the study, there were difficulties in this process. Due to time pressures (which followed from a considerable wait for final approval from the relevant research and development departments), recruitment was restricted to being carried out within a few months. During this time, adverse weather conditions affected both those sending out the invitations to take part and the postal service. This may have contributed to one potential participant response being received too late to be interviewed, despite the maximum number of participants not having been reached. It is unfortunate that interested and available participants could not be included due to time pressures.

In terms of the participants, the use of mothers was specifically chosen as a way of focusing on the primary attachment relationship and how that relationship may have been affected by the surgical process. However, the results of the interviews show that, in fact, this relationship, although relevant and important, was not as prominent as other aspects of the interviews. In addition to this, the parental relationship and the sharing of experiences between partners was highlighted. In hindsight, therefore, it may have been more appropriate to interview both parents.

Another important consideration is the retrospective nature of this study. The largest amount of time since surgery for those interviewed was only 18 months however this may have affected the intensity of the emotions felt, with the memory of the experience perhaps being different from the experience within the present. However, the impression given by participants was that the intensity of the experience meant that the prominent aspects were not lost and the hope is that this is captured within the themes.

Although a qualitative methodology is concerned with individual experience rather than representative participation, it is important to note here the lack of cultural diversity of the participants within this study. This is most likely a reflection of the cultural diversity of the South Wales region, however, these results are very much wedded to a Caucasian, British population and therefore, may be less relevant for

other ethnic backgrounds. Literature looking at other cultural experiences, such as the Weatherley-White et al. (2005) study, highlighted different outcomes and therefore the background of the individual needs to be considered when using this study as a guide to others' experiences.

4.3.3. Homogeneity of the group

In order to gain as broad a view of CLP as possible, as well as to maximise the number of potential participants available for the study, the inclusion criteria were developed to allow mothers of babies with all types of clefts to be eligible to take part. In doing that, however, the homogeneity of the group was compromised. For example, issues such as appearance may have been less relevant for those participants who had a cleft palate only. The emergent themes therefore, may have differed within these particular groups.

Similarly, the mothers who participated in this study varied in the number of children they had. Elements of being a first time mum, such as adapting to the new role of motherhood and the learning curve associated with aspects of having a baby, such as feeding, may have differed to those who had had children previously. These feelings may have influenced the themes which developed and therefore it may have been useful to separate these groups.

4.3.4. Validity of the results

Although guidelines relating to the quality of the data and analysis were followed and the development of the themes was verified with a supervisor, it would have been beneficial to discuss the research findings with the participants themselves. In this way the process would have become circular and would have provided assurance that the participants felt that their voice was still being heard through the themes. Unfortunately, due to time pressures, this was not possible.

4.4. Implications for Future Research

Although the emphasis of this study was attachment, few solid conclusions can be drawn regarding the effect of CLP repair surgery on the primary care giver-infant attachment relationship. Attachment was one of the main perspectives of the research but the study did not have enough of a structured attachment focus for substantial conclusions to be drawn. However the findings do add to the literature relating to perioperative care, as it adds, not only to CLP as a condition, an area which has been neglected in the literature in terms of perioperative care, but also to possible considerations for perioperative care more for families of small babies undergoing surgery, as the literature tends to be focused more readily on surgery in older children rather than babies. This study also adds to the research relating to family resilience, as it highlights the importance of elements of resilience, such as finding meaning in the adverse event (how the individual understood the surgery), the importance of communication within the family and having a positive outlook. For this reason, future research could apply a resilience model, such as the Family-Systems-Illness Model (Rolland, 1994), to CLP, in order to better understand the relevance of this approach in promoting and developing resilience in families facing the CLP journey.

However, as little research has been conducted concerning the experience of surgery in CLP, there seems to be ample opportunity for further study in this area.

This research naturally leads to further investigation into the experience of parents, rather than focusing on mothers alone. This seems particularly important following this study, as the parental relationship and the support which was derived from that relationship, was shown prominently as a way of coping. Therefore, further exploration of that relationship, as well as examining the experience from the view of parents as a unit, would add to the foundation which this study provides.

This study also highlighted that individual differences are vital in understanding how someone will react to the experience of surgery. Fiona highlighted that relatively routine surgery can be devastating. Further research concentrating on those who

experience a traumatic reaction to appearance change and attachment would help to uncover, not only the warning signs to this reaction, but also an increased understanding of the experience. The hope would be that this would aid professionals with interventions to support these individuals as effectively as possible.

This research provides a qualitative view of the experience of surgery and, in doing so, provides a richness of understanding. However, its methodology restricts its generalisability. In order to improve its applicability to a wider population, the themes developed here could be used as the basis for a questionnaire. This method would allow a larger population to be targeted, whilst being based on the themes developed within this study. It would allow the surgical experience to be understood on a larger scale and would help to validate these emergent themes.

On a more general level, more research into the impact of surgery for the families of infants undergoing procedures would be beneficial as little research is available. The present research has shown that although surgery can be reasonably straightforward, it can in turn be distressing and life changing. More research is required to understand the impact of taking a child into surgery for the families who have to go through this potentially challenging and difficult experience.

4.5. Conclusions

In conclusion, this study provided an insider's view into mothers' experience of repair surgery in babies with CLP. It emphasised the complexity of the emotional experience as well as the coping network which is required to deal with that. It provided possible suggestions for improvements to this experience in terms of information provision and possibilities for additions to the professional support provided. Although attachment issues were a focus of the study this was found to be less prominent than suspected, although if attachment difficulties were present, as with the participant Fiona, then they can be devastating. It therefore stressed the

importance of the individual experience, something that perhaps would not have been emphasised if a quantitative methodology had been chosen.

4.5.1. *Personal reflections*

Looking back on the research project as a whole, it was an emotional and challenging venture, which reflects the journey that the mothers interviewed have had to take. Despite the difficulties, frustrations and time constraints, it has been an absolute privilege to share the participants' experiences. It has been fascinating to discover the complicated and sometimes confusing experience which accompanies having a baby with CLP undertake surgery. Looking back on my initial reflections, I believe I have done my best to remain open-minded and not impose my own beliefs and assumptions onto the emerging outcomes. It seems as if my initial thoughts on surgery have been reflected in the research, in terms of elements such as needing to know the professionals involved and the importance of support. However, I do not believe this reflection is due to my own ideas and beliefs being overly influential. My initial reflections were tied up in how I personally felt about surgery taking place on a loved one, which is exactly what the participants themselves were focusing on. Therefore our feelings on the subject seemed to overlap.

Although at the beginning of the study I believed that attachment would be a pivotal part, this was not the case. It is, of course, present, but its influence is not as significant as I first thought. I feel this stressed that the themes which emerged did so through the evidence available within the interviews rather than being created with my own views at the forefront.

What the study has also emphasised for me is the applicability of using a systemic framework when working with mothers of babies with CLP. The study indicated the complex interaction of different aspects of the experience and the different systems involved. Being able to appreciate different perspectives is therefore vital in understanding the experience.

On studying the emergent themes and the recommendations derived from those themes, there seems to be particular relevance in terms of current models of service provision. The stepped care model of healthcare provision highlights differing levels of care in order to provide patients with the least restrictive intervention applicable, in order to create a service which is as efficient as possible. This study highlights the potentially differing needs of parents of children with CLP, as well as the usefulness of resources such as written information. These ideas are consistent with a stepped care model, which suggests that different levels of care should be available to individuals depending on need. The use of written information may provide one of the steps on the model, allowing parents to carry out their own learning where appropriate. This study therefore could emphasise the potential usefulness of applying a stepped model to the CLP treatment journey in order to incorporate the individual differences in need between families affected by a CLP.

I believe this study will provide a valuable resource to professionals working with families of children undergoing cleft repairs, by providing a starting point for reflecting on what the experience may be like for families. I am proud to have been able to give these mums a voice and I hope I have done so accurately and comprehensively.

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Appendix I

Table to show the search strategy for the literature review

Database	Term used	Combined with	No. of hits	Hits reduced by
<i>Scopus</i>	"Cleft Lip and Palate"	Mothers	254	Surgery – 25
		Parents	353	Surgery - 74
		Surgery	1395	Experience - 115
		Attachment	35	
		Psychological	208	Adjustment - 7
		Adjustment	75	
		Visual difference	3	
		Visible difference	11	
		Facial Disfigurement	11	
		Coping	14	
	"Lip repair"	Mothers	9	
		Parents	18	
		Surgery	352	Mothers – 6; Experience – 32; Parents - 10
		Attachment	5	
		Psychological	15	
		Adjustment	2	
		Visual difference	0	
		Visible difference	0	
		Facial Disfigurement	1	
		Coping	0	
	"Palate repair"	Mothers	7	
		Parents	16	
		Surgery	310	Mothers – 3; Experience – 33; Parents – 5

Database	Term used	Combined with	No. of hits	Hits reduced by
<i>Scopus</i> (continued)	"Palate repair" (continued)	Attachment	3	
		Psychological	5	
		Adjustment	2	
		Visual difference	0	
		Visible difference	0	
		Facial Disfigurement	0	
		Coping	0	
	Surgery	Experience	88470	Coping – 298; Infants AND Coping – 13; Family AND Coping - 66
		Adjustment	6672	Infants AND Coping – 4; Family AND Coping - 29
		Hospitalisation	1415	Infants – 89; Babies – 2; Family - 49
<i>Web of Science</i>	"Cleft lip and palate"	Mothers	177	Surgery - 19
		Parents	333	Surgery – 78
		Surgery	2304	Experience – 142
		Attachment	47	
		Psychological	146	Adjustment - 10
		Adjustment	106	
		Visual difference	0	
		Visible difference	2	
		Facial Disfigurement	11	
		Coping	15	
	"Lip repair"	Mothers	4	
		Parents	13	
		Surgery	534	Experience - 39

Database	Term used	Combined with	No. of hits	Hits reduced by
Web of Science (continued)	"Lip repair" (continued)	Attachment	5	
		Psychological	9	
		Adjustment	5	
		Visual difference	0	
		Visible difference	0	
		Facial Disfigurement	1	
		Coping	0	
	"Palate repair"	Mothers	2	
		Parents	12	
		Surgery	505	Experience – 48
		Attachment	5	
		Psychological	2	
		Adjustment	2	
		Visual difference	0	
		Visible difference	0	
		Facial Disfigurement	0	
		Coping	0	
	Surgery	Experience	100000	Coping AND Paediatric - 4; Infants AND Coping - 5; Family AND Coping - 22
		Adjustment	9928	Coping AND Paediatric – 2; Infants – 135; Family - 124
		Hospitalisation	1698	Coping – 7; Infants – 23; Family - 12
	Swetwise	"Cleft Lip and Palate"	Mothers	49
Parents			66	

Database	Term used	Combined with	No. of hits	Hits reduced by
Swetwise (continued)	"Cleft lip and palate" (continued)	Surgery	253	Experience – 15
		Attachment	13	
		Psychological	27	
		Adjustment	12	
		Visual difference	0	
		Visible difference	0	
		Facial Disfigurement	3	
		Coping	4	
	"Lip repair"	Mothers	3	
		Parents	2	
		Surgery	44	
		Attachment	1	
		Psychological	1	
		Adjustment	0	
		Visual difference	0	
		Visible difference	0	
		Facial Disfigurement	0	
		Coping	0	
	"Palate repair"	Mothers	1	
		Parents	4	
		Surgery	51	
		Attachment	0	
		Psychological	0	
		Adjustment	0	

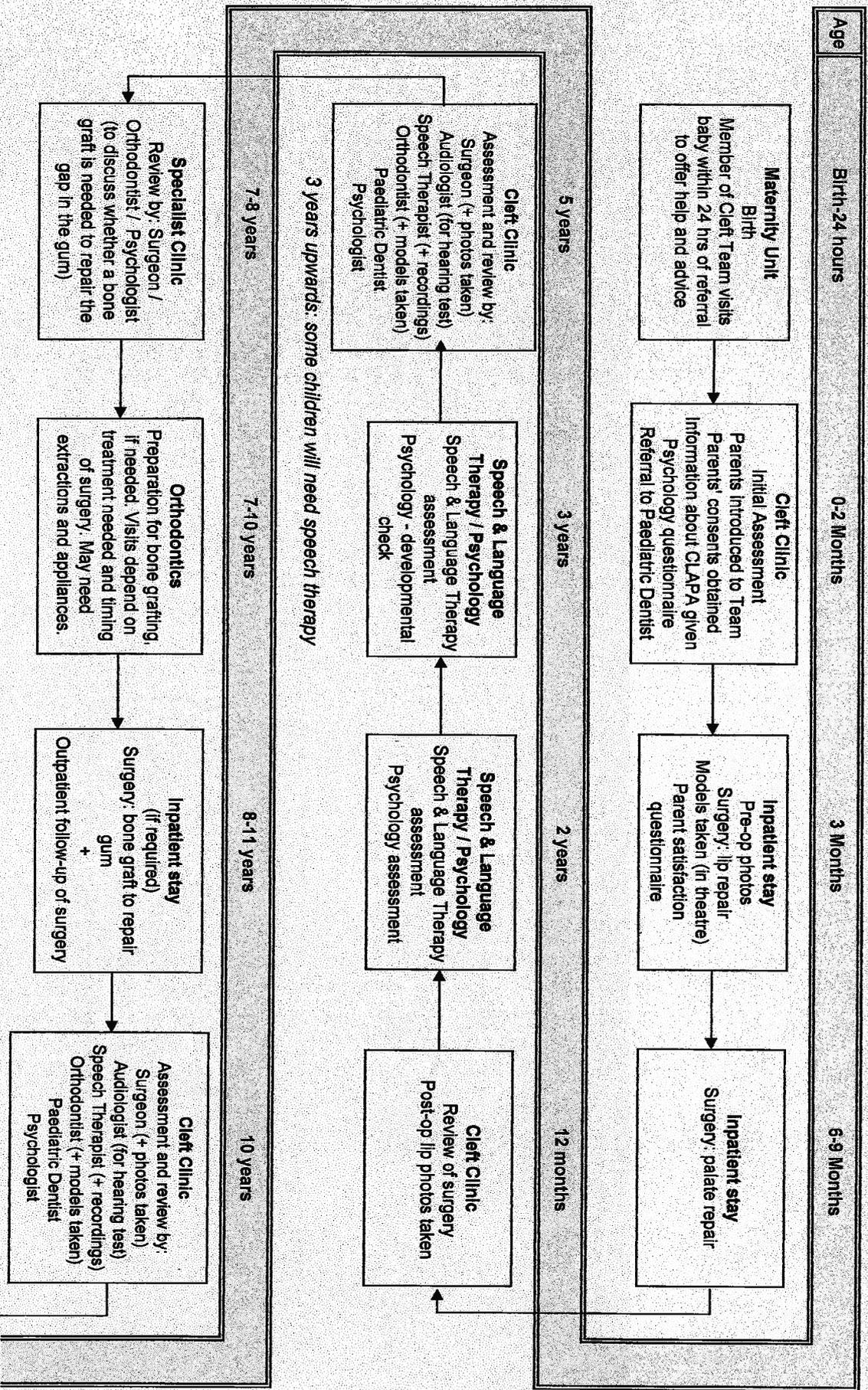
Database	Term used	Combined with	No. of hits	Hits reduced by
Swetwise (continued)	"Lip repair" (continued)	Visual difference	0	
		Visible difference	0	
		Facial Disfigurement	0	
		Coping	0	
	Surgery	Experience	497	Coping – 29; Infants – 85; Family - 25
		Adjustment	409	Coping – 17; Infants – 4; Family - 3
		Hospitalisation	72	
OvidSP which includes: <i>Medline; EMBASE; PsychInfo</i>	"Cleft Lip and Palate"	Mothers	202	Surgery - 14
		Parents	345	Surgery – 44
		Surgery	740	Experience – 44
		Attachment	35	
		Psychological	93	Adjustment – 4
		Adjustment	48	
		Visual difference	0	
		Visible difference	1	
		Facial Disfigurement	11	
		Coping	19	
	"Lip repair"	Mothers	5	
		Parents	12	
		Surgery	139	Experience – 8
		Attachment	3	
		Psychological	8	
Adjustment		3		
Visual difference		0		

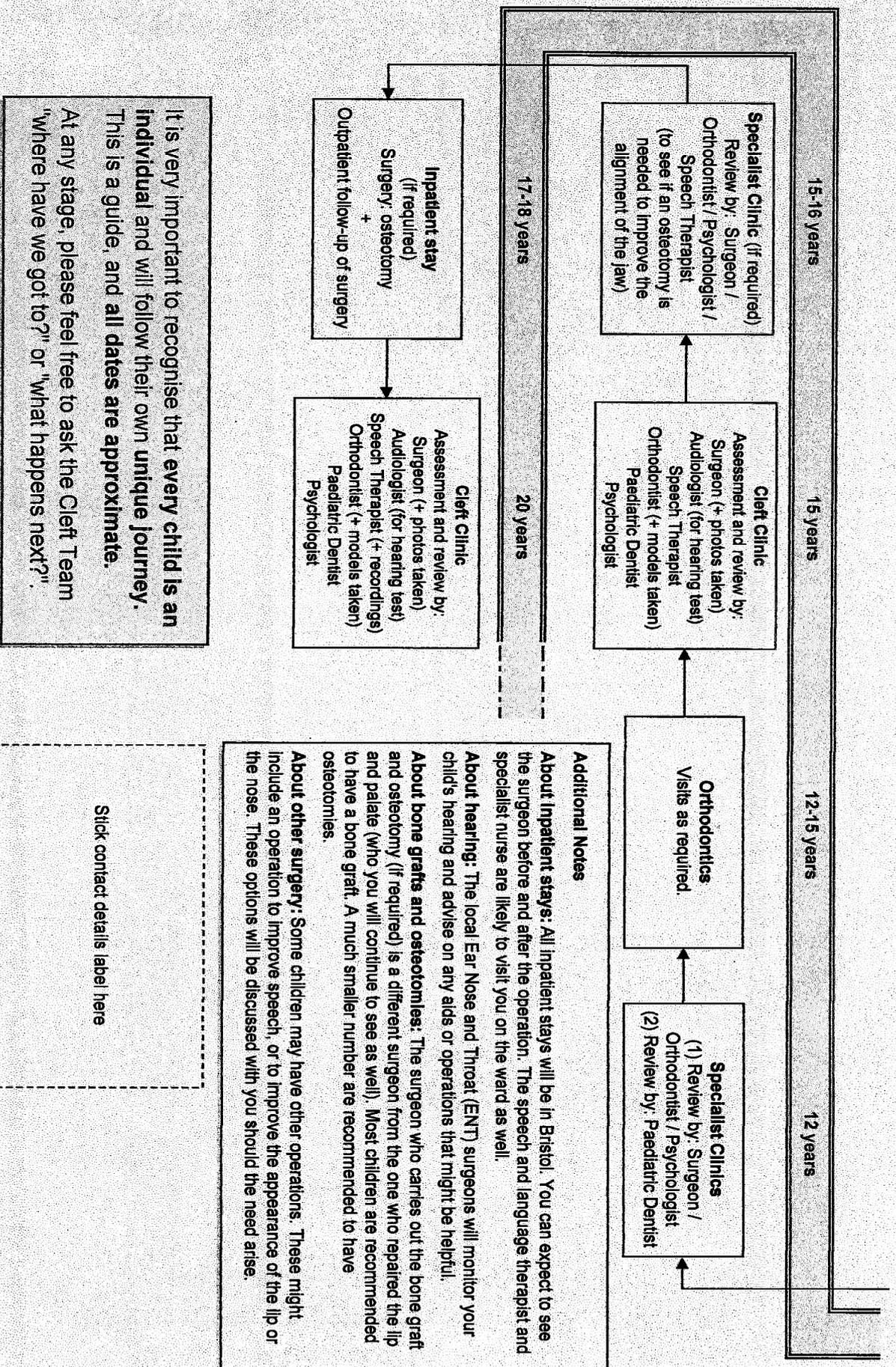
Database	Term used	Combined with	No. of hits	Hits reduced by
<i>OvidSP</i> (continued) which includes: <i>Medline; EMBASE;</i> <i>PsychInfo</i>	"Lip repair" (continued)	Visible difference	0	
		Facial Disfigurement	1	
		Coping	0	
	"Palate repair"	Mothers	1	
		Parents	10	
		Surgery	145	Experience – 14
		Attachment	3	
		Psychological	1	
		Adjustment	2	
		Visual difference	0	
		Visible difference	0	
		Facial Disfigurement	0	
		Coping	0	
	Surgery	Experience	84453	Coping – 206; Infants AND Coping – 1; Family AND Coping – 14
		Adjustment	8346	Infants – 55; Family – 52
		Hospitalisation	1287	Infants – 13; Babies – 2; Family - 11

Appendix II

Chart showing the typical treatment journey for a child with Cleft Lip and Palate treated within the South Wales South West Managed Clinical Network

South Wales South West Managed Clinical Network Typical Patient Journey for a child born with a Cleft Lip and Palate





Additional Notes

About inpatient stays: All inpatient stays will be in Bristol. You can expect to see the surgeon before and after the operation. The speech and language therapist and specialist nurse are likely to visit you on the ward as well.

About hearing: The local Ear Nose and Throat (ENT) surgeons will monitor your child's hearing and advise on any aids or operations that might be helpful.

About bone grafts and osteotomies: The surgeon who carries out the bone graft and osteotomy (if required) is a different surgeon from the one who repaired the lip and palate (who you will continue to see as well). Most children are recommended to have a bone graft. A much smaller number are recommended to have osteotomies.

About other surgery: Some children may have other operations. These might include an operation to improve speech, or to improve the appearance of the lip or the nose. These options will be discussed with you should the need arise.

It is very important to recognise that every child is an individual and will follow their own unique journey. This is a guide, and all dates are approximate. At any stage, please feel free to ask the Cleft Team "where have we got to?" or "what happens next?".

Stick contact details label here

Appendix III

Extracts from the Research Diary

Research Diary

August 2010

I'm going through a really emotional time at the moment. Personally I'm going through a pretty tough time at present and the prospect of going to the ethics meeting is quite daunting. I don't imagine there will be any particular difficulties but it is hard having never experienced such a meeting before. I really hope I will be able to answer any questions they ask sufficiently. I just hope that the process, including any changes which need to be made, can be achieved quickly so I can begin.

September 2010

Thankfully the changes required for the ethics committee were reasonably easy to amend and their response back was very quick. However, subsequent responses from the R&D departments don't seem to be as swift. It's really frustrating to be waiting for a response before I can get going with the first steps in collecting data. It feels like time is slipping away from me and I'm feeling a bit helpless as I can't actually make a start until I receive confirmation. Hopefully that will happen soon.

December 2010

The first interview went well. I was a bit nervous but once the interview started I felt much more relaxed. I felt that I may have spoken too much in the interview, so I will bear that in mind in subsequent interviews to make sure I don't interrupt the participants in their flow of experience. I was also aware that on occasions I was providing suggestions rather than merely prompting. I will attempt to lessen this in future interviews. This interview was very valuable and I think it has provided me with a few new prompts to ask. It feels brilliant to be hearing aspects of the experience that I hadn't expected. Also I feel very fortunate at having the opportunity at hearing this mum's story and meeting the babies themselves.

I'm starting to get worried about whether I will be able to get enough participants. It is incredibly frustrating that I haven't got control over sending out invitations. I realise why this is but I hate feeling as if I can't do anything about it, that I just have to sit and wait. The weather hasn't helped either – difficult to determine whether the post will even be getting through. So frustrating. Hopefully in the new year there will be more interest, once the Christmas holidays and the snow is out of the way. Fingers tightly crossed.

January 2011

I am so relieved. Four more participants. That takes it up to seven, which falls into the range I'm looking for. I'm going to try and get these interviews organised and carried out as soon as possible so I can plough on through the transcriptions. I have re-discovered the tedious nature of transcribing but I feel it is important for me to do it myself as it allows me to revisit the interviews and the voices of the participants which will help, I hope, when I start the analysis process.

February 2011

I have found a really useful IPA book which provides me with a really clear and understandable framework for completing the analysis. This is quite exciting actually as it feels I am really starting to get to grips with the project, starting to reveal the main elements of the experiences.

I have started my analysis and I am having flash backs to my previous experience of qualitative analysis! That slightly confused feeling of not being sure if I am doing the correct thing and at points feeling that you have it sorted and the main points of the interview have been expressed well and at others thinking you are at a loss. It's really difficult actually. Even if the process itself is relatively straightforward, the actual practice of doing it is very different. There are worries that I may be missing things or that I'm not looking deeply enough into the language. Some parts are difficult because the analysis can be superficial, in terms of not requiring much interpretation. Whilst being worried about this I also don't want to overanalyse and see too much within the transcript. It's a difficult balancing act.

March 2011

Certain aspects of the experience are starting to become clear within the analysis. Firstly, despite the interview being focused around surgery, other factors within CLP are also being mentioned, such as feeding and diagnosis. I am finding it quite a challenge to know whether to analyse these aspects alongside all the information about surgery. I don't think this makes sense as it will turn the project into a study of the overall experience of the CLP journey from birth. Although fascinating, the unique aspect of this study is the focus on surgery. However, it is still important to acknowledge the other factors mentioned by the mums because it provides a context to the surgical experience. Difficult though, especially as some experiences of surgery and reactions to it are dependent on the reactions of other factors in the CLP experience. I am going to have to think carefully about how I incorporate this into the results section, making sure it isn't lost but doesn't supersede the experiences on surgery.

I met with Kate Gleeson today and she was really helpful. It was great to have someone look over one of the interviews as it reassured me that I have conducted them in a satisfactory way. She really helped me with my questions on the incorporation of the 'other factors' which have come up. And it was reassuring that at this stage it was not vital to be answering all the questions which come up and there is a danger in answering them too quickly.

Appendix IV

Approval by the Cardiff and Vale University Local Health Board Research
and Development Department



GIG
CYMRU
NHS
WALES

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Ffôn 029 2074 7747
Ffacs 029 2074 3838
Minicom 029 2074 3632

Eich cyf/Your ref
Ein cyf/Our ref
Welsh Health Telephone Network 1872
Direct line/Llinell uniongyrchol

Tel: 029 20746986
Fax: 029 20745311
CAV_Research.Development@wales.nhs.uk

From: Professor JI Bisson
R&D Director
R&D Office, 2nd Floor TB2
University Hospital of Wales
Cardiff
CF14 4XW

04 October 2010

Miss. Amy Fletcher
Trainee Clinical Psychologist
South Wales Doctoral Programme in Clinical Psychology
1st floor, Archway House
77 Ty Gas Avenue
Llanishen
Cardiff
CF14 5DX

Dear Miss. Fletcher

Project ID: 10/RPM/4871 : Mothers' Experience Of Surgery In Babies With Cleft Lip And/Or Palate

Thank you for your recent letter notifying us of amendments to your study documentation requested by the South West Wales Research Ethics Committee. Updated documents received and reviewed were:

Protocol	4	27 August 2010
Participant Information Sheet	5	27 August 2010
Patient Consent Form	5	27 August 2010
Structured Interview Schedule	2	27 August 2010

I can confirm that the above documentation has been favourably reviewed.

Further to recent correspondence regarding the above project, I am now happy to confirm receipt of:

- Evidence of favourable opinion from South West Wales Research Ethics Committee

- Evidence of R&D management approval from the host organisation, Abertawe Bro Morgannwg University Health Board.

Please accept this letter as confirmation of sponsorship by Cardiff and Vale UHB and permission for the project to begin.

May I take this opportunity to wish you success with the project, and to remind you that as Principal Investigator you are required to:

- Ensure that all members of the research team undertake the project in accordance with ICH-GCP and adhere to the protocol as approved by the Research Ethics Committee
- Inform the R&D Office if any external or additional funding is awarded for this project in the future
- Inform the R&D Office of any amendments relating to the protocol, including personnel changes and amendments to the actual or anticipated start and end dates
- Complete any documentation sent to you by the R&D Office or University Research and Commercial Division regarding this project
- Ensure that adverse event reporting is in accordance with the UHB adopted Cardiff and Vale NHS Trust Policy and Procedure for Reporting Research-Related Adverse Events (refs 164 & 174) and Incident Reporting and Investigation (ref 108)
- Ensure that the research complies with the Data Protection Act 1998
- Ensure that arrangements for continued storage or use of human tissue samples at the end of the approved research project comply with the Human Tissue Act, 2004 (for further information please contact Sharon Orton, HTA Coordinator OrtonS@cf.ac.uk).

If you require any further information or assistance, please do not hesitate to contact staff in the R&D Office.

Yours sincerely,



Professor Jonathan I Bisson
Cardiff and Vale University Local Health Board R&D Director

CC Dr Sue Channon, Academic Supervisor

Appendix V

Approval by the Abertawe Bro Morgannwg University Health Board
Research and Development Department

Please reply to: Research & Development Department
Clinical Research Unit
Abertawe Bro Morgannwg University
Health Board
Morriston Hospital
SWANSEA
SA6 6NL

Telephone: 01792 704056
Fax:
E-mail: jemma.hughes@wales.nhs.uk

Miss Amy J Fletcher,
Trainee Clinical Psychologist
Cardiff and Vale NHS Trust
1st Floor, Archway House
77 ty Glas Avenue, Llanishen
CARDIFF
CF14 5DX

20 September 2010

Dear Miss Fletcher,

ID: S10Psync966 Mothers' experience of surgery in babies with cleft lip and/or palate surgery

Thank you for your letter dated 7th September 2010, providing details on the updated documents requested by South West Wales REC for the above study (REC approved 31st August 2010). The documents received and reviewed were:-

Protocol version 4 dated 27.8.10
Participant Information Sheet version 5 dated 27.8.10
Participants Consent Form version 5 dated 27.8.10
Structured Interview Schedule version 2 dated 27.8.10

I am pleased to inform you that these changes have been given R&D Management approval on the basis of the information provided and our records have been updated.

Please ensure that any further changes made to the study are submitted to the R&D Department for review and approval, including:

- Notification of Amendment (copy of all documentation sent to Ethics is also required by R&D)
- Adding new Sites and Investigators(CV's to be included)
- Progress and Safety Reports
- Notifying of the End of study

Kind regards

Yours sincerely



Jemma Hughes

**Research & Development Manager
Abertawe Bro Morgannwg University Health Board**

Appendix VI

Approval by the South West Wales Research Ethics Committee

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Investigator CV	1	15 July 2010
Protocol	4	27 August 2010
CV - S J Channon		
CV - Dr J A Hunt		
REC application	1	16 July 2010
Covering Letter	1	15 July 2010
Interview Schedules/Topic Guides	2	27 August 2010
Letter of invitation to participant	2	01 June 2010
Participant Information Sheet	5	27 August 2010
Response to Request for Further Information	1	27 August 2010
Participant Consent Form	5	27 August 2010

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators

- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/WMW02/17

Please quote this number on all correspondence

Yours sincerely



Roy L. Evans
Chairman

Enclosures:

"After ethical review – guidance for researchers"

Copy to:

*Jonathon Bisson, Cardiff and Vale University Local Health Board
Dr Sue Channon, Card & Vale UHB
[R&D office for NHS care organisation at lead site]*

Appendix VII

Participant Information Sheet

Participant Information Sheet

Mothers' experiences of surgery in babies with Cleft Lip and/or Palate.

We would like to invite you to take part in our research study. Before you decide if you want to take part we would like you to understand why the research is being done. This sheet explains the study and what your participation would involve.

Introduction

The reason for the study is to explore mothers' experiences of surgery in their babies with Cleft Lip and/or Palate. Research and experience has shown that surgery is one of the biggest concerns for parents after birth, however, this hasn't been explored in detail. By conducting interviews with mums, we hope to ask about the surgery and the time before and after, including areas such as the information you were given, ways of coping, worries and concerns and the impact of the surgery generally.

What is the purpose of the study?

It is hoped that the outcome of this research will lead to recommendations for the improvement of services given to parents leading up to, during and after their child's surgery. You are being asked to take part due to your baby having had a cleft lip and/or palate repair in the last two years.

The study will also be used as a required part of a doctoral qualification in Clinical Psychology with Cardiff University.

Why have I been invited?

You have been invited to take part as your baby has had a cleft lip and/or palate repair at the Morriston hospital in Swansea in the last three years.

Do I have to take part?

It is up to you to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

What will happen to me if I take part?

The study will involve you taking part in an interview that will last about an hour. Nothing else would be required.

What will I have to do?

The interview will be conducted at a time and place of your convenience with one researcher present. The interview will involve you answering questions about your experiences before, during and after your baby's surgery.

What are the possible disadvantages or risks of taking part?

It is not anticipated that there will be any disadvantages or risks to taking part. However, it is acknowledged that discussing your baby's surgery may be a sensitive and emotional subject. If

you were to become distressed during the interview, it would be stopped and you would be offered a meeting with a Clinical Psychologist to discuss it further.

What are the possible benefits of taking part?

There are no direct benefits of taking part. Unfortunately we can't offer you payment for taking part. However, your experiences will aid understanding of surgery in babies with Cleft Lips and/or Palates.

What happens when the research stops?

Following the interview your participation in the study will end. When the study is completed, it will be used as part of a doctoral qualification in Clinical Psychology. It is also hoped that the study will be published to allow others within the field of Cleft Lip and Palate to gain a greater understanding of this area.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (contact details can be found at the end of this information sheet). If you remain unhappy and wish to complain formally, you can do this NHS Complaints Procedure. Details can be obtained from the NHS website (www.nhs.uk).

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against Cardiff and Vale University Health Board but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

Will my information be kept confidential?

The interviews will be recorded and those recordings will be stored securely to retain confidentiality. The information taken from the interview will be made anonymous, again to maintain confidentiality. Information from the interview will remain confidential.

It is acknowledged that sensitive issues could arise from the interview and therefore confidentiality will be strictly observed. However, if a disclosure is made during the interview that indicates or suggests any potential harm to yourself or other people, including your child, the researcher will be duty bound to report such issues and therefore confidentiality will have to be broken. If this is the case, it will be thoroughly discussed with you.

The initial interviews will be handled by the researcher however, anonymised information may also be seen by the clinical and academic supervisors involved in the study.

What happens if I don't want to carry on with the study?

If you decide at any time (before, during or after the interview), to withdraw from the study, your interview information will be destroyed. Your standard of care will not be affected if you decide to withdraw from the study.

What will happen to the results of the study?

The information gathered from the interviews will be collated into a report as part of doctoral research with Cardiff University. Direct quotes from the interviews will be used in the report to

highlight elements of the research, however, identification of individuals who participated will not be possible.

Who is organising and funding the research?

The research is being conducted as part of a doctoral qualification in Clinical Psychology with Cardiff University. It is being funded by the NHS.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the South West Wales Research Ethics Committee.

How might participation affect me?

As the interview involves discussing your baby's surgery, it might involve you talking about difficult or distressing times, which may evoke strong emotions. If you feel at all distressed following the interview, a psychologist can be contacted to discuss any feelings or concerns you may have.

We cannot promise the research will help you but the information we gain from this study may help to improve the experience of parents in the future.

Do I need to take part?

Participation is voluntary. If you agree to take part, you will be asked to sign a consent form. However you are free to withdraw at any time, without giving a reason, regardless of having signed the consent form. If you decide to withdraw, any information already gathered will be destroyed.

If you have any queries or concerns regarding participation, please do not hesitate to speak to the researcher in person. Contact details can be found below.

Contact Details:

Amy Fletcher

Tel: 029 20206464

Email: amy.fletcher2@wales.nhs.uk

South Wales Doctoral Programme in Clinical Psychology
1st Floor, Archway House, 77 Ty Glas Avenue,
Llanishen, Cardiff, CF14 5DX

Appendix VIII

Participant Consent Form

Consent Form

Title of Project:

Mothers' experiences of surgery in babies with Cleft Lip and/or Palate.

Name of Researcher: Amy Fletcher

Please place your initials in the boxes to indicate your agreement with the following statements.

1. I confirm that I have read and understand the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my (or my child's) medical care being affected.
3. I understand that I am free to ask questions at any time. If I experience any discomfort owing to taking part, I am free to withdraw and/or discuss my concerns with Dr. Jenny Hunt, Clinical Psychologist and clinical supervisor of the study (details below).
4. I understand that any information provided by me will be securely held and will remain confidential. I understand that this information may be retained indefinitely.
5. I understand that my interview will be audio recorded and secured securely. I understand that following the completion of the study, this recording will be destroyed.
6. I agree to take part in the above study

Name of Participant (Printed)

Signature

Date

Name of Researcher (Printed)

Signature

Date

Contact Details for Clinical Supervisor on the project:

Dr. Jenny Hunt, Clinical Psychologist, Cleft Lip and Palate Service, Morriston Hospital, Swansea, SA6 6NL
Tel: 01792 618816 Email: jenny.hunt2@wales.nhs.uk

When completed: 1 for participant; 1 for researcher

Appendix IX

Participant Invitation Letter

Dear

My name is Amy Fletcher and I am hoping to conduct some research into mothers' experiences of surgery in babies with Cleft Lip and/or Palate.

Research and experience has shown that surgery is one of the biggest concerns for parents after the birth of their baby, however, the parental experience of the surgery hasn't been explored in detail. The research would involve taking part in an interview with me that would last around an hour. An information sheet explaining the research in detail has been included with this letter.

You have been contacted because your baby has had Cleft Lip and/or Palate repair surgery in the last three years. Your experiences would be invaluable in our understanding of this experience.

It is hoped that the outcome of this research will lead to recommendations for the improvement of services given to parents leading up to, during and after their child's surgery.

This letter has been sent out for me by the administration team of the Cleft Lip and Palate service based at the Morriston Hospital in Swansea. I therefore have had no access to your contact details.

If you are interested in taking part or would just like to find out more about the research, please fill in the slip below and return in the stamped addressed envelope provided within a month of receiving this letter and I will be happy to get in touch with you to discuss it further.

Thank you for your time

Yours Sincerely

Amy Fletcher
Trainee Clinical Psychologist

✂-----

Mothers' experiences of surgery in babies with Cleft Lip and/or Palate.

Name:

Address:

Contact Number:

I am interested in taking part in the study and would like the researcher to contact me to discuss this further.

Signed:..... Date:.....

Appendix X

Semi-Structured Interview Schedule

Semi-Structured Interview

Mothers' experiences of surgery in babies with cleft lip and/or palate.

- ◆ Can you tell me a little about your experience of having a son/daughter with Cleft lip and/or palate, starting from when you found out the diagnosis.
 - ◆ When did you find out that your baby would require surgery?
 - ◆ How did that make you feel?
 - ◆ What were your main concerns or worries?
 - e.g. baby's appearance, feeding, danger of surgery, outcomes
 - Did you feel able to express them?
 - If not, what would have helped you to express them?
 - If so, how were they dealt with?
 - ◆ Tell me about your experiences of the time when your baby was in hospital having the surgery.
 - ◆ What were your worries after surgery?
 - e.g. Baby's new appearance, subsequent bonding with baby
 - ◆ What factors made the process of surgery easier for you to cope with?
 - e.g. aspects of care, family support, information, counselling, professionals involved, personal ways of coping.
 - ◆ Was there anything that made the surgery harder for you to cope with?
 - e.g. lack of information, it being out of your control, lack of support
 - ◆ Tell me about your relationship with your baby. Do you think the surgery has affected it in any way?
-

Appendix XI

Extract from an Individual Interview Transcript with Analysis

Fiona, Faith, Finn

Experiences of going alone - continuation of previous. No. may need for support prepared for difficulties. Support is needed early on.

it hasn't gone right you've still got your problems that are dwelling on and you're all on your own, no other cleft baby and you know and that's when yeah I would have preferred to have been able to know people beforehand.

Experience of being alone.
Timeliness of support/info.

So it might have been as simple as putting you in touch with other families or having some sort of meeting where you could get the contacts yourself so that you had people to talk to, so you weren't going through it alone, someone you could talk to on the same terms.

need for more information

Yeah because after I'd had Faith I was very surprised that there wasn't a lot of meetings that went together. So I arranged a meeting of my own and got in contact with CLAPA, they couldn't obviously give me the information so I gave them the flyer to post out and I think about four turned up to the coffee morning I put on. And they were of all different levels of cleft and all of them said yeah, it was nice, at the beginning they'd say you'd got this mum, they'd bring the photos out to the first meeting that they'd give you and they'll say there are certain mums that will talk and that but like they said you never find the one that you actually need at that time so yeah, the lack of information is my main issue and the lack of emotional and support of where can I go to actually get someone to help me get what I need is my main problem.

Need for shared experience.

Need for more information re: emotional support? From other mums? Cleft had what said... (unclear)

So it sounds like when you met the cleft lip and palate team then, they were giving you information but it wasn't necessarily the information you needed or wanted and it maybe wasn't presented in a way that was useful to you. Did you feel you could ask them question or was that difficult?

Lack of info support.

Timeliness of info - wanting main info earlier or knowing (initially) had need of info. as info is presented - who is the team or other parents

No, I probably could of. But, I think because they came out so soon after you're told, I think you've got questions in your head that don't relate to wanting to meet other people, it's sort of, well why is this. I think if they'd come out again and said, look this is a list of people that you can contact as well as ourselves and we'll contact you and so forth, then that would have been more sunk into my brain than showing me some photos of babies that yeah that had had the ops and they were very pretty but to me, it was nice that they were trying to relate but

Timeliness of info.

Shared experience (people who have been there).

It wasn't the same

Info to deal with shock of diagnosis. Mainly via verbal explanation also... (unclear)

It wasn't the same no. I'd never had or expected to have cleft baby. All you ever know about cleft babies is if you have cleft in the family, you will have a cleft or there's a possibility. And because there's no clefts in our families at all, when you're told you're having a cleft

Other factors -> Diagnosis -> Expectations

Fiona, Faith, Finn

you just don't know where to go or what to do or who to blame or what to blame and yeah it's as if that is sort of bypassed. And they just come in with the lingo they should be coming in with, with well this is what we're now going to do and this is how it'll all pan out with they weren't dealing with how I was actually feeling.

Other factors
↳ Cause
"Going through the motions." - Process
Emotions & Support

Going through the motions rather than focusing on the individual.

Emotions rather than process
Feeling to be dealt with
Feeling that not individual

Right, so it sounds like how it felt to you was that they were going through the motions, they had a job to do, their job was to tell you what was going to happen and to help you through that process, but they weren't maybe paying as much attention as you needed to how you were feeling or the issues you wanted to talk about and it sounds like one of the big worry for you was why was it that my baby had a cleft. And even if their answer had been we don't know but these are some of things that we think could have been the cause that might have been reassuring.

Yeah.

Okay, so Faith was born. Was the cleft team still keeping in contact?

Yeah they were. The cleft team made contact until Faith had her second op and then it was, I didn't hear off them then. If I needed something I rung them which was disheartening because it was as if, oh well, surgery is done, goodbye. And I thought, no, I'm sorry, I know that I could phone you, but it wouldn't have been, you know it would have been nice for a phone call once in a blue moon to say how are you doing, have you got to a certain place, are you doing okay, coz obviously after Faith had her second op the palate was repaired, she's going from milk to food, now obviously the transition of changing her from milk to food is bad enough but it's getting the spoon right, it's getting the consistency right it's knowing how to feed them, what's going to happen when they're fed, and nothing, you know, there was no support for me to do that or where's the best place to get the stuff and what's the best ones to use. I think I bought that many spoons I could have kitted out my own little shop trying to find the best one. You know, the same with when she went from a bottle to a cup, again I went through loads, I must have bought about twenty odd cups until I knew that she could get the right one. Because you ultimately think the palate's fixed, her sucking's back. So all the cups now are this non-spill cup so they've got to suck really hard to get it out and bite down. You buy them, they are no good, they're hopeless, there was no way she could ever use it, so of course you bought another one to try, something else, and then you bought a different one and in the end I think it was about a 50 pence one that, the old fashioned three holes in the top,

Surgery = end of support

Contact with service

Support with FEEDING

Surgery as end of support
Hard to ring/hard to contact
as surgery is over part

Not wanting to ask for help, possibly someone to do it

chain of what approach (milk to food). Knowing details.

is much to take in & to know

importance of knowing what to do

Feeding

Fiona, Faith, Finn

works, fab, you know, people may say common sense you should have used that in the first place but you automatically think the op's down, everything is going to fall into place, because no-one has told me that there might be another rollercoaster somewhere.

Surgery as soldier
Emotional Reaction

And is that how it felt to you in terms of the surgery then, did it feel like ok it's done now, it's sorted. Is that how it felt?

Yeah, because I had it in my head that this was going to be, you know her lip was going to be fixed at three months which would give her her facial features and so forth, her palate would be done so it would fix, close everything up so you know she shouldn't have milk coming back down her nose, and the sucking and the muscles in her mouth should start then working, and you're like yep, great, yeah and she'll have another one at five years old to reconstruct, fab, apart from Faith's missing gum so I knew that one was going to be a different one. So yeah it's right, okay, this is all done, that's done so when's she's had that, until she's five I don't have to worry. And it wasn't.

Surgery as soldier

Surgery as soldier
- end

Hasn't worked out that way.

No, it's not worked out that way. Faith now has complications that the palate hasn't fully worked.

In terms of the repair?

The repair's fixed. Faith's tonsils are really enlarged, which are pushing the palate forward, scarring and she continually has every five minutes tonsillitis. So they want the tonsils out but it's finding a surgeon that's competent to do it. Now I've had four hospitals refuse, I'm still fighting tooth and nail. Faith has been put onto a thickened consistency drink, she can't drink any normal fluids because it comes back down the nose still, it's going down the wrong gullet in the throat, so it's choking her, it's going onto the lungs, the fluid is so it's causing bronchitis. She can't talk, well, she says between five to ten words that mean absolutely nothing, apart from mummy, hi, bye, you know, nothing on the curriculum so she's now eight months behind in her curriculum standard and she's due to go to school. What else? And all of that has been a knock on from surgery where I'd assumed that everything would go back to normal and it hasn't. And of course it would have been nice to pick up the phone or someone to have rung and said look do you need a hand with changing the food over, you know, spoons, and the sort of best of cups, is there anything else going wrong, well apart from the new team of twenty that I have now got on my case, no everything's fine. Everything with a cleft baby you have to fight for. There is no-one

Fight for needs

Expectation of
Surgery - soldier
Need for support.

Fight for needs

Surgery seen as the solution to all difficulties.

Up & down - mixed emotions.

Surgery as the soldier "fixed" - all better.

Graphing words she begins.

re end; "done" finished. So women after that.

More difficulties.

Fighting" - a battle to get it done

Feeding

Description

Speech

Expectation of surgery - all better - all better - all better

Practical help.

To pick up the phone means - to pick up the phone - to pick up the phone - to pick up the phone

Fighting" - battle

Appendix XII

Table showing the Super-ordinate, Master themes and the breakdown of the master themes

Super-ordinate Themes	Master Themes	Breakdown of Master Themes
<i>Context of CLP</i>	Diagnosis Birth Cause Feeding and Weight View of CLP as 'cosmetic'	
<i>Emotions</i>	Diversity of Emotion Expression of Emotion Empathy for the Baby Impact and Timeliness of Emotion	Shock and Upset Anxiety Excitement and Happiness Exhaustion Relief Other emotions
<i>Coping</i>	Coping Strategies Need to focus on and be with the baby Coping 'Frame of mind' Personality and Attitudes	Emotions 'controlling actions' Inevitability and Constancy of emotion Emotions changing over time Distraction Laughter Blocking Out Impact of the Environment Here and Now - 'One step at a time' 'Going through the motions' 'Getting it out of the way' As an active process

Super-ordinate Themes	Master Themes	Breakdown of Master Themes
<i>Impact of Others</i>	Comparison with others	Similarity - 'Sharing experiences' Difference - 'could be worse'
	Staff Attributes	Meeting and Knowing Staff Staff personality and expertise
	Reactions of Others	
	Perception of Support	As being there if needed As being a choice As explicit
	Support from Others	Family and Friends Partner
	Need for information and preparation	
<i>Information and Expectations</i>	Usefulness of Information	Type and communication of information Timeliness of information Saturation of information
	Need for 'Normality'	'Normality' Reassurance
	Basis of Expectations	Previous Experience View and Perceptions of Surgery
	Choice	
	Anticipation of Surgery	
<i>Considerations of Surgery</i>	Concerns of Surgery	
	Consequences of Surgery	Changes in the baby Relationship with baby

Appendix XIII

Graphical representation of the Super-ordinate Themes

CONTEXT

of CLP

