

**CONGENITAL FACIAL DEFORMITY: EXPERIENCES OF MOTHERS OF
TWINS**

by

MELISSA FERNIHOUGH

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SUPERVISOR: ELMARIÉ VISSER

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Student number: 42560187

I declare that **CONGENITAL FACIAL DEFORMITY: EXPERIENCES OF MOTHERS OF TWINS** is my own work and that all sources that I have quoted have been indicated and acknowledged by means of complete references.

Signature

(Miss M. Fernihough)

Date

Abstract

The topic of cleft lip and/or palate is widely researched in literature. However no research to date has focused on mothers' experiences raising twins when one twin is born with a cleft lip and/or palate. This qualitative study aims to explore the unique experiences of these mothers. The epistemological foundations of this study are postmodern, social constructionist and systemic. In accordance with a qualitative methodology data was collected in the form of the participants' personal written stories. This was done from a post-modern paradigm, from a systemic perspective. Themes that were extracted from the stories according to thematic content analysis, not only reflect the experiences of mothers raising twins when one twin is born with a cleft lip and/or palate, they also provide an in-depth understanding of these mothers' experiences and unique situations. Recommendations for future research are offered.

Key terms: Congenital facial deformity, cleft lip and/or palate, twins, mothers, family systems, post modernism, support systems thematic content analysis and qualitative research.

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Chapter 1

Introduction

A tree that can fill the span

Of a man's arm

Grows from a downy tip;

A terrace nine stories high

Rises from hodfuls of earth;

A journey of a thousand miles

Starts from beneath one's feet.

Lao- Tzu

Introduction

For most parents the news that they are to have twins comes as both a surprise and a shock. Few parents ever imagine having and certainly few have seriously thought about what is involved in looking after more than one baby at the same time. The situation is further complicated when parents receive the devastating news that one of their twins has a congenital facial deformity such as a cleft lip and/or palate.

Clefts are regarded as one of the most common congenital birth defects worldwide and more than 250 000 babies born worldwide each year have some form of congenital deformity. In South Africa the incidence of clefts per 1000 births is estimated at 2.7 for the Asian population, 1.3 for the Caucasian population and 0.6 for the Black population (Genetic Services, South African Department of Health, n.d.). A cleft is defined as an opening in the lip or the roof of the mouth that results from arrested midline facial development during the first trimester (Endriga, Speltz, Maris, & Jones, 1998; Viera, 2008).

Children with cleft lips and/or palates and their families experience a range of emotional and psychological difficulties associated with this congenital anomaly (Lockhart, 2003). Klein, Pope and Thompson's (2006) research indicates that the psychosocial well-being of children with craniofacial anomalies has received fairly extensive attention in the literature but very little research has focused on parenting experiences within this population. Even less information is available with regards to maternal experiences. The research that is available tends to focus on infants and young children (Speltz et al., 2005). During the literature review process the researcher was unable to find any research that focused specifically on mothers raising twins where one twin is born with a cleft lip and/or palate. These mothers'

unique situation and the challenges they face are thus not acknowledged in the available literature.

The researcher's interest in congenital facial deformities stems from her postgraduate training in clinical psychology. During that time she was introduced to the Pretoria Cleft Palate and Facial Deformities Clinic at the Oral and Dental Hospital. At the clinic she was exposed to parents' distress when attempting to parent a child with a cleft lip and/or palate. She thus became aware of the challenges parents face in raising a child with a facial deformity. Being a twin herself, she experienced parental care as one of twins and she thus became interested in mothers' experiences of raising twins where one child is noticeably different from the other. These differences are not only in terms of appearance but also in terms of the demands the deformity places on the mother. The researcher wanted to know more about mothers' experiences and the interrelatedness of various variables.

The researcher's postgraduate training focused on postmodernism, social constructionism and the systemic framework (these concepts are explained in chapters 2 and 3) and she thus became aware of the importance of understanding individuals' unique experiences. The researcher thus wanted to generate an in-depth understanding of the experiences of these mothers.

The Aim of the Study

The intention of this study was to create a safe space in which the three participants could share their own personal and unique accounts of what it feels like to raise twins when one twin is born with a congenital facial deformity. It was hoped that the in-depth and sensitive method of enquiry used in this study would yield rich information regarding mothers' experiences of raising twins within this context.

According to Dickerson and Zimmerman (1996, p.243) people give “order, coherence and meaning to events when they relate their stories”. Dickerson and Zimmerman (1996) also explain that social constructionists challenge dominant beliefs or stories that tend to dictate single accounts of reality. Social constructionists view these singular accounts of reality as shaping the context for the development of problems. This is because these dominant belief systems have a tendency to pathologise those who do not fit into the ascribed or expected norms (Rapmund, 2000). The researcher therefore aimed to provide the participants in this study with a space where they could be heard and acknowledged. This is important as society often expects parents to put their children’s needs ahead of their own and simply cope with any difficulties that occur. This expectation ignores the systemic principle of circular processes whereby the impact that a child with a deformity has on the mother also impacts the child as the mother is the primary care-giver.

Chapter Outline

This study consisted of an extensive review of the relevant literature as well as the application of certain theoretical concepts in order to provide the reader with a better understanding of mothers’ experiences of raising twins where one twin is born with a congenital facial deformity such as a cleft lip and/or palate. In order to realise the aims of the research this research report includes the following chapters:

Chapter 2 – Theory and Literature

This chapter serves as the point of departure for the study and provides a description of the relevant literature on congenital facial deformities such as cleft lip and/or palate and the experience of raising twins. The chapter also discusses the systemic epistemology that is the theoretical foundation of this study. The historical

development of this epistemology is briefly discussed and pertinent concepts in family systems theory are highlighted and applied to the research topic.

Chapter 3 - Research Design and Method

This chapter focuses on methodology and provides the reader with an explanation of the focus of the research, the aims of the study, the research method and the techniques that were applied to conduct the research. It also provides details concerning the process of analysis.

Chapter 4 - Discovering the Participants' Voices

This chapter presents the interpretation and analysis of the participants' stories. The chapter delves into the themes identified by the researcher as a result of an in-depth analysis of the participants' stories.

Chapter 5 - Conclusions and Recommendations

This is the final chapter in the study and provides the reader with a brief overview and evaluation of the study. It also includes recommendations for the application of findings and indications of possible avenues for future research.

Conclusion

This study aimed to explore the experiences of mothers' raising twins where one twin is born with a congenital facial deformity such as a cleft lip and/or palate. The next chapter explores and reviews previous research concerning the subject of congenital facial deformities such as cleft lips and/or palates. It also provides a brief overview of the literature relating to mothers' experiences of raising twins. Finally, it also includes information regarding the family systems perspective.

Chapter 2

Theory and Literature

“The strongest reinforcer of any human behaviour is an interpersonal relationship.”

(Anonymous)

Introduction

This chapter explores various theories and literature appropriate to the study of mothers' experiences of raising twins when one twin is born with a congenital facial deformity such as a cleft lip and/or palate. The systemic approach forms the epistemology from which this topic is studied. The involvement of family, friends and extended support structures is reviewed. The family life cycle is also reviewed with the aim of providing the reader with a theoretical understanding of the way in which an individual functions as a member of a system. During the process of researching literature regarding mothers' experiences of raising twins when one twin is born with a congenital facial deformity, it was revealed that this topic addresses a significant gap in the research, particularly within the South African context.

Western culture's myopic view of children dictates that all children should be smart, cute and healthy and ultimately attain a position of personal, social and economic importance in the world. Given this dominant worldview it is unsurprising that parents are typically unprepared for the news that their infant is not quite the same as other

children (Bugental, 2003). Most parents, families and friends fail to realise that the possibility of a less than perfect child is a reality.

Most families hope and expect to avoid all of the losses, changes, traumas and tragedies that are part of the total life experience (Carr, 2006). However, when a trauma or significant stressor does occur it becomes an integral part of the family's life experience and collective memory. In these situations (Johnson, cited in Dell Orto, & Power, 2007) families tend to focus their resources and make the necessary accommodations in order to reach a level of functioning that is balanced and manageable. When a child is born with a facial deformity such as an orofacial cleft, parents are acutely aware and afraid that people may only see their child's deformity and not the child him or herself (Hunt, Burden, Hepper, Stevenson, & Johnston, 2007; Nelson, O'Leary, & Weinman, 2009). Various studies indicate that observers attribute more positive attributes to attractive individuals and more negative attributes to unattractive individuals (Adams, Barden, Ford, Wilhelm, Rogers-Salys, & Salys, 1988; Langlois & Stephan, cited in Barden, 1990).

Defining Cleft Lip and/or Palate

It has been estimated that, each year, more than 250,000 babies worldwide are born with some form of congenital abnormality. A cleft lip and/or cleft palate are but one of many defects that may be present at birth (Collet & Speltz, 2006; Endriga, Speltz, Maris & Jones, 1998; McDonald & Berlin, 1979). Allen and Vessey (2004) describe cleft lip and/or cleft palate as ranking among the most commonly occurring birth defects. They found that the generally accepted incidence rate of clefts worldwide is 1 in 700 births, although some ethnic differences do exist. Studies indicate that cleft

lip and/or cleft palate are common birth defects in South Africa with it occurring at different rates in different populations (Hardy & Bütow, 1999). Within the South African population, it is estimated that cleft lip and palate occurs in 1 in 700 live births and is the most common congenital anomaly (South African Cleft Lip and Palate Society, 2006). The incidence of clefts per 1000 births in South Africa is estimated at 2.7 for the Asian populations, 1.3 for the Caucasian population and 0.6 for the Black population (Genetic Services, South African Department of Health, n.d.). No data is available regarding the incidence of twins born with a congenital facial deformity such as a cleft lip or palate.

A cleft is defined as an opening in the lip or the roof of the mouth that results from arrested midline facial development during the first trimester (Endriga et al., 1998; Viera, 2008). Cleft lip and palate often occurs in association with other birth defects (Mossey, Little, Munger, Dixon, & Shaw, 2009).

A cleft lip can range from a simple notch in the upper lip to a complete gap in the lip that runs into the floor of the nostril. A cleft of the lip may be complete or incomplete and can involve either one side (unilateral) or both sides (bilateral). The upper gum (alveolus) may also be involved (Cullis, 2006). (Refer to figure 1 and figure 2 on page 9 and page10).

A cleft palate can involve only the soft palate at the back of the mouth or may extend into the bone of the hard palate up to the back of the alveolus. As with the lip, one or both sides may be affected (Cullis, 2006). (Refer to figure3 on page 11).

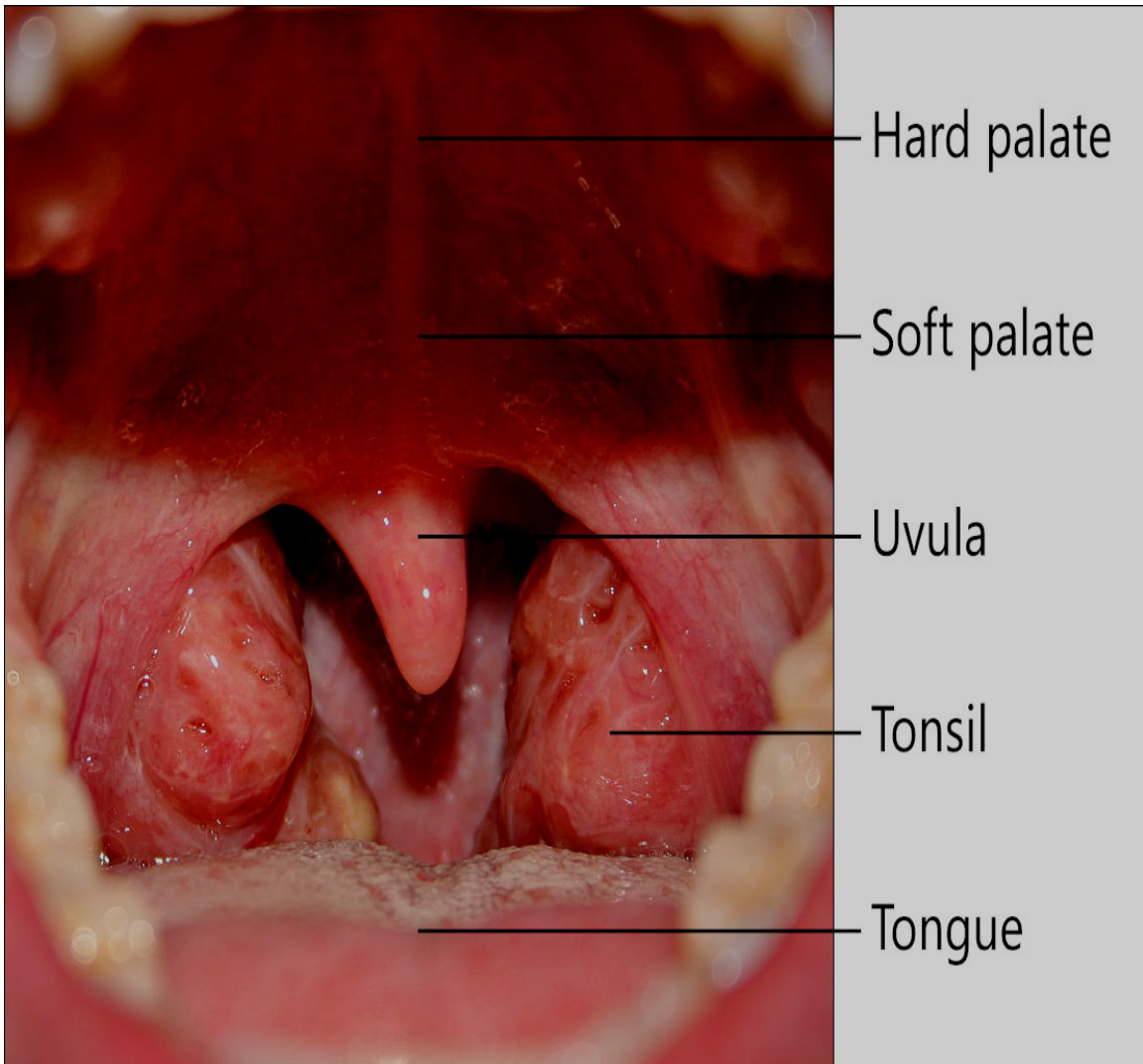


Figure 1 – Areas of the mouth (Genetic Services South African Department of Health. n.d.)

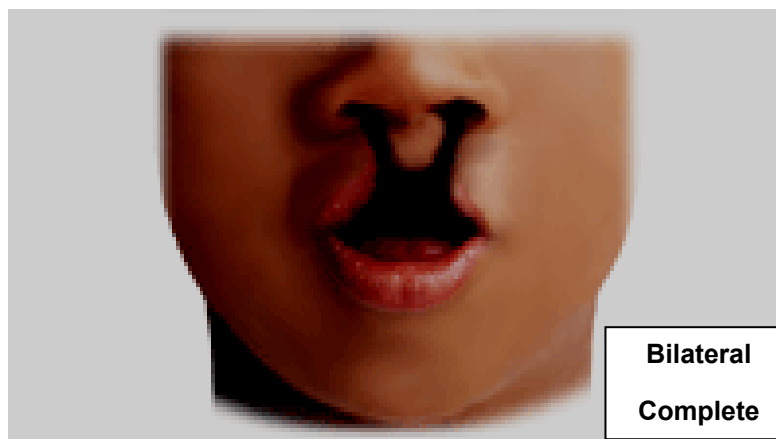
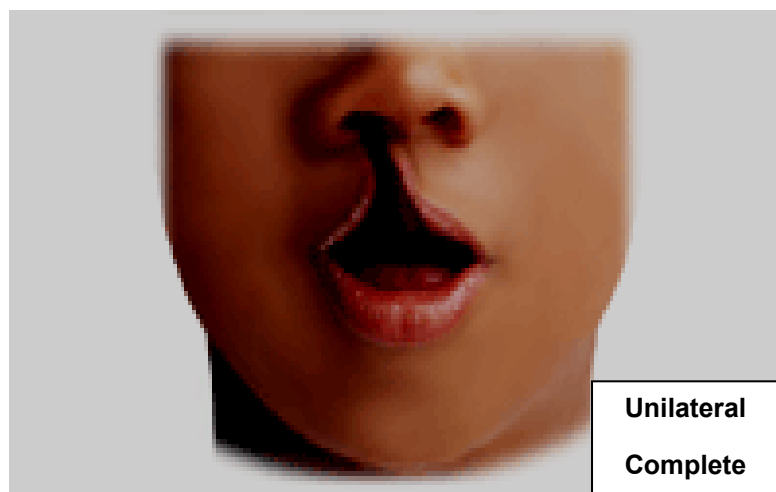
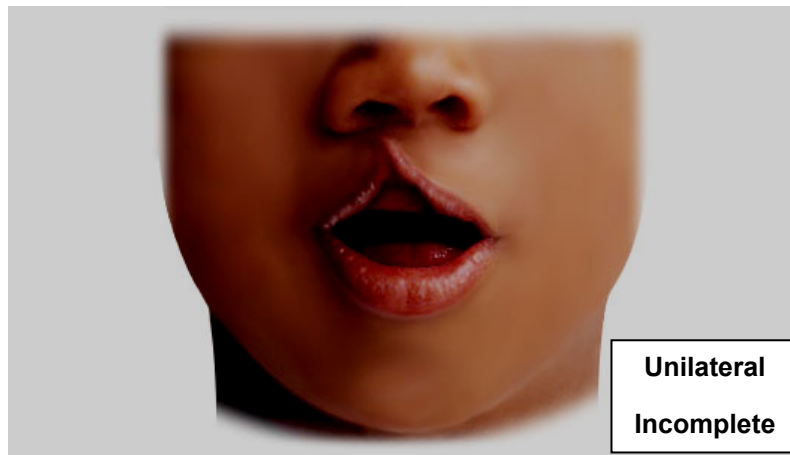


Figure 2 - Types of Cleft Lip

(<http://www.lpch.org/DiseaseHealthInfo/HealthLibrary/craniofacial/cleft.html>)

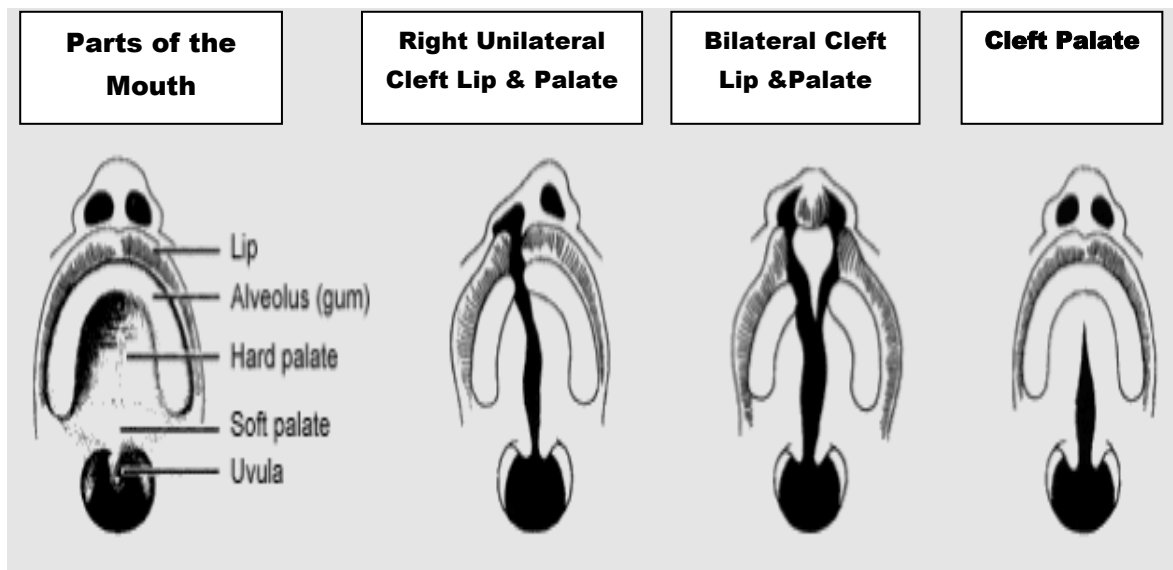


Figure 3 – Types of cleft lip and palate (Genetic Services, South African Department of Health. n.d.)

A cleft of both the lip and palate involves one (unilateral) or both (bilateral) sides of the lip, base of the nose, gum and palate. The lip and palate develop independently and it is therefore possible to have a cleft of the lip or a cleft of the palate separately or the two clefts may occur together. An unrepaired and uncovered cleft lip can be a distressing sight and researchers suggest that the visible facial deformity may cause parental strain (Chuacharoen, Ritthagol, Hunsrisakhun, & Nilmanat, 2009). Most clefts are treated through surgery.

Clefts are divided into two categories: nonsyndromic and syndromic. Most clefts are classified as nonsyndromic (Mossey et al., 2009; Viera, 2008), this means that the cleft is not part of a pattern of malformation affecting other organs and systems. Syndromic clefts are usually grouped into categories based on the underlying etiology or defect (Allen, & Vessey, 2004).

The specific cause and etiology of clefts is unknown. Research data suggests that many different aspects contribute to the creation of a cleft. Genetics do play a role but they are not the only factor (Nusbaum et al., 2008). A number of environmental factors including drugs, alcohol or medications may be responsible for disrupting normal patterns of development thereby contributing to the development of a cleft lip and/or palate (Snyder, Berkowitz, Bzoch, & Stool, 1990; Chuacharoen et al., 2009).

Medical Interventions

The Multidisciplinary Approach

The treatment of cleft lips and/or palates has changed and improved considerably over the last 50 years. The incorporation of new team members in the treatment team and enhanced intervention and surgical techniques have led to improved outcomes for patients (Hardin-Jones, & Jones, 2004).

A facial cleft deformity or cleft lip cannot be treated successfully by only one discipline or speciality (Bütow, 1995). Caring for children born with these defects generally involves many disciplines including nursing, plastic surgery, maxillofacial surgery, otolaryngology, speech therapy, audiology, counselling, psychology, genetics, orthodontics and dentistry (Mossey et al., 2009). Interaction and consultation between various disciplines enhances understanding of the possibilities and limitations of the various disciplines involved (Bütow, 1995). This type of multidisciplinary approach is followed at the Pretoria Cleft Palate and Facial Deformities Clinic at the Oral and Dental Hospital, Pretoria. This clinic is the largest cleft treatment facility in Southern Africa and has more than 3174 patients. The clinic

was established in 1983 by Professor Kurt W. Bütow. At the time Professor Bütow was the Chief Specialist in Maxillofacial and Oral Surgery and Head of the Department at the University of Pretoria.

Surgical Repair

The treatment of a cleft lip and/or palate affects many aspects of the affected individual's life. The treatment period is long, beginning shortly after birth and extending late into adolescence (Marcusson, Paulin, & Ostrup, 2002). A cleft lip only repair is usually done at five months while the repair of a cleft palate only, starts at seven months with follow up surgeries. In the case of cleft lip and palate, repair of the palate occurs at five months while repair of the palate lip occurs at seven months, repairs to the child's jaw starts at nine years with a bone implant and follow up osteoplasti (Bütow 1995). The goal of surgery is to normalise the face with scars that are hardly visible, a nose that is symmetrical with airways that are open and functional, a cleft area that has alveolar integrity, teeth that are aligned, and a palate that is intact and will allow for normal speech development (Marcusson et al., 2002). At the Facial Deformities Clinic at the Oral and Dental Hospital Pretoria, a timetable is followed for scheduling certain treatment aspects. (Refer to Table 1).

The purpose of the therapy protocol is:

- To treat a baby, child and adolescent at the most optimal time.
- To treat a baby, child and adolescent with the most optimal surgical technique.

- To avoid surgical and orthodontic over-treatment which in the long-term would result in a dental/functional and/or speech and/or aesthetic cripple (Bütow, 1995, p. 4).

This timetable is reproduced in table 1 below.

TIMING	PROCEDURES	TYPE OF CLEFT
3 ± 3 Days	Consultations	
	Facial deformity examination (team)	All
	Advice on feeding	
	Treatment plan	
	Pediatrics	
	Full examination	All
	Orthodontics	
	Functional – orthognathic suction and drinking palate	LAP
	Suction and drinking plate	hPsP, (sP)
	Headgear (after 3 weeks)	LA[b], LAP[b]
	Genetics	
	Parent counselling	All
	Psychology	

	Parent counselling	All
5±1 months	<p>Surgery</p> <p>Velum repair (and tensor sling)</p> <p>Hard palate repair (only in bilateral cleft, one side)</p> <p>Ear, Nose and Throat</p> <p>Examination</p>	<p>LAP</p> <p>LAP[b]</p> <p>LAP, hPsP, sP</p>
7± 1 months	<p>Surgery</p> <p>Velum repair</p> <p>Hard palate repair</p> <p>Anterior nasal floor reconstruction</p> <p>Lip repair</p>	<p>hPsP, sP</p> <p>LAP</p> <p>LA, LAP</p> <p>L, LA, LAP</p>
12±1 months	<p>Surgery</p> <p>Columella lengthening</p>	<p>L[b], LA[b], LAP[b]</p>
1½ – 8 years	<p>Speech–language therapy</p> <p>Active treatment</p>	<p>LAP, hPsP, sP</p>

	Fluorographic and/or naso-endoscopic examination (3½ – 4½ years)	LAP, hPsP, sP
4½ ±1 years	<p>Pedodontics</p> <p>Preventative treatment</p> <p>Prosthodontics</p> <p>Obturator (for an oronasal fistula)</p> <p>Speech bulb prosthesis</p> <p>Surgery</p> <p>Velopharyngeal flap</p> <p>Oronasal fistula</p>	<p>All</p> <p>LAP, hPsP</p> <p>LAP, hPsP, sP</p> <p>LAP, hPsP, sP</p> <p>LAP, hPsP, sP</p>
7±½ years	<p>Surgery</p> <p>Periosteoplasty (or at later stage, osteoplasty)</p> <p>Orthodontics (secondary)</p> <p>Preventative treatment (anterior crossbite – selective extraction)</p>	<p>LA, LAP</p> <p>LA, LAP</p>
12±years	<p>Orthodontics (tertiary)</p> <p>Final treatment (in orthognathic cases, treatment will commence at 15</p>	LA, LAP, L, hPsP, sP

	± 2 years) Surgery Osteoplasty (secondary)	LA, LAP
16±2years	Surgery Orthognathic surgery Prosthodontics Final rehabilitation Surgery Aesthetic revision (Lip, Nose) Genetics Adolescent counselling	All LA,LAP L,LA,LAP All

Table 1. The Therapy Protocol (Bütow, 1995, p. 3–4, *Treatment of Facial Cleft Deformities An Illustrated Guide*. Ishiyaku EuroAmerica, Inc Publishers.)

Abbreviations

L = cleft lip

LA = cleft lip and alveolus

LAP = cleft lip, alveolus, hard and soft palate

hPsP = cleft hard and soft palate

sP = cleft soft palate

b = bilateral

Discovery of the Cleft

Prenatal diagnosis of cleft lip by ultrasound scan can be performed as early as 12 weeks into pregnancy, and the child's prognosis is generally considered to be dependent upon the presence and type of associated anomalies. Parents often view ultrasound as a way of obtaining a first picture of their baby. Because they are usually not expecting the identification of a cleft, the moment they are first told of the diagnosis can be emotionally distressing. Despite the emotional distress the diagnosis can bring, it can also offer the opportunity to prepare for the child's future needs. Contrary to expectations, few advantages were found for having a prenatal diagnosis. Those parents with early knowledge of their child's condition did not report greater satisfaction with information, support, and treatment outcomes, although they had more time to learn and prepare for the child's condition (Robbins et al., 2010).

Feeding

In addition to concerns about their child's appearance, parents often have fears regarding possible feeding problems. Research indicates that babies with cleft lips only do not usually have feeding difficulties. However, since the early 1600s parents have known that babies with cleft palates have feeding difficulties (Reid, cited in Owens, 2008), a finding that has been confirmed by recent research (South African Department of Health, n.d.).

The most immediate concern for a baby with a cleft palate is good nutrition. Feeding and maintaining weight becomes a goal for both parents and medical professionals treating such babies (Owens, 2008). For babies with cleft palates feeding is often lengthy and tiring. The baby may also be restless due to not being able to suck sufficient milk, and many mothers find this very upsetting. In addition, frequent stops

are required during feeding as excessive air is swallowed owing to the difficulty in sucking (South African Department of Health, n.d.). These babies may experience additional problems such as nasal regurgitation, long feeding times, and difficulty coordinating swallowing and breathing (Owens, 2008).

Regardless of what feeding system a mother chooses for her baby, most health care providers agree that breast milk is the best food for newborns. Breast-feeding at this time not only provides nutritional benefits and protection against infection, but can also comfort and reassure both the baby and mother. Should breastfeeding not be an option, expressed breast milk in a bottle is also recommended. Learning that breastfeeding is an unlikely option can be a source of disappointment and sadness for some mothers. At this time it is recommended that mothers give themselves time and space to grieve this loss (South African Department of Health. n.d.). Teaching new mothers to feed their babies is vital as it assists them to overcome negative feelings regarding their baby's abnormality. During this process a mutually rewarding relationship is established by ensuring that the mother bonds with her baby and begins to accept her baby's abnormality and that the baby receives adequate nutritional intake.

It is recommended that when babies are bottle fed, long, soft bottle teats with an enlarged opening be used. It is also recommended that a plastic bottle that can be squeezed should be used to aid the flow of milk. The mother requires support when learning to interpret when to squeeze the bottle in response to the demand from the baby (Owens, 2008). Other options include spoon-feeding or using a syringe or dropper, but these options do not provide the baby with the necessary sucking experience. It is recommended that in these instances, mothers should supplement

these methods with a dummy and a specifically designed dummy may be recommended (South African Department of Health. n.d.).

The Family Experience of a Cleft Lip and/or Palate

Although the birth of a child is a commonplace event for the two individuals who become parents it is nothing short of miraculous. Becoming a parent is regarded as a definitive stage of life (Carter, & McGoldrick, 1999). The transition to parenthood is a major life event and both the new mother and the new father have to adapt to the changes brought about by the responsibility of raising a child. (Refer to Table 2, Stage 3 on page 24). As with any major life change having a baby can be extremely stressful. It entails some degree of risk and the challenges involved in raising children causes new problems and highlights existing vulnerabilities for both parents (Cowan, & Cowan, 1992). Van Staden and Gerhardt (1994) explain that the birth of a child profoundly affects the family system into which it is born. They explain that even in the case where the pregnancy is planned and the child perfectly healthy, a newborn requires ongoing emotional and physical nurturing, education and varied support systems to unfold its potential. These challenges are escalated if the child is born with a disability.

The transition to parenthood usually involves the taking on of new roles and role behaviours, assuming tasks of parenthood and learning the knowledge base attached to these roles (Carter & McGoldrick, 1999). All persons in our society become partially socialised into these roles through absorbing common understandings of appropriate behaviour and watching role models in the persons of their own parents, siblings and friends. Therefore at the time of birth expectant

parents are somewhat prepared for parental roles. These are the roles of parents of a child who meets all the expectations but not a child that is different, for example a child born with a congenital facial deformity. Child care is the primary concern of this phase and involves addressing the work–family dilemma and shared parenting (Carter & McGoldrick, 1999). This involves defining roles and responsibilities within the family unit. Having a child with a disability in the family changes family life in many ways, many of which involve potential problems. Parents in this situation and especially during the first year of their child’s life have to meet and discover each other in a position completely unknown to either of them

According to Schoen-Johnson (1995) the characteristics of the parents as individuals and as a dyad influence their ability to engage in competent parenting. The general mental health of the parents and the quality of their marriage influence their interactions with their children. Anderson and Sabatelli (cited in Allen & Vessey, 2004) describe a family stress model introduced by Hill that investigates the psychosocial impact of the normative and non-normative stressors on families.

According to the underlying principles of this model, the following is assumed:

- Ongoing demands for change continually place families under some degree of stress.
- At times, families need to alter task management strategies to respond to stress.
- A family’s ability to adapt to stress influences its capacity to function effectively over time.

- Adaptive families who are able to construct strategies to reduce individual and collective stress will concurrently support the growth of all members (Anderson & Sabatelli, 1999, cited in Allen & Vessey, 2004).

This model suggests that although the diagnoses and management of childhood disabilities place children and family members at risk for particular relational and psychological disorders, these effects are variable, with a majority of families making a successful adaptation. This model suggests that families experience stress but that they have the ability to reduce stress. Childhood disability such as cleft lip and/or palate can be regarded as a major stressor, however if the family can apply or develop strategies to reduce stress the family will be able to adapt successfully. The family life cycle perspective offers a valuable framework for understanding a family's challenges, adjustments and its flexibility in adapting to changing conditions. Most families, regardless of structure or composition or cultural heritage, progress through certain predictable marker events or phases (such as marriage, the birth of a first child, children leaving home, and death of grandparents). Zilbach, (cited in Goldenberg and Goldenberg, 2004) explains that each stage is precipitated by a particular life event referred to as a family stage marker that demands change and a new adaptation. These passages may occur because of a sudden major change in family composition such as the birth of a child or perhaps due to a major shift in autonomy when children move out of the family home (Goldenberg & Goldenberg, 2004). Roles and responsibilities change as the family moves through each stage of the cycle. In order to move to the next stage of development, the family needs to successfully master the previous stage's tasks (Goldenberg & Goldenberg, 2004).

These stages are presented in table 2 below.

Table 2. The Family Life Cycle. (Carter & McGoldrick, 1995, p.2, *The Expanded Family Life Cycle – Individual, Family, and Social Perspectives* (3rd ed.). Allyn and Bacon).

FAMILY LIFE CYCLE STAGE	EMOTIONAL PROCESS OF TRANSITION: KEY PRINCIPLES	SECOND-ORDER CHANGES IN FAMILY STATUS REQUIRED TO PROCEED DEVELOPMENTALLY
STAGE 1		
Leaving home: single young adults.	Accepting emotional and financial responsibility for self.	<ul style="list-style-type: none"> a. Differentiation of self in relation to family of origin. b. Development of intimate peer relationships. c. Establishment of self in respect to work and financial independence.
STAGE 2		
The joining of families through marriage: the new couple.	Commitment to new system.	<ul style="list-style-type: none"> a. Formation of a marital system. b. Realignment of relationships with extended families and friends to include spouse.

STAGE 3		
Families with young children.	Accepting new members into the system.	<ul style="list-style-type: none"> a. Adjusting marital system to make space for children. b. Joining in child-rearing, financial and household tasks. c. Realignment of relationship with extended family members to include parenting and grand-parenting roles.
STAGE 4		
Families with adolescents.	Increasing flexibility of family boundaries to permit children's independence and grandparents' frailties.	<ul style="list-style-type: none"> a. Shifting of parent /child relationships to permit adolescent to move into and out of system. b. Refocus on midlife marital and career issues. c. Beginning shift toward caring for older generation.
STAGE 5		
Launching children and moving on.	Accepting a multitude of exits from and entries into family system.	<ul style="list-style-type: none"> a. Renegotiation of marital system as a dyad. b. Development of adult- to -adult relationships.

		<ul style="list-style-type: none"> c. Realignment of relationships to include in-laws and grandchildren. d. Dealing with disabilities and death of parents (grandparents).
STAGE 6		
Families in later life.	Accepting the shifting generational roles.	<ul style="list-style-type: none"> a. Maintaining own and/or couple functioning and interests in face of physiological decline. b. Support for more central role of middle generation. c. Making room in the system for the wisdom and experience of the elderly , supporting the older generation without over-functioning for them. d. Dealing with loss of spouse, siblings, and other peers and preparation for death.

Healthy development depends on repeated, varied positive interactions between the growing child and the environment resulting in a spiral of mutually effective interactions. Bzoch (1979) argues that the development of a child takes place within a context of interactions with others. During the early phases of development these

interactions occur within the family unit. In this context the family members act as social mirrors, providing the child with information about him or herself. Perceptions of being valued and accepted and perceptions regarding attitudes expressed towards him/her impact the child's own concept of him/her self and his/her body. During interactions with others the child becomes aware of the effect of his/her appearance on others (Bzoch, 1979). The inclusion of the family life cycle provides the reader with an understanding of normal developmental processes that individuals and families undergo, highlighting the challenges and adjustments that are necessary when a family experiences the birth of a child with a cleft lip and/or palate. Additionally the inclusion of this model contextualises the birth of a child with a cleft lip and/or palate as an unusual challenge that the family has to adapt to.

The Birth of Twins

The aim of this section is to highlight the challenges of the birth of twins as well as the additional challenges parents may experience when one of their twins is born with a cleft lip and/or palate.

For most parents the news that they are having twins comes as both a surprise and a shock. Few mothers ever imagine having twins and most parents have never seriously considered the difficulties involved in looking after more than one baby at the same time. When parents discover that they are expecting twins, they are aware that their children will receive more attention because they are two (Sandbank, 1999).

Both clinical and qualitative studies and popular literature portray the twin relationship and the interaction between twin siblings as having unique characteristics. Twin relationships are unique in that twins often find themselves so bound up in one another's experiences that both are equally affected by the experience (Ainslie, 1985). The closeness of twins' relationships is strongly influenced by the nature of their twin relationship. An extensive study by Koch (1966) examined the way twins' relationships were affected by their sex and their zygosity (identical/fraternal) and found that different twin types tended to display common characteristics. The study found that identical twins tended to display closer relationships than fraternal. Identical girls also had closer relationships than identical boys. Fraternal same sex twins were less close to one another than identical twins. Fraternal boys had the most rivalrous relationship. Fraternal opposite sex twins were generally the least close (Koch, 1966).

As with all humans the development of twins does not occur in isolation but within a network of influences operating on many levels. A variety of personal, interpersonal and contextual factors operate separately and together to shape each individual's life course. Environment can either enhance or diminish the alternative developmental context of twins as opposed to that of single-born children. Twins typically create more interest and receive more attention than single-born children (Smilansky, 1992). Cultural attitudes and predispositions towards twins are still relatively stereotypical and environments still tend to treat twins as a single unit. People often expect twins to display both opposite and complementary characteristics and many people expect identical twins to be alike in every aspect, both physically and mentally (Koch, 1966). The more alike twins are the more fascinated people are by them.

With the discovery that one of their babies has a deformity, parents are often concerned that their child will be treated differently and that there will be a constant reminder that one child has a defect and the other does not. This can be very stressful for the family and the relationship between the mother and her twins (Steward, 2000). It may be from this social attention that parents feel the need to emphasize the twinness of their twins, yet this may not be a possibility when one twin differs, especially when he or she has been born with a conspicuous congenital facial deformity. And yet at the same time society may still only see them in terms of their relationship to one another, not as individuals but rather as twins, where one twin is regarded as more fortunate than the other. But what is the impact of one twin having a congenital facial deformity, such as a cleft lip/ palate on their co twin and how does this impact mothers' experiences of raising their children?

The Impact of a Cleft Lip and/or Palate

Parents' Experiences of a Cleft Lip and/or Palate

The birth of a child with facial cleft/palate and the subsequent diagnosis is understandably difficult for many parents since few parents are prepared for the birth of a child who is different from other babies in some important way (Hunt, Burden, Hepper & Johnston, 2005). It comes as no surprise that so many parents report being shocked and confused upon learning of their child's condition. Van Staden and Gerhardt (1994) note in a review of the literature that parents who find themselves faced with the birth of a child with a facial deformity, usually react with shock and disbelief. However they also explain that these emotions usually dissipate fairly quickly and the process usually continues to one where the child is integrated within

the family system (Van Staden & Gerhardt 1994). Rigazio-DiGilio and Cramer-Benjamin (2000) found that individual and family reactions to childhood disabilities are similar to the experience of grieving and loss. Although the exact process varies for each individual it usually includes phases of shock, refusal, guilt, bitterness, envy, rejection and finally adjustment to the child's disability and the response of the wider community (Rigazio-DiGilio & Cramer-Benjamin, 2000). A study exploring the reflections on the cleft experience by South African adults, conducted by Patel and Ross (2003) found that 16 of the 20 participants felt that their families had reacted in some way to their child's cleft. The participants' comments highlighted grief, shock, and subsequent acceptance as dominant themes in their families' reactions. Allen and Vessey (2004) found that parents of appearance impaired children often experience feelings of depression and hopelessness.

For parents having a child with a facial cleft raises anxieties about the cause of the condition, concerns about the reactions of peers and others to their child and questions regarding the developmental implications of the disorder (Collett & Speltz, 2006). Researchers such as Dar, Winter, and Tal (1974) and Drotar, Baskiewicz, Irvin, Kennell and Klaus (cited in Collett & Speltz, 2006) found that parents' initial worries focus on the pragmatics of feeding, timing of lip repair surgery and possible embarrassment upon introducing the newborn child to others. Parents' concerns later turn to determining the cause of the deformity, the duration of craniofacial care and the risk for future pregnancies.

The literature seems to assume that parents' reactions to the cleft are somehow transmitted to the child. For example, Spierstersbach and Macgregor (cited in Clifford & Crocker, 1981) state that the adjustment of patients with clefts is partially a function of parental adjustment and attitudes towards the cleft. Baker, Owens, Stern

and Willmot (2009) and Chuacharoen et al., (2009) also share similar views. According to Pope and Snyder (2005) having a child with a facial cleft places unique medical, social, financial and emotional stressors on families and these stressors may impact the parent-child relationship and this in turn may impact the child's psychosocial adjustment.

Bzoch (1979) suggests that parents' negative feelings about the defect may ultimately affect the child. In some cases the birth is experienced as a severe disruption in the familial patterns and leads towards family disintegration. Versluys' (cited in Van Staden & Gerhardt, 1994) research suggests that stress resolution is a family task and the family's ability to deal with a cleft tends to be prognostic of future coping. A family's early inability to handle the stress surrounding the birth of a baby with a disability is thus usually predictive of later family disorder and breakdown (Versluys cited in Van Staden & Gerhardt, 1994). A disability therefore has an impact on the entire family and not just on the disabled child (Van Staden & Gerhardt, 1994). The family is the main environment for the developing child and the development of the family is powerfully influenced by the child and by the demands of raising a child with a cleft lip and/or palate (Allen & Vessey, 2004). In the case of a child with a cleft lip and/or palate everything from the use of time and space to financial arrangements for medical treatment and communication among family members must be negotiated (Baker et al., 2009).

Various studies have investigated different aspects of family functioning, including problem solving, communication and coping, and most studies have yielded mixed results. Some studies suggest that many families with an individual with a chronic condition function well and do not perceive the condition to be the dominant focus of their life (Bohacahick & Anton; Donally; Rehm & Cantazaro; Sawyer cited in Allen &

Vessey, 2004). However, other studies (Cornman; Ferrel et al.; Kopp et al.; Park & Martinson cited in Allen & Vessy, 2004) have documented impaired family functioning, particularly in the spousal subsystem.

The family's response to the birth of a child with a birth defect cannot be easily summarised. Reactions range from guilt, to avoidance, to strong support and assistance. Chuacharoen et al., (2009) found that parents' needs varied over time according to the developmental phases of the child and focused mainly on feeding, speech problems, surgery and financial support. Emotional stress may extend beyond the parents and include siblings, grandparents and even friends. A study by Benson, Gross and Kellum (1999) found that parents of children with craniofacial anomalies displayed higher levels of depression (as measured by Beck's Depression Inventory) than other parents. These parental reactions are likely to have a profound effect on all the children in the family (Benson et al., 1999). Baker et al.'s (2009) study found that although families experienced a number of impacts related to the child's disability overall negative outcomes were rare. The study also found that the way in which parents coped with their child's condition and the level of support they received had implications for both caregivers and the family unit (Baker et al., 2009).

Locker, Jokovic, Kenny, Thompson and Guyatt's (2002) research demonstrated the pervasive effects of oral and oro-facial conditions on the functioning of parents/caregivers and the family as a whole. The study found that a large percentage of the parents/caregivers reported frequent family impact in the first three months of the child's life. The most common areas of impact involved the child requiring more attention, financial difficulties, taking time off work, and parental feelings of guilt, worry and distress in connection with the child's condition. The findings indicated that oral and oro-facial conditions impact parent and family

activities, influence parental emotions and can result in conflict in the family (Locker et al., 2002).

Baker et al., (2009) point out that most of the research on craniofacial conditions such as a cleft lip and/or palate has focused on the impact of the condition on the affected person but the impact on the family has received less research attention. The small body of research that does exist (Speltz et al., 1993) suggests that mothers of children with congenital facial deformities experience greater stress, feel less competent and report more marital conflict than mothers of children without congenital facial deformities. However, some research (Kramer, Baethge, Sinikovic, & Schliephake, 2007) suggests that having a child with a cleft lip and/or palate has little impact on parents' quality of life.

The literature makes it clear that feeding interactions are an important domain in the mother-infant social relationship during the first year of an infant's life (Endriga, Speltz, Maris, & Jones, 1998). Various studies have examined the importance of dyadic feeding behaviours in the early months. Early research by Field and Vega-Lahr (1984), Hoekma and Clarren, (1991) and Barden, Ford, Jenson, Rogers–Slayer and Slayer (cited in Endriga & Speltz, 1997) found that infants with craniofacial anomalies and their mothers were less responsive to each other than mother-child dyads in which the infant had no birth defect. These findings have been interpreted as evidence for the adverse effect of abnormal facial appearance on maternal care giving.

Speltz, Goodell, Endriga and Clarren (cited in Endriga & Speltz, 1997) found that mothers of infants with cleft lip or cleft palate had to be more directive when feeding their infants and hypothesised that this could compromise their sensitivity to their

infant's social and emotional cues. The study also found that greater maternal sensitivity during feeding interactions was linked to maternal reports of infant temperament and greater social support.

It is when the child is involved in interactions with others that he becomes aware of the effect of his appearance on others (Bzoch, 1979). Bzoch (1979) explains further that a basic tenet of personality theory is that early developmental experiences influence later behaviour. Consistent with that tenet, emergent psychological processes and experiences may then be affected by a number of conditions associated with a cleft lip and/or palate. However, according to McDonald and Berlin, (1979) the child's emotional development will be shaped to a large extent by parental reactions to a child's cleft (McDonald & Berlin, 1979). How parents deal with the challenges and stressors brought about by the diagnosis of a cleft lip and palate as well as how they feel about, and act towards their children will affect the way those children come to view themselves. This view may cause life-long effects on later social relationships, career decisions or lifestyles for the child.

Siblings' Reactions to a Cleft Lip and/or Palate

Relationships between siblings are ascribed rather than voluntary and include some history of intimate family experiences. These relationships are enduring and often last for the individuals' entire life-spans (Cicirelli, 1995). According to Cicirelli (1995) young children who have siblings with disabilities tend to be unaware of the afflicted sibling's condition or have only a limited understanding of the condition. However, as non-affected siblings age they often feel concerned and confused about their sibling's condition (Cicirelli, 1995). Siblings are often also exposed to the emotional distress of their parents and other family members, heightened parental attention to

the afflicted child and frequent disruptions of family plans. Children don't have problems just because their brother or sister has a disability. They may develop problems if their own relationships with their parents are interrupted and if their lives are affected by the stressors within the family.

Hunt et al., (2006) found that siblings experience pressure related to the disabled child's hospitalisation. Simple explanations from parents help the other children in the family to deflect their anxieties about themselves (Hunt et al., 2006). A study by Skipper and Leonard (cited in McDonald, 1979) found that mothers who were well-informed about their children's operations experienced less stress than the control group of mothers who were given no information. The mothers' confidence also seemed to be reassuring to siblings at home. Research that has explored the impact of the presence of a disabled child on their siblings has reported uneven findings. No research was found exploring the impact on the relationship between twins where one twin is born with a cleft lip and/or palate.

The Impact of a Cleft Lip and/or Palate on the Child's Self Concept and Adjustment

Numerous studies (Goffman; Fitts; Kapp-Simon, cited in Turner et al., 1998) have examined the social and psychological adjustment of children with cleft lips and/or palates. Health psychologists have increasingly focused on psychological adjustment associated with perceived abnormalities of appearance (Moss & Carr, 2004). Moss and Carr's (2004) research indicates that individuals with a disfigured appearance are likely to elicit avoidant and socially awkward behaviour in others.

Most of the previous research concerning the psychosocial aspects of a cleft lip and/or palate has focused specifically on the personality of the individual born with the cleft (Bzoch, 1979). This research is underpinned by assumptions about the

effect of the social and cultural milieu upon the individual and specifically the role of physical attractiveness and physical deviance in society. This body of research (Bzoch, 1979; Van Staden & Gerhardt, 1994) found that society is orientated toward the physically attractive and failure to measure up to a societal norm of attractiveness or adequate functioning may result in an individual becoming stigmatized. The literature constantly highlights the theme that people have specific stereotypes concerning facial attractiveness (Tobiasen, 1987). This theme suggests that people tend to ascribe positive characteristics to individuals who are physically attractive. According to Van Staden and Gerhardt (1994) this position also works negatively, that is that faces that are disfigured or deformed may be seen as bad. A study by Bershied and Walster (cited in McDonald, 1979) found that even during the pre-school period children's acceptance by peers was influenced by physical attractiveness. Bershied and Walster's (cited in McDonald, 1979) study indicates that a child's self-concept is largely a function of his or her social relations. They found that unattractive children were perceived by their peers to be more aggressive and less self-directed than their attractive peers.

According to researchers Bzoch, (1979); Van Staden and Gerhardt, (1994); Allen and Vessey, (2004), mentioned earlier in the chapter, there seems to be an assumption that the effects of the impact of cleft lip and or palate on the parents are somehow transmitted to the child. This seems to give rise to the positions taken by Spierstersbach and Macgregor (cited in Clifford & Crocker, 1971) that since the adjustment of patients with clefts is, in part, a function of the parental adjustment and the attitudes they have toward the defect, the parents' attitudes about the cleft affect the child's adjustment.

The literature reviewed clearly indicated that self-concept has been a primary interest for researchers investigating social-emotional outcomes in children with clefts. Most of the research suggests that children with clefts internalise the differential treatment they receive from others, which often includes negative responses to physical appearance or speech, and therefore tend to develop negative self-perceptions (Collett & Spletz, 2006).

The face plays a critical and unique role in human development and social interactions (Cole, 1998) and therefore having a congenital facial deformity puts a child at higher risk for psychosocial difficulties than their non-affected peers (Blakeney et al., 1993; Broder, 2001; Meyer et al., 1995; Tobiasen & Hiebert, 1993). Stigmatizing social responses to facial disfigurement can lead to negative self-perceptions of competence and physical attractiveness (Kapp-Simon et al., 1992). Alterations in facial appearance have also been shown to impact a child's perception of him/herself at an early age (Speltz et al., 1997).

From a social-cognitive perspective, the self-concept is viewed as a multi-faceted, dynamic and hierarchal information processing network. The self-concept guides behaviour through self-regulation and guides information processing in relation to self-relevant information. Moss and Carr (2004) view the self as consisting of various self-aspects (e.g. roles, relationships, attitudes, traits). These self-aspects vary in terms of degree of internal elaboration as well as closeness of relationship to other self-aspects. Individuals differ in terms of the relative importance of the self-aspects, the degree to which positive and negative adjectives within the aspect are grouped or compartmentalized, and the complexity of the self-concept. The importance of particular self-aspects will have implications for the individual's overall self-worth and

if valued (central) self-aspects are seen as inadequate, this will have a greater impact on the individual's overall level of self-esteem than if less important aspects are valued (Moss & Carr, 2004).

The research indicates that children with oro-facial clefts have distinctly elevated risk for a variety of adverse social-emotional outcomes including behaviour problems, poor self-concept and parent-child relationship difficulties (Collett & Spletz, 2006). However, much of this research has been based primarily on theories of facial appearance and social bias, a handful of empirical studies and clinical impressions (Collett & Spletz, 2006). Literature dating back to the 1950s describes children with clefts as experiencing elevated rates of social-emotional development problems. These findings may be related to the highly visible and socially stigmatizing nature of the conditions, high rates of parental anxiety and distress and the stressful demands of medical treatment (Collett & Spletz, 2006). A study by Richman (2004, cited in Collett and Spletz, 2006) found that children with clefts were more socially withdrawn and inhibited than controls. In contrast a study by Leonard, Brust, Abrahams and Sielaff (cited in Collett & Spletz, 2006) found that self-concept scores for youths with clefts were in the moderate to high range relative to test norms. None of the participants in this study reported abnormally low self-concept.

The social, emotional and self-concept outcomes for children with clefts are diverse and reflect a range of different factors, which are likely to be unique to each individual case. In general it appears that children born with clefts are prone to more social inhibition than children born without clefts. These children may also show a passive and self-conscious pattern of interaction, which can be seen and understood as a self-protective effort to avoid attention and possible teasing (Collett & Spletz, 2006). Given society's tendency to judge individuals based on their physical

appearance it is not surprising that the parents of children with physical deformities fear that their child will experience rejection and stigma (Turner, Rumsey, & Sandy, 1998).

A Systemic Framework

This study focuses on the experiences of mothers who are the parents of twins, where one twin is born with a congenital facial deformity. To conceptualise the parenting experience of mothers of twins where one twin is born with a congenital facial deformity, family systems theory is useful in explaining the family interaction and to help understand the mothers' perspectives of their family life and experiences of raising a child with a congenital facial deformity. The use of this perspective to explore and understand the mothers' experiences will enable the researcher to view their experiences in the larger contexts of their relationship patterns and family dynamics.

Looking at the mother in isolation would be very reductionistic as the relational context within which the mother fulfils her parenting role would be ignored. The use of a systemic perspective to explore and understand the mothers' experiences of raising a child with a congenital facial deformity would enable the researcher to view the mother and her twins in the larger context of their relationship system, the parental system as well as viewing the said systems in the larger context of the family system and its dynamics. Only by taking the broader system context into consideration, in other words by looking at the parental system, the spousal system, and the sibling system, together with how these systems are structured in the larger

family context and societal context can the mothers' experiences be better understood.

A family is more than a collection of individuals sharing time and space together. Families occur in a diversity of forms and represent vastly different cultures and heritages, but are always considered a natural social system (Goldenberg & Goldenberg, 2004). Families with a child with a congenital facial deformity, like all families, come in many shapes and sizes, and can be rich and poor and black, white and coloured. In other words, the only similarity between these families is that fact that they all contain a child who was born with a congenital facial deformity.

The family is the main environment for the developing child. Family behavioural patterns, parents' concepts about raising a child with a facial deformity, parents' emotional responses to the loss of their imagined 'perfect' child and parents' interactions with the child all influence the child's development (Bugental, 2003). In addition, family development is strongly influenced by the child and the demands associated with raising a child with a congenital facial deformity. The needs associated with the treatment of the child's facial deformity have a significant impact on the family in terms of the use of time and space and the financial arrangements and travel plans associated with corrective surgery. In this way the facial deformity impacts all family members and ultimately even influences the family's self-image. Families come to view themselves as competent or incompetent and nurturing or not nurturing. From the discussion above, the idea of circular causation is evident in that the child born with a congenital facial deformity such as a cleft lip and/or palate influences and is influenced by their family of origin – their siblings, parents, grandparents and extended family members.

Parenting is always dynamic, multifaceted and complex. Various individuals, families and institutions fulfil parenting functions such as nurturing and nourishing a child and creating an environment in the child can learn skills for social participation and acceptance of personal responsibility. The parenting process thus consists of tasks, roles, rules, communication, resources and relationships (Goldenberg & Goldenberg, 2004).

General Systems Theory

Family systems theory was to a large degree influenced by the concepts of general systems theory. According to Goldenberg and Goldenberg (2004) general systems theory, first proposed by biologist Ludwig von Bertalanffy in the late 1920s represents an ambitious attempt to promulgate a comprehensive theoretical model that would have relevance to all living systems. According to Von Bertalanffy (1968), a system can be defined as a group of elements that are interrelated by a dynamic interchange of energy, information or materials into a product of the outcome, for use within or outside (the environment) the system. Von Bertalanffy (1968) further argued that in order to understand phenomena, attention has to be given not only to individual elements, but also to the interrelationships between elements and suggested that the focus of understanding should fall on system processes.

The emergence of general systems theory led to a new and different way of thinking that could be applied to various contexts. General systems theory is thus regarded as a meta-theory that contains a set of interdisciplinary principles applicable to systems in general, regardless of the nature of the elements or systems involved. Through careful observation of the behaviours and patterns of entire systems

researchers can gain insight into the dynamics that connect, change and shift entire systems and the ways in which the individual elements of a system mutually influence each other (Hoffman, 1981).

The idea that a system contains emergent characteristics is central to systemic thinking (Dallos & Draper, 2008). This means that when two people interact they are involved in a creative process or a joint construction of actions and meanings. It is therefore impossible to fully predict how two or more people will interact or what sort of relationship will emerge. Systems theory stresses the interdependence of action in families and other relationships. Every person influences the other person/s and their responses in turn influence each other and influence the first person's response (Dallos & Draper, 2008), thus creating a cycle. Every action is therefore also seen as a response and every response is also seen as an action.

Family Systems Theory

According to Goldenberg and Goldenberg (2004) various prominent researchers and therapists who worked with families and couples contributed to the development of family systems theory. Family systems theory emphasises the family as an emotional unit or network of interconnected relationships best understood from a trans-generational perspective. This theory expresses the idea that neither people nor their problems exist in a vacuum. Key to the development of family systems theory was Gregory Bateson and the formation of the Palo Alto Group who, initially focused on communication patterns in families, marking the beginning of a shift, from content to pattern and process, in the treatment of families. The adoption of this new approach meant that researchers and therapists had to adopt and develop a new

language. They found the general systems theory a useful way to express their new way of thinking about families as supra-individual phenomena (Becvar & Becvar, 2006). These changes also meant that researchers and therapists, working from a systemic perspective, would now focus on the what and how of phenomena, and not on why things happen the way they do (Hoffman, 1981). The systemic researcher will for example be curious about who the family members are, what the patterns, rules and processes of the family system are and what the system's meaning making processes and patterns are.

Definition of a system

Goldenberg and Goldenberg (2004) define a system as "a set of interacting units or component parts that together make up a whole arrangement or organisation" (p. 512). These naturally occurring systems have their own properties, their own set of rules, their own forms of communication and their own ways of negotiating and problem solving that allow various tasks and duties to be performed effectively (Goldenberg & Goldenberg, 2004). The systems also ascribe specific roles to their members. The relationships between members of a family system are deep and multi-layered and are based on a shared history and purpose as well as internalised perceptions and assumptions about the world (Goldenberg & Goldenberg, 2004).

The physical, emotional and social functioning of family members is profoundly interdependent and changes in one part of the system reverberate in other parts of the system. Watzlawick et al., (1974) refers to this as the wholeness of a system. The systemic perspective highlights recursive organisation or reciprocal causality (Becvar & Becvar, 2006). This means that people and events are seen in the context of relatedness, mutual interaction and mutual influence. The system is also recursive

and self-corrective through the process of feedback, whereby information about past behaviours is fed back into the system in a circular manner. Recursion thus refers to the impact of the behaviour on the system and the response of the system to that behaviour.

Several key principles of systems theory are discussed in the sub-sections below. These principles are discussed as it is believed that they are particularly relevant to the research topic.

Recursion

Postmodern or non-linear perspectives are usually referred to as “systemic, ecological, ecosystemic, circular, recursive or cybernetic” (Keeney, 1983, p. 14). While linear causality suggests that A causes B and B causes C circular causality does not offer such a clear cut explanation. In circular causality any elements or parts that have a linear relationship with respect to causality are not viewed as forming a whole or a system (Goldenberg & Goldenberg, 2004).

Recursiveness or reciprocal causality views people and events in the context of mutual interaction and mutual influence (Becvar & Becvar, 2006). From this perspective it is not possible to understand the child’s cleft as an event that linearly impacts on the mother or the family in a certain predetermined manner. Instead, reciprocal causality focuses on the relationships between the units in a system and the way in which these relationships (rather than the actual units) organise the system (Goldenberg & Goldenberg, 2004). Relationships between individuals are seen as vital and researchers examine these relationships and investigate how they interact with and influence each other. Instead of seeking a plausible cause or initiator researchers choose to focus on what is happening between the people

involved in the interaction and the ways in which they are mutually influenced in a circular communication process (Watzlawick et al., 1967). For the purposes of this research the focus was on the mutual influence in the parental sub-system, especially with regard to the relationship between the mother figure and the child born with the cleft. The manner in which other systems, including extended family and friends, respond to the child and the mother of the child was also investigated.

Although the research specifically focused on the experience of mothers, it is acknowledged that the mothers' stories cannot be viewed in isolation. Instead these individual stories form part of an ecology in terms of the mothers' interactions with other family members, the community and the broader cultural context. As a result of this complexity the research makes use of a reciprocal causality model instead of a linear causality model in order to describe the family system. When reciprocal causality is present within a system the system relies on feedback-loops in order to monitor and govern functioning (Goldenberg & Goldenberg, 2004).

Feedback processes

Feedback is a process whereby information about past behaviours or output is fed back into the system in a circular manner affecting the input of a system (Becvar & Becvar, 2006). Feedback loops are circular mechanisms that introduce information about a system's output back to its input (Goldenberg & Goldenberg, 2004). This information is used to change, correct and ultimately govern the system's functioning. Feedback can be viewed as either positive or negative depending on the impact of the behaviour on the system and the response of the system to the behaviour. Feedback processes serve to regulate the system by evaluating and

monitoring and by adjusting for stability, fluctuations and new information. Feedback can thus be seen as a system's self-corrective mechanism.

Within a system negative feedback or deviation-correcting feedback provides information about the system's performance and this information is fed back into the system and triggers the changes that are needed to maintain homeostasis. Negative feedback keeps deviation in a system within certain parameters. In contrast, positive feedback or deviation amplifying feedback leads to further change in the system by augmenting or accelerating the initial deviation (Goldenberg & Goldenberg, 2004). Positive feedback-loops are error activated and are regulated through behaviour in the system that seeks to change certain aspects of the system's functioning. Positive feedback resets the system's parameters, rules, structure, values, patterns and norms. This allows more variation within the system and thus increases the system's adaptability. Systems survive by constantly balancing their tendencies towards both stability and change. This results in a dynamic equilibrium between these processes (Becvar & Becvar, 2006).

In the context of understanding mothers' experiences of raising twins when one twin is born with a congenital facial deformity an understanding and awareness of feedback processes is vital. If the birth of a child with a cleft lip and/or palate is understood as new information that needs to be adjusted for and processed by the system, it can be expected that this new information may disturb the delicate balance between the system's tendencies towards stability and towards change. The birth of twins where one is born with a cleft lip and/or palate may in fact push the system into a crisis increasing the threat to its survival, by destabilising many of the formerly stable patterns and processes. This may occur at a time when stability is required. Additionally the system may reduce variety of information allowed into the system,

making the system more rigid at a time when flexibility is required. It is also important to consider that the birth of twins where one is born with a cleft lip and/or plate may or may not resonate with the pre-birth system dynamics such as unstable, unhappy, dysfunctional relationships and roles within the system which may further add to the volatile of the later. This may manifest in the rejection of the baby, the escalation of conflict in the spousal system, environment or disengagement between individuals in the system. The instability in the system may escalate to a point where the system's rules, patterns and values are adjusted or transformed to accommodate new circumstances. Positive feedback facilitates change in a system, change in members, roles, responsibilities and boundaries to ensure the survival and stability of a system. Despite the difficulties and adjustments involved in dealing with a physically challenged child, it has been found that most families do adjust and that parents dealing with these issues have no less stable marriages than those who do not have a child with a similar condition (Barden, 1990).

Morphostasis and morphogenesis

A system's ability to remain stable in the context of change and to change in the context of stability is explained by the concepts of morphostasis and morphogenesis (Becvar & Becvar, 2006). Morphostasis refers to a system's tendency toward stability, which is defined as a state of equilibrium within a context of change that is accomplished through negative feedback (Becvar & Becvar, 2006). In contrast morphogenesis refers to the tendency of a system to move towards growth and development while maintaining stability and functionality. Morphogenesis is accomplished through positive feedback (Haley, 1979). It involves the action taken by the system when the system accepts that there is a problem and adapts itself to the new situation and to finding alternate solutions. Keeney (1983) likened this

process to that of the tightrope walker who makes frequent adjustments to achieve balance on the high wire. Without these constant but barely noticeable changes the acrobat would be unable to maintain stability on the wire and would not be able to perform the pattern of change.

In other words a balance between morphostasis and morphogenesis is necessary for a system to remain functional. This means that the rules of a system will allow for a change in the rules when such a change is in order or required, and will resist a change at times when it is inappropriate or threatens the system. For example, in order to maintain stability, a family must constantly adjust to internal and external changes such as the addition of new members, the developmental changes of its members, diagnosed disabilities of a member, change of job and other environmental changes to remain functional. However, if the same family predominantly emphasises morphostasis over morphogenesis by sticking to outdated rules, or predominantly emphasises morphogenesis by permitting too many or too frequent rule changes, the previously established stable degree of family functioning will be threatened. As explained by Keeney (1983) balance between morphostasis and morphogenesis is therefore vital to a system's functioning. In stressful events this balance protects the family regardless of how open and flexible the system is to new information. This new information is seen to be functional, creating a new balance that ensures the survival of the system.

The researcher is interested in whether these families will be able to maintain balance between morphostasis and morphogenesis and how this is done will be explored in the research.

Functional families are open systems with selectively permeable boundaries, which allow a constant exchange of information to and from the system. All families are regarded as open but vary in the amount of information that they allow into their system. Alexander (1985), explains that a system characterised by a balance between morphostasis and morphogenesis can be said to be more responsive towards input that allows for increased differentiation of functions and roles within the family. An example of such a system would be a relatively closed system when children are young that develops into a more open system when the children reach adolescence.

Patterns rules and boundaries

Patterns are habitual ways of communicating, behaving and relating to one another. Watzlawick, Weakland & Fish (1974) explain that patterns provide stability in interactions, which are characterised by continuous changes over time. This means that patterns are seen as interactional stabilities within a context of continuous change and may therefore be regarded as to be the rules of the system.

The rules according to which a system operates are comprised of the characteristic relationship patterns within the system. The rules within a system express the values of the system and dictate the roles appropriate to the behaviour of that system (Becvar & Becvar, 2006). A system's rules distinguish it from other systems.

Families are governed by rules, which control the boundaries between sub systems such as the spousal system, parental system and the sibling system within the family system and within the environment, thereby determining their interactional patterns. The family is viewed as an interdependent unit. What this means is, that when stress

is applied to one family member, all other members will feel the stress to a different degree.

From this it can be said that rules form the boundaries of a system. Goldenberg and Goldenberg (2004, p. 85), define a boundary as “an invisible line of demarcation that separates an individual, a subsystem, or a system from outside surroundings”. Becvar and Becvar (2006) make it clear that such rules or boundaries are not visible but rather must be inferred from repeated patterns of behaviour. They state further that the concept of boundary also implies the notion of a hierarchy of systems. What this means is that any system exists as part of a larger system, therefore the family is one system but within the family exist smaller subsystems such as the sibling and parental subsystems. Boundaries mark the shape of the family system and its subsystems. In terms of families, three subsystems have been identified, namely the spousal (or couple), parental and sibling subsystems, each with its respective boundaries and rules (Minuchin, 1974; Minuchin & Fishman, 1981).

The development of the marital or spousal subsystem is partly the product of what the individual partners bring to the relationship including their family of origin's beliefs, patterns and rules which have been carried forward and general life experiences. This development implies that both individuals accommodate and negotiate their roles in creating a partnership with each other. The parental and sibling subsystems develop with the birth of the couple's first child, as set out in the family life cycle, stage 3 (Carter & McGoldrick, 1995). The parental subsystem requires renewed accommodation, negotiation and role allocation between the partners, accessibility of both parents to the children, nurturance of the children, use of authority, guidance and control in raising the children, as well as accommodation and negotiation of the developmental stages of the children, parents and family. The

sibling subsystem is regarded as the place where children learn to co-operate, negotiate and compete. This subsystem is vital to the development of children and should be protected from over-involvement by the parental subsystem (Becvar & Becvar, 2006).

Boundaries between systems and subsystems, and between systems and their external environment, differ in nature, can be evaluated in terms of their relative permeability and are described as either rigid, clear or diffuse (Becvar & Becvar, 2006).

Rigidity or rigid boundaries refer to an arrangement between sub-systems and imply disengagement within and between the sub-systems (Becvar & Becvar, 2006). In such families the members are isolated from one another and from the systems in the community. Such segregation, when carried to the extreme may be dysfunctional. Transactions between the parents/caregivers and children are restricted and neither system can respond to each other's needs. Members in such families turn to systems outside the family for their support and nurturance (Becvar & Becvar, 2006). Rigid boundaries imply disengagement between and within systems. This means that family members are isolated from one another, subsystems within the family are rigidly segregated and the family system as a whole is isolated from other systems, such as the extended family or society (Becvar & Becvar, 2006). In families where rigid boundaries and disengagement are problematic, access and interaction across subsystems and between the system and the environment are severely restricted and the family system lacks cohesion and adaptability (Minuchin, 1974). In these families, family support and unity often only occur in the face of an extreme crisis.

Clear boundaries are the ideal as they are firm, yet permeable. This permeability implies appropriate access across subsystems and systems and allows for the negotiation of developmental, expected and unexpected changes in the family system (Becvar & Becvar, 2006). This also implies an appropriate balance between mutual nurturance, support, taking of responsibility and making allowances for an appropriate amount of autonomy amongst system members and subsystems. This allows for the protection of the system and subsystems, as these boundaries move toward rigidity and decreased permeability in times of internal or external crises, but relax when the threat has passed, ensuring, once again, appropriate openness and movement of members and information across subsystems and between the system and the environment (Minuchin, 1974).

Diffuse boundaries can be regarded as the opposite of rigid boundaries in many ways. Enmeshed relationships are characteristic of diffuse boundaries. Also, in contrast to rigid boundaries where autonomy is prominent, systems with diffuse boundaries are characterised by over-involvement, with all members constantly involved in one another's business (Becvar & Becvar, 2006). Consequently, within these systems there is a loss of autonomy, limited differentiation and inappropriate dependence, which makes the system vulnerable to both external influences and internal tension (Minuchin, 1974).

The extent to which a system permits and prevents the input of new information determines the system's openness or closedness. Dallos & Draper (2008) explain that an open system is one with boundaries that allow a continuous flow of information to and from the outside world, while a closed system is one with more rigid boundaries that are not easily permeable. The openness of living systems

refers to the fact that they are in continual interaction with their environment. Becvar and Becvar (2006) explain that an appropriate balance between openness and closedness is required for system survival. Such a balance would imply boundary flexibility to enable the system to move on a continuum from more closed to more open, depending on the context. If the system is too open, or if the input into the system is too different from the system's values, this may threaten the identity and also the survival of the system. In the same way when input is denied at a time when it is necessary, or when there is too little input into the system, the identity and survival of the system may also be threatened.

In the context of this study, the birth of twins, and specifically the birth of a child with a congenital facial deformity such as a cleft lip and/or palate can be understood as information entering the family system and all systems related to and in interaction with this system. In this regard, this unique stressor, the birth of a child with a cleft lip and/or palate may bring previously unknown or unconsidered information about the family system and the subsystems within the said system. The news and discovery that a child has a congenital facial deformity such as a cleft lip and/or plate is likely to represent information that is in conflict with the mother's and the family's worldview. For example, the parents and family may have held a worldview that negative events only happen to bad people and the birth of a child with a congenital deformity may be seen as a form of punishment. This difference in information represented by birth of a child with a congenital facial deformity such as a cleft lip and/or palate, compared to the system's norms, values and worldview, may threaten the family system's identity and survival.

From a systemic perspective, the researcher is concerned with the impact of this information on the mothers and their families and with how they deal with this

information and accompanying threat to their systems' survival. In this regard the concepts of closedness and openness are important. The mothers and the subsystems within their families may respond to the birth of a child with a congenital facial deformity such as a cleft lip and/or palate, and the information it brings into their system, by predominantly maintaining closed boundaries. For example these families may keep the birth of their child a secret from anyone outside of the nuclear family, socially isolating themselves, or they may refuse to seek professional help when it is needed. This may limit the possible sources of support, such as family, friends and professional care that is needed for these families and specifically for these children. Closed boundaries limit the influx of potentially new and helpful information into the system at a time when it is needed. Alternatively, these families may also move towards the other extreme side of the openness-closedness continuum, by being too open and allowing too much information into the system. For example these families may allow over-involvement of other individuals and systems. Too much information and too many people becoming involved in the family system may add to or maintain, rather than reduce, the instability and chaos initially experienced by the family and subsystems within the family system, following the birth of a child with a congenital facial deformity such as a cleft lip and/or palate.

Relationship patterns

Becvar and Becvar (2006) stated that two individuals relating to each other are not independent, but are mutually influencing one another. These relationships are characterised by redundant patterns of interaction. One of the fundamental tenets of systems theory is that the whole is greater than the sum of its parts. In the context of redundant patterns of interactions this means that the interaction provides the context

of the relationship between the two individuals (Becvar & Becvar, 2006). As the size of the family increases so too does the complexity of the system.

In family systems theory three styles or patterns of interaction are typically found in relationships (Becvar & Becvar, 2006). These interactions can be observed by taking the entire system into account as well as the context within which the behaviour occurs.

In complementary relationships the interactional style between partners is characterised by an exchange of high frequencies of opposite kinds of behaviours. Examples could include dominance and submission, closeness and distance, cruelty and kindness and aggressiveness and passivity. If the relationship is regarded as flexible, then partners can alternate between one-up and one-down positions and the partners will exchange different types of behaviour. When the relationship is rigid the partners remain in their respective positions.

In symmetrical relationships the interactional pattern between partners is characterised by high frequencies of similar kinds of behaviours. Examples could include both partners displaying withdrawal, criticism, initiation or advice offering. This type of relationship is seen as competitive as the two people involved in the relationship emphasise their symmetry with one another.

The parallel relationship involves a combination of the above two patterns. In this kind of relationship both complementary and symmetrical behaviours are exchanged. The roles, positions and communications of this type of relationship are characterised by flexibility and variety. Partners alternate between one-up and one-down positions, depending on system's requirements. Partners are able to respond with complementary behaviours by alternating between giving advice and receiving

advice. Symmetrical behaviours also occur, such as where one partner's attempts for more closeness are followed by even more closeness from the other partner. For example, the researcher would expect following the news that a child has a congenital facial deformity such as a cleft lip and/or palate, mothers would require more support and understanding from their spouses and communication of this need would allow spouses to provide more support and understanding during this time.

The need to define the relationship is a normal, ongoing and mostly implicit part of any relationship. Issues of power and control form part of the relationship definition. This could involve deciding who is responsible for generating an income and running the household and also involves assigning care-giving roles such as disciplining the children. Negotiations within this process often include the distribution of power and control within the relationship (Haley, 1963). The process of defining a relationship is continuous and therefore every interaction and behaviour is regarded as either a confirmation of the definition or a request for a different definition. Haley (1963) coined the term 'manoeuvres' to describe this interaction, which consists of requests, commands or suggestions that the partner do, say, think or feel something, or alternatively consists of comments concerning the other person's communicative behaviour.

Within the context of this study it is assumed that prior to the birth of their twins the couples in this study already had varying degrees of settled or unsettled relationship definitions and patterns and varying degrees of flexibility in terms of these relationship definitions and patterns. The birth of a child with a congenital facial deformity is likely to have had a significant impact on their relationship and the habitual behaviours of partners.

Communication and information processing

According to Becvar and Becvar (2006) communication and information processing are central to systemic thinking. Three basic principles form the foundation of these concepts:

- Principle 1: One cannot not behave.
- Principle 2: One cannot not communicate.
- Principle 3: The meaning of a given behaviour is not the true meaning of the behaviour. However, it is the personal truth for the person who has given it a particular meaning.

The first principle states that it is impossible to do nothing. In other words, even supposedly not acting involves an act. The second principle is linked to the first and suggests that "...all behaviour in the context of others has message value..." (Becvar & Becvar, 2006, p. 70). This means that while communication at the verbal level may be absent or unsatisfactory non-verbal communication still occurs and gives meaning to behaviour even when that behaviour is silence (Bateson, 1979). The third principle refers to the fact that all messages or communications may be interpreted in various ways and emphasises that no particular interpretation is more correct than any other interpretation. All interpretations are influenced by the assumptions made by the interpreter and are personal truths for that individual. It is possible that parents and family members may have different interpretations regarding the cleft lip and/or palate.

Communication is a vital aspect of systems and essential for effective family functioning. Communication also defines the nature of relationships within a system.

Becvar and Becvar (2006) explain that according to system theory three modes of communication have been identified:

- verbal or digital
- non-verbal
- context

The verbal or digital mode refers to the spoken word or report aspect of a message and this aspect is regarded as the least significant in defining how a message will be understood. The non-verbal mode, which is also referred to as the command aspect of a message, includes tone of voice, facial expressions, gestures and inflection. It tells a person how a message is to be understood. This mode can also be referred to as the relationship-defining mode of communication, as it defines the intent of the person who sends the message and his view of the relationship. The context includes aspects such as other people, the place where and time when the communication takes place. It further defines or modifies the meaning of the message (the non-verbal mode) and also defines how the people in the context are to relate to one another and how they interpret one another's communication.

Related to the discussion above are the content and process levels of communication. The content level refers to the verbal information portion of a message, while the process level refers to the combination of the non-verbal and context information of a message. Congruency is achieved when these two levels match and it means that the communication each person is sending and receiving is clear and understood. When these two levels do not match, the communication is described as incongruent and the person receiving the communication is faced with two conflicting messages (Becvar & Becvar, 2006). Although the verbal or digital

mode is the spoken aspect of the communication process, it is only a part of the total message and is the least powerful in determining how the recipient receives and interprets the message. For example a wife tells her husband to “leave me alone”, while the process or non-verbal level of the message communicates something different such as “I need you to comfort me” which is displayed by her crying. The person receiving the message is placed in a difficult position, and has to choose which message to respond to.

Functional families are open systems with selectively permeable boundaries that allow a constant exchange of information to and from the system. Open communication within the system is vital. This study focused on the communication patterns of the couple and within the family as a whole. It was expected that misinterpretations, incongruent communications and double binds would occur and that these would contribute to distance, disengagement, rigid boundaries and isolation between partners and family members.

Triangulation

Early research into communication and interactional patterns focused exclusively on dyadic or two-person exchanges (Hoffman, 1981). However, research focus soon shifted to triads or three-person exchanges (Becvar & Becvar, 2006). Bowen (1985) found that dyads often tend to incorporate a third person into the system in order to alleviate tension between the original pair. However, the inclusion of a third person may cause further tension within the system and further complicates the difficulties already present amongst the original pair (Bowen, 1985). Hoffman (1981) noted that the triangulation of a third person often causes a rippling effect within the system and activates other triangles that are linked and reactive to one another. Severe stress

such as the birth of a child with a congenital facial deformity such as a cleft lip and/or palate may destabilise the spousal dyad to such an extent that another party, such as a family member or a friend may be triangulated into the spousal dyad to diffuse or redirect attention away from the dyad.

The literature reports contrasting findings with regards to the effect of the birth of a child with a disability on the spouse sub-system. Research by Van Staden and Gehardt (1994) found that some parents experienced a strengthening of their relationship due to an increase in maturity, honesty, emotional sharing and support. In contrast a study by Pelchat, Bisson, Ricard, Perreault and Bouchard (1999) found that parents of children with some form of deformity or disability are likely to develop problems communicating and relating to one another. This may be a result of the renegotiation of time, energy, finances and career responsibilities that must occur in order to care for the child (Barden, 1990). The researcher was curious about the impact of the birth of a child with a congenital facial deformity such as a cleft lip and/or palate on the spousal relationships.

Change and homeostasis

According to Keeney (1984) systems are organised through a process of change. Healthy individuals respond to changing situations with a set of diverse behaviours and emotions. They may shift between love, guilt, despair and hope in order to maintain some balance in the changing process. For Minuchin and Fishman (1981) the family is not a static entity, instead they see the family in a process of continuous change, as are its social contexts. They explain that the family is constantly subjected to demands for change, coming from within and without the family. They see families as living systems, which exchanges information and energy with the

outside. Fluctuation within the family system, either internal or external, is normally followed by a reaction or a response that returns the system to its previous more stable state. Alternatively, when the fluctuation amplifies, the family may enter a crisis in which transformation results in a different level of functioning that may also make coping possible (Minuchin & Fishman 1981). This view of the family as a living system suggests that the family will undergo periods of disequilibrium and periods of homeostasis and that the fluctuation within the system remains within a manageable range. As mentioned earlier in this chapter research by Van Staden and Gerhardt (1994) concluded that parents of children with cleft lips and/or palates are able to make adjustments and live with the reality of their child's disability.

Conclusion

The family is seen as the most appropriate unit of analysis for understanding the manifestation and meaning of childhood deformities as co-constructed between individuals and families (Allen & Vessey, 2004). Family systems theory stresses the interdependence of action within families and other relationships. Each member in the system influences and is influenced by the other system members (Dallos & Draper, 2008). All actions are therefore also seen as responses and all responses are also seen as actions.

In order to understand the effects of the birth of twins on a family system (particularly the effect on the mother) when one twin is born with a congenital facial deformity on the family system it is vital to have an understanding of the systems in which the individuals and family function. How a family adjusts to the stress and the challenges involved in raising a child with a facial deformity has an effect on all the individual members. The literature suggests that during the first few months following the birth

of a child with a facial deformity parents require high levels of support in order to help them adjust and work through their loss (Pelchat et al., 1999). Support from within the family system and support from external systems appear to assist in adjustment. This support can take the form of friends and family or doctors and nurses from the hospital (Barden, 1990). Pelchat et al., (1999) found that parents who manage to effectively adapt to their situation over time have a more positive influence on their child's development.

As discussed in this chapter, it is clear systemic thinking lends itself well to the analysis of the dynamics, behaviours and interactions of mothers within their family systems and the subsystems that form part of those said systems, within the context of congenital facial deformity. The application of a systemic perspective provides the researcher with a broader view and understanding of the mothers' experiences of raising twins where one twin is born with a congenital facial deformity such as a cleft lip and or palate. A systemic perspective allows the researcher to acknowledge and consider the pre-existing patterns, processes, rules, histories and meanings of the mothers within their contexts of living. This allows the researcher to place the mothers' experiences of raising twins when one twin is born with a cleft lip and/or palate within their larger relational context.

Furthermore, by taking a systemic perspective, and focusing on the dynamics and meanings in these systems, this allows the researcher to move away from content issues and linear explanations regarding raising twins where one is born with a cleft lip and/or palate.

In the next chapter, the research design and method for this study will be discussed, which will highlight and inform the reader of the manner in which the study will be approached and how the information collected from the participants will be analysed.

Chapter 3

Research Design and Method

Not everything that can be counted counts, and

not everything that counts can be counted.

Albert Einstein 1879 - 1955

Introduction

This chapter provides a description of the research process followed in order to access the information for this study. All research projects are guided by a basic set of beliefs and assumptions that inform the researcher's thinking and practice. A description of the research design is vital as it positions the research within the theoretical model on which it was based.

This chapter begins with an explanation of the research methodology and a description of the research question. The research design that was used as a framework is then described through focusing on central terms such as postmodernism, social constructionism and qualitative research. This chapter also contains information regarding the choice of and motivation for selecting a qualitative research method and the implications of this choice of methodology. The final section of the chapter discusses the data collection and data analysis methods used to address the research question.

In order to ensure that the research process proceeds in a meaningful and productive manner it is essential that a series of steps is followed. The research process begins with selection of a topic or area of study (Neuman, 2000). If the choice of topic is too broad the researcher will not be able to conduct meaningful research. Topics must therefore be limited to the scope of a specific research question. For this study the specific research question was:

What are the experiences of mothers raising twins when one twin is born with a congenital facial deformity such as a cleft lip and/or palate?

This topic was chosen as a result of the researcher's own personal experience of being a twin and in meeting and dealing with mothers with children with a cleft lip and/or palate at the Pretoria Cleft Palate and Facial Deformities Clinic at the Oral and Dental Hospital. The researcher was struck by the challenges these mothers were facing in caring for a child with a cleft lip and/or palate. This personal experience led to curiosity regarding mothers' experiences of raising twins when one twin is born with a congenital facial deformity. In addition, as discussed in chapter 2 this research topic addresses an area that has received very little research attention, particularly within the South African context.

Research Method

Terre Blanche and Durrheim (2006) stated that "methodology specifies how researchers may go about practically studying whatever they believe can be known" (p. 6). Creswell (2003) stated that the selection of the research method is a critically important decision because it provides the researcher the opportunity to critically consider how each of the various approaches may contribute to, or limit, the study. Methodology is a core component of a researcher's paradigmatic stance and refers

to the lens through which he or she views the world (Terre Blanche & Durrheim, 2006). The research method also provides information regarding the relationship between the researcher and that which is being researched. The present study made use of a qualitative research paradigm. The reasons for this choice are discussed in the section below. The section also contains information regarding the contributions of the postmodern and social constructionist approaches.

The Research Design

The research design sets out the purpose of the research, the theoretical paradigm informing the research, the context or situation within which the research is conducted and the research techniques employed to collect and analyse data (Terre Blanche & Durrheim, 2006). According to Denzin and Lincoln (2000) the research design can be seen as situating the investigator in the world of experience. For the purposes of this research a qualitative research paradigm was used. Qualitative research designs tend to be more open, fluid and changeable than quantitative research designs (Terre Blanche & Durrheim, 2006).

Denzin and Lincoln (2000) listed several fundamental aspects of a research design:

- How the design will be linked with the chosen theoretical perspective or paradigmatic stance.
- What the focus of inquiry will be.
- How the inquiry will be conducted.
- The research methods that will be used for collecting and analysing the information obtained from the inquiry.

The chosen paradigmatic approach

A paradigm refers to a set of presuppositions about what the world is like, what problems are worthy of investigation and which methods are appropriate for the investigation of these problems (Kuhn, 1962, cited in Becvar & Becvar, 2006). Terre Blanche and Durrheim (2006) stated that “paradigms are all-encompassing systems of interrelated practice and thinking that define for researchers the nature of their enquiry along three dimensions: ontology, epistemology, and methodology” (p. 6).

Ontology refers to “the nature of reality that is to be studied, and what can be known about it” whilst epistemology refers to “the nature of the relationship between the researcher (knower) and what can be known” (Terre Blanche & Durrheim, 2006, p. 6). Epistemology therefore refers to the set of rules pertaining to the nature of knowledge or reality underpinning any research study. These principles influence the way in which the researcher sees and acts in the world and collectively form a paradigm or interpretive framework (Denzin & Lincoln, 2000).

Terre Blanche and Durrheim (2006) identified three specific paradigms, namely positivist, interpretive and constructionist paradigms.

Positivist research and postmodernism

The positivist approach is based on the assumption that through the use of appropriate, well-established methods the researcher can obtain knowledge concerning the world and its workings. Researchers working within this paradigm usually prefer quantitative research methods that correlate with a modernistic epistemological viewpoint.

According to the literature reviewed research on twins has traditionally been oriented towards the study of genetics. The exceptional 'experimental device' of twins has been used to study the respective roles of heredity and environment in the development of many physical, somatic, cognitive, psychiatric and personality-related traits. The literature concerning individuals with congenital facial deformities, specifically cleft lips and/or palates, is also largely quantitative and positivistic in nature. Quantitative studies are usually designed to gain information that can be generalised to all people in similar contexts. It often ignores personal stories and experiences and was therefore not considered suitable for this research topic.

Qualitative research is often linked to postmodernism, which is a term that refers to many different approaches that oppose the coherence and rationality of the modern world (Terre Blanche & Durrheim, 2006). Postmodern approaches reject the notion of a universal and objective truth or knowledge and contend that the world is not controllable, that there is no cause and effect and that there is also no certainty (Lynch, 1997). These approaches avoid providing an ultimate singular explanation or interpretation of the world and instead allow for alternative accounts and descriptions.

Postmodern approaches also involve a movement away from the study of the intrapsychic self towards the study of the person in a network of social relations or a relational self (Kvale, 1992). The self is no longer considered as an isolated or autonomous human being with fixed characteristics, but instead is seen as a participant in multiple relationships and as varying between contexts. In addition, the approaches view the 'self' and the 'problems' as expressed through language and having meaning only within a specific relational context (Becvar & Becvar, 2006). Postmodernism thus acknowledges that people and 'problems' are embedded in a

particular historical and cultural context. Postmodern research thus focuses on the interrelatedness between the individuals and the context as well as on the social and linguistic manner in which people co-construct their realities.

The interpretive approach

This approach holds that reality consists of people's subjective perceptions of the world. Interpretative research approaches thus attempt to understand, describe and interpret people's feelings (Kelly, 1999). These approaches believe that it is not possible to "apprehend human experience without understanding the social, linguistic and historical features which give it shape" Kelly (1999, p. 398). Thus, individuals' experiences must always be understood within their historical and cultural contexts. Individuals cannot be considered in isolation. This focus on context is also a crucial part of social constructionist theory. Social constructionism is consistent with interpretative methods and argues that people's thoughts, feelings and experiences are the products of systems of meanings that exist at a societal level rather than an individual level (Terre Blanche & Durrheim, 2006).

A social constructionist perspective

Becvar and Becvar (2006) defined epistemology as "how we know what we know or how we make valid knowledge claims based on a particular theoretical framework" (p. xiv). The epistemological approach used to guide this research was thus influenced by the researcher's personal belief system and the lens through which she sees the world. Bias is therefore inevitable and the researcher recognises that the manner in which she sees things and analyses information is only one possible worldview. The researcher's choice of a social constructionist epistemology allowed her to explore the meanings and discourses around mothers' experiences of raising

twins when one twin is born with a congenital facial deformity such as a cleft lip and/or palate.

Social constructionism holds that human experience, including perception, is mediated historically, culturally and linguistically. Therefore, perceptions and experiences are never direct reflections of the environmental conditions but are rather a specific reading of those conditions (Willig, 2008). Individuals construct concepts, models and schemes to make sense of experiences. These constructions are continually tested and modified in the light of new experiences (Schwandt, 2000). Individual meaning is constructed based on shared norms, values and experience (Furman, Jackson, Downey, & Shears, 2003). The researcher wants to elicit those meanings and experiences in order to understand the impact of a congenital facial deformity on mothers' experiences of raising twins, where one twin has the deformity and the other not.

Social constructionist epistemology suggests that we socially construct reality through our use of shared and agreed meanings communicated via language. From this viewpoint beliefs about the world are seen as social inventions. This focus on language as the shaper of belief links social constructionism to various other postmodern approaches (Rapmund, 2000). Social constructionism views the human life-world as fundamentally constituted in language and is concerned with the broader patterns of social meaning encoded in language (Terre Blanche, Durrheim, & Painter, 2006). In the context of this research this means that the literature review was constructed by the researcher and thus represents one particular reading of the literature concerning the experiences of mothers raising twins when one twin is born with a congenital facial deformity rather than an absolute truth concerning the topic.

“For the social constructionist, language is not a reporting device for our experience, or representationalism. Rather, it is a defining framework.” (Becvar & Becvar, 2006, p. 91). From a social constructionist point of view language concerns itself with how people express their experiences and create meaning from their experiences. Through language multiple realities are created and become possible. Language allows people to tell their stories and through this story-telling people make sense of the world. Reality is thus co-created in a social context (Becvar & Becvar, 2006). In the context of this research this means that the reality of the participants’ experiences will be co-created in the context of them sharing their stories with the researcher. Through sharing their stories the participants will be able to construct a new reality where they could try to make sense of their experiences. The development of a new narrative creates a common general language through which the experience is shared.

Quantitative and Qualitative Approaches

Quantitative and qualitative approaches represent two distinct methodological stances within the social sciences. The two approaches differ markedly in terms of their methodology, choice of data and research tools used.

The quantitative approach is based on research in the physical sciences and makes use of structured methods in such a way so as to guarantee, as far as possible, objectivity, generalizability and reliability (Creswell, 2003). The researcher is viewed as external to the research and results must be replicable. In contrast, the qualitative research approach is concerned with meaning and focuses on the quality and texture of the experience rather than on the identification of cause-effect relationships (Willig, 2008).

Qualitative research designs tend to be more open, fluid, and changeable than their quantitative counterparts (Terre Blanche & Durrheim, 2006). These research designs are also not defined in purely technical terms. Instead research is viewed as an iterative process that requires a flexible, non-sequential approach.

The choice of a qualitative or quantitative research method impacts of the research process. This study made use of a qualitative research method. The choice of methodology was considered appropriate based on the formulated research question:

What are the experiences of mothers raising twins when one twin is born with a congenital facial deformity such as a cleft lip and/or palate?

The choice of a qualitative research methodology was also in keeping with the social constructionist postmodern epistemology used in the research. A quantitative research methodology would not have allowed for the in-dept analysis of the mothers' experiences.

Qualitative research

In its broadest sense the qualitative research paradigm involves research that elicits participants' accounts of meaning, experience or perceptions. Descriptive data is produced through the participants' own written or spoken words. Qualitative research thus involves identifying the participants' beliefs and values underlying the phenomena (De Vos, 1998). Qualitative research's concern with meaning (Willig, 2008) made it the logical choice of methodology for the study of the subjective experiences of mothers' raising twins when one twin is born with a congenital facial deformity. The research topic aimed to explore the lived experience of the

participants and the in-depth analysis offered by a qualitative methodology was in keeping with this aim.

Qualitative research is often linked to the postmodern and social constructionist worldviews. Qualitative research focuses on the description and analysis of the ways in which social relationships are constructed. Social relationships are therefore seen as vital resources for observing and making sense of lived experience. In the context of this study it was important to view the participants in relation to their social and cultural environments.

Qualitative research is interested in documenting people's personal accounts (Neuman, 1997). The qualitative research design was thus chosen because it supported the theoretical framework of the study and allowed the researcher to interact openly with the participants. Within qualitative research the researcher is seen as playing a vital role in the research process. During the research process the researcher and the participants mutually influence each other and the research process. Through this process new meanings are created. Qualitative methods allow for the in-depth study of issues as they focus on details and attempt to identify and understand the categories of information that emerge from the data (Terre Blanche & Durrheim, 2006). In this way the researcher is seen as an integral part of the research and can never be neutral or objective (Becvar & Becvar, 2006). This means that the researcher's own social and cultural contexts are influential in her interpretation of the data. The researcher acknowledges that her interpretation and findings are inevitably subjective and personal. It therefore follows that the themes she identifies will be coloured by her personal perspective or lens and these themes may not necessarily represent the absolute truth about the realities of the participants. Additional themes could be identified from the participants' stories and

the researcher acknowledges that the reader or other researchers may interpret and understand the participants' stories and experiences very differently. However, in keeping with her ontology and epistemology, the researcher regards these possible alternative understandings and additional themes as part of the ongoing process in the context of this research. More importantly, by making known the lens through which she looks at and understands the world, the researcher attempted to create a context for the participants' stories that allows the richness of their accounts to emerge.

As was mentioned previously this research is grounded within a qualitative framework. The research focus is experiential and focuses on the participants' own lived experiences. In keeping with the principles of qualitative research the researcher is not regarded as an expert in the subject but rather as a subjective participant who plays a specific role in terms of co-constructing meaning (Rapmund, 2000). In keeping with this worldview the participants are also regarded as co-researchers.

According to Kvale (1992, p.44) "knowledge is neither inside a person nor outside the world, but exists in the relationship between person and world". This statement reflects the social constructionist view that ideas, concepts and memories arising from social interchange are mediated through language (McNamee & Gergen, 1992). All knowledge thus evolves in the space between people (McNamee & Gergen, 1992) and is created between people through their interaction and language. The theoretical framework for this study acknowledges and incorporates the subjective nature of reality and argues that our worlds are seen as multiverses

that we co-create and reconstruct through observation (Terre Blanche & Durrheim, 2006).

The holistic quality

The use of a qualitative research design allows the researcher to appreciate the holistic quality of the research (Denzin & Lincoln, 2000). This means that the researcher considers and is sensitive to the bigger picture, which includes the contexts of all people, behaviour and experiences. Thus each participant's experiences of being the mother of a twin with a congenital facial deformity will be acknowledged and taken into account when analysing the information. In addition, the influence of the broader societal and familial context will also be acknowledged.

Understanding as opposed to making predictions

In postmodern research the researcher is regarded not as an objective neutral observer but rather as influencing and being influenced by the research. The conclusions that are reached will be based on a reality that is co-created by the researcher and the participants. The participants are thus regarded as co-researchers and not just as subjects. Postmodernism emphasizes multiple realities and meanings and rejects the idea of a universal 'expert', singular and objective knowledge. The 'voice' of the participant is therefore not drowned out by the expert voice but is rather seen as important in its own right.

Qualitative research also allows the researcher to focus on the process rather than on outcomes. This focus allows for the emergence of meaning and patterns in the research context. Qualitative research understands that meanings are highly variable across contexts. Qualitative research results are thus not intended to be

generalisable to some larger theoretical population but rather for transferability. Transferability is achieved through the production of rich, detailed descriptions of contexts (Howitt & Cramer, 2008). These descriptions provide an account of the meanings developed in a specific research context and thus allow the reader to make a decision regarding the transferability of the research findings to similar contexts.

The role of the researcher

In qualitative research the researcher expands on the data in order to provide 'thick' descriptions and multiple layered interpretations of the information received from the participants. The researcher is thus seen as the primary instrument for both collecting and analysing data. As mentioned previously, the qualitative researcher is not seen as neutral but as a co-participant in the research context. This means that the researcher is influenced by her own context, such as her social and cultural context in her interpretation of the data. The research report should also include a description of the researcher's own biases and ideological preferences (Graham cited in Denzin & Lincoln, 2000) as qualitative researchers often draw on their own experience as a resource during the research. Qualitative researchers should acknowledge that their findings may be influenced by their own accounts of reality. In the context of this research it is possible that the findings were influenced by the researcher's own particular worldview and by her use of a social constructionist epistemology.

Qualitative research allows the researcher to engage in open-ended, inductive exploration. Qualitative research methods describe and interpret people's feelings and experiences in human terms rather than through quantifications and

measurement. This view of research is in keeping with the interpretive paradigm, which focuses on harnessing and extending the power of ordinary language and expression to better understand the lived world (Terre Blanche & Durrheim, 2006).

The choice of a qualitative research design for study was also influenced by the link between qualitative methodology and the systems approach discussed in the previous chapter. According to Andreozzi (1985) it is important that data analysis procedures match the conceptual reality of both family and systems therapy. This link was identified when a call for new research methodologies, consistent with system's theory used in family therapy was made (Andreozzi, 1985; Keeny & Morris, 1985). According to Steiner (1985) qualitative research methods tend to be more effective than quantitative research methods when tackling the complexity of systems theory. Qualitative research focus on the social context, multiple perspectives, complexity, individual difference, circular causality, recursion and holism which is in keeping with many of the basic principles of systems theory. Qualitative research thus provides a systematic and scientific way of understanding a family holistically.

The focus of inquiry

Participants

The selection of research participants is usually based on a number of factors.

These factors include:

- The participant has personal experience of the topic being researched;
- The participant is able to provide rich descriptions of their experiences;

- The participant is able to articulate their experiences and is willing to give a complete and sensitive account (Wilson & Hutchison, 1991).

The participants in this study were all recruited through the Pretoria Cleft Palate and Facial Deformity Clinic, the largest in Southern Africa with more than 3174 patients.

The participants were all mothers who are raising twins where one twin was born with a congenital facial deformity such as a cleft lip and/or palate. To facilitate in-depth analysis a small number of participants was selected through a process called theoretical sampling (Strauss & Corbin, 1990). The participants were selected based on their ability to provide unique and in-depth views and experiences and be rich sources of information.

Sample size

Qualitative research does not specify a particular sample size and even single person populations (i.e. case studies) are acceptable. Qualitative research findings are based on the interpretations and the meaning that each individual attaches to the concept being studied and the fact that different people can have different meanings in a single situation is accepted (Rosnow & Rosenthal, 1996). In this context of this research a sample size of three was deemed adequate. The three participants were all mothers of twins, where one twin was born with a congenital facial deformity.

The means of inquiry

Data collection

The primary source of data is the participants' own written stories concerning raising twins where one twin was born with a congenital facial deformity. This method of data collection was chosen in order to minimise the researcher's influence on the

participants' initial stories. Thereafter unstructured interviews were conducted to clarify any uncertainties the researcher experienced regarding the participants' written stories. Written consent to participate in the study and for personal data to be used in the study was requested and obtained. The data collection was conducted through the use of a social constructionist approach where the research participants and the researcher are seen as partners in the co-construction of meaning. The researcher then re-constructed the participants' stories in the form of identified themes. These themes are based on the researcher's own understanding of the experience.

Analysing the information

Analysis of information involves imposing order, structure and meaning on the mass of information that is collected during a qualitative research study. Analysis is the process of bringing order to the data obtained during the study and then organising this ordered data into patterns, categories and basic descriptive units (Patton, 1990).

This research focused on mothers' experiences and descriptions of raising twins when one twin was born with a congenital facial deformity. The participants' stories provided an overview of their life stories starting with the birth of the twins and proceeding to the discovery that one twin has a cleft lip/palate, the reactions of others to their baby's deformity and their road to recovery.

Thematic analysis

Thematic analysis is a method for identifying, analysing and reporting patterns or themes within data (Braun & Clarke, 2006). Thematic analysis is widely used in qualitative research, but there is no clear agreement concerning what thematic

analysis is or how it is conducted. The method can be essentialist or realist method, focusing on reporting experiences, meanings and the reality of participants, or it can be constructionist, focusing on examining the ways in which events, realities, meanings and experiences are the effects of a range of discourses operating within society (Braun & Clarke, 2006).

Braun and Clarke's (2006) step-by-step guide for conducting thematic analysis guided the thematic analysis in this research. The approach is discussed below.

Phase 1 - Familiarization with the data: Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.

The first phase involves the researcher immersing him or herself in the data. The researcher needs to become familiar with the depth and breadth of the content. Immersion usually involves repeated active reading of the data in order to identify meanings and patterns. During this phase the researcher should start taking notes or marking ideas for coding in subsequent phases (Braun & Clarke, 2006). Once this phase is complete the formal coding process can begin. However, it should be noted that coding continues to be developed and defined throughout the entire analysis (Braun & Clarke, 2006).

Phase 2 - Generating initial codes: Coding interesting features of the data in a systematic fashion across the entire data set; collating data relevant to each code.

The second phase begins when the researcher has read and familiarized him or herself with the data and has generated an initial list of ideas about the content and areas of interest within the data (Braun & Clarke, 2006). This phase involves the production of initial codes from the data. According to Boyatzis (cited in Braun &

Clarke, 2006) these codes should identify a feature of the data (semantic or latent content) that appears interesting to the analyst. These codes represent the most basic analysable segments of the raw data. These segments of coded data differ from the units of analysis (themes) that are developed in the next phase, which are often broader in scope. The development of themes in the next stage involves an interpretative analysis of the data in relation to the specific phenomena under investigation. Coding also depends to a certain extent of whether the themes are more 'data-driven' or 'theory-driven' (Boyatzis cited in Braun & Clarke, 2006)

Phase 3 - Searching for themes: Collating codes into potential themes, gathering all data relevant to each potential theme

The third phase begins once all the data has been initially coded and collated and the researcher has generated a list of the different codes that he/she has identified across the data set. During this phase the researcher re-focuses the analysis at the broader level of themes, rather than at the narrow level of codes. This involves sorting the different codes into potential themes and collating all the relevant coded data extracts within the identified themes. During this process the researcher starts to analyse his/her codes and consider how different codes may combine to form an overarching theme. The researcher then starts thinking about the relationships between codes, between themes and between different levels of themes. As a result of this process tentative main overarching themes and sub-themes within them are identified. This phase ends with a collection of these candidate themes and sub-themes (Braun & Clarke, 2006). The researcher must also ensure that all the extracts of data have been coded in relation to these themes.

Phase 4 - Reviewing themes: Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.

The fourth phase begins once the researcher has devised a set of candidate themes and involves the refinement of those themes.

This phase involves reviewing and refining the themes on two levels. The first level reviewing considers the themes at the level of the coded data extracts. All the collated extracts are examined in terms of their relationship to each theme with the aim of determining whether or not they form a coherent pattern. If the researcher's identified candidate themes do appear to form a coherent pattern the researcher then moves on to the second level of this phase. However, if any of the candidate themes do not fit the researcher must determine whether the theme itself is problematic or whether the data extracts are simply not a good match for that theme. Based on this determination the researcher will have to rework or discard the theme (Braun & Clarke, 2006).

The second review level involves a similar process in relation to the entire data set. The researcher considers the validity of individual themes in relation to the entire data set and determines whether or not the candidate thematic map 'accurately' reflects the meanings evident in the data set as a whole. Coding is viewed as an ongoing process and therefore during this phase the researcher needs to re-read the entire data set in order to ensure that the themes are appropriate for the data set and to code any additional data that was missed in earlier coding stages. Once the thematic map is satisfactory the next phase in the thematic analysis can begin (Braun & Clarke, 2006).

Phase 5 - Defining and naming themes: Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.

During this phase the researcher defines and further refines the themes he or she will present in the analysis (Braun & Clark, 2006). This phase also involves the analysis of data within each theme. Researchers need to identify the 'essence' of the themes (individually and as a group) and determine which aspect of the data each theme captures. This process involves returning to the collated data extracts for each theme and organizing these extracts into a coherent and internally consistent account, accompanied by a narrative. The researcher needs to conduct and write a detailed analysis for each theme. This analysis involves identifying the 'story' that each theme tells and simultaneously considering how this 'story' fits into the overall 'story'. These stories should be considered in relation to the research question/s in order to ensure that overlap between themes is minimised.

Phase 6 - Producing the report: The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back to the analysis to the research question and literature, producing a scholarly report of the analysis.

The final phase begins once the researcher has a set of fully worked out themes and involves the final analysis and write-up of the report. The production of a written scholarly report provides an overview of the thematic analysis process that was followed. This report must be comprehensive enough to convince the reader of the merit and validity of the analysis. The written account of the analysis should provide a concise, coherent, logical, non-repetitive and interesting account of the story the

data tells. In addition, the written account must provide sufficient evidence of the themes within the data and should include enough data extracts to demonstrate the prevalence of the themes (Braun & Clarke, 2006).

Informed consent and ethical considerations

Dealing appropriately with ethical issues is fundamental to any research study. Ethical considerations are particularly important in qualitative research as the main method of collecting information is through human interaction. There are inherent risks associated with interaction, including embarrassment, anger, violation of privacy, intrusion, misunderstandings, differences in opinions and values and potential conflict. Ethical concerns in qualitative research centre on issues of informed consent, confidentiality and competence (Terre Blanche & Durrheim, 2006).

Within the context of this study informed consent was obtained by clearly explaining the aims and purposes of the study to the participants when they are first contacted. All participants were asked to sign an informed consent form prior to sharing their stories. This form contained material relating to issues of confidentiality, nonmaleficence and beneficence. The philosophical principle of nonmaleficence requires that the researcher ensure that no harm befalls participants as a direct or indirect consequence of the research, while the philosophical principle of beneficence requires that the researcher attempts to maximise the benefits that the research will afford to those that participate in the research study (Wassenaar cited in Terre Blanche, Durrheim & Painter, 2006).

The principle of confidentiality refers to access to participants' personal information disclosed during the course of the study (King cited in Forrester, 2010). In the context of this research confidentiality was considered of primary importance due to

the sensitive nature of the topic. All participants are referred to by pseudonyms in all published data. Participation in the study was voluntary and participants were informed that they were free to leave at any stage during the process. Participants were also informed that debriefing would be available following their participation in the research and they were invited to contact the researcher if they needed to discuss any sensitive information. The participants were also assured of access to any published material resulting from the study.

Validity in qualitative research

Validity refers to the degree to which research conclusions are sound. In qualitative research validity “refers to the trustworthiness of interpretations or conclusions” (Stiles, 1993, p. 601). In the paragraphs below the validity of this study is discussed with reference to the specific actions proposed by Stiles (1993).

- Coherence - this implies that the researcher will guard against writing his/her study in a linear (cause-effect) manner which contracts the underlying philosophy of qualitative research. This means that the idea of coherence includes the quality of fit of all the elements of the study, namely the researcher’s intentions in carrying out the study, the literature reviewed, his/her theoretical framework, ontological and epistemological lens, the information gathering methods, and the interpretations of the participants’ experiences and stories. A study’s coherence is assessed by its readers.
- Triangulation – This involves a process whereby the researcher must substantiate his or her data, interpretations and conclusions by referring to multiple sources of information. During the course of this study various primary and secondary resources and publications will be utilized and

documented. Within qualitative research triangulation is seen as an important measure of validity and allows the research to access multiple perspectives regarding the research data. Triangulation involves looking for information from multiple data sources, using multiple methods and multiple prior theories or interpretations and assessing the convergence of these data sources, methods, theories and interpretation. In this study triangulation was achieved by gaining information from a review of existing literature, and through the use of multiple data collection techniques (written accounts and unstructured interviews). The study also achieved triangulation through reviewing and re-reading the participants stories (thus using researcher's meta-observations as an additional source of information) and by engaging in dialogue with the supervisor of the study.

- Uncovering self-evidence - This refers to the process whereby the researcher makes sense of his or her experience and interpretations and determines whether his or her concerns have been answered. Rosenwald, (cited in Stiles, 1993) referred to this as self-evidence, which means that the research and interpretations must feel right to both the reader and the researcher and they must also yield appropriate action.
- Reflexive validity - Refers to the way in which the research process (including the participants' stories and experiences and the researcher's interpretation of this material) has changed the researcher's way of thinking about the topic. Reflexive validity also refers to changes in the way the researcher interprets, understands and views the information. In the context of this research the participants' experiences altered the way in which the

researcher thought about and understood mothers' experiences of raising twins when one twin is born with a congenital facial deformity such as a cleft lip and/or palate.

- Catalytic validity - Refers to the degree to which the research process re-orientates focuses and energises participants. This process is similar to the processes involved in uncovering internal processes within the researcher and the reader. It is hoped that this study enabled the participants to uncover different views and interpretations regarding their experiences and thus enabled them to construct alternative stories that allow for change, growth and enrichment.

Every researcher has the responsibility of validating his or her findings (Sekaran, 2003). The data collected during the research process must be used to inform the research findings. If this data is not verifiable the research findings are seen as potentially suspect. Within qualitative research validity is not defined in terms of the extent to which the operational definition corresponds with the construct definition, but rather in terms of the degree to which the researcher can produce observations that are believable for his/herself, the subject being studied and the eventual readers of the study (Terre Blanch & Durrheim, 2006). In the context of qualitative research validity refers to the coherence of all the elements in the network of meanings around a study.

Reliability in qualitative research

A study is considered reliable if another researcher using the same procedure and studying the same phenomenon arrives at similar, or comparable, findings (Sekaran,

2003). Reliability has traditionally been described as “the extent to which a research endeavour and findings can be replicated” (Kopala & Suzuki, 1999, p. 26). However, social constructionism disputes the existence of a singular, stable and unchangeable external reality that can be investigated. Instead the information obtained during the research process is viewed as a co-construction between the researcher and participants.

However, in order to ensure that quality is not compromised in qualitative research the researcher must maintain a comprehensive protocol of his or her study, in case other researchers are interested in checking the study’s reliability (Sekaran, 2003). Researchers are often confronted with a variety of variables that may impinge upon the reliability of the research findings (Terre Blanche & Durrheim, 2006).

According to Stiles (1993) “reliability refers to the trustworthiness of observations or data” (p. 601). Stiles (1993, pp. 602-607) identified several strategies with regard to ‘reliability’ that are also relevant to this study:

- Disclosure of orientation - This refers to the researcher’s expectations, preconceptions and theoretical allegiance.
- Grounding of interpretations - This refers to the linking of interpretations to the content and the context and should be substantiated by linking themes with examples from the excerpts.
- Asking ‘what’ not ‘why’ – This allows the experiences to be grounded in context.

- Description of internal processes of investigation. The researcher must refer to his/her own internal processes, including the impact of the research on the researcher.

Trustworthiness of data

Guba and Lincoln (1989) proposed four criteria for trustworthiness in qualitative research. These criteria correspond to the criteria employed by positivist investigators: credibility (in preference to internal validity); transferability (in preference to external validity/generalisability); dependability (in preference to reliability); and confirmability (in preference to objectivity). In the context of this research the techniques proposed by Shenton (2004) were followed to ensure that Guba & Lincoln's (1989) criteria were met. These techniques are discussed below.

Credibility refers to the extent to which the findings are congruent with reality. The following techniques were used to ensure credibility:

- The use of thematic content analysis for qualitative data analysis.
- Triangulation involving the use of different methods. In this study triangulation was achieved through conducting a review of the existing literature, making use of multiple methods of data collection, using the researcher's meta-observations as an additional source of data and engaging in dialogue with the study's supervisor.

Transferability is concerned with the extent to which findings can be applied to other situations. The following techniques were used to ensure transferability:

- Ensuring that sufficient contextual information is provided concerning the fieldwork and that a detailed description of the phenomenon is provided in

order to enable readers to transfer the findings to mothers in the same situation where one of their twins is born with a congenital facial deformity such as a cleft lip and/or palate.

Confirmability refers to the extent to which the research results reflect the views of the participants and not the characteristics and preferences of the researcher (Shenton, 2004). The following techniques were used to ensure confirmability:

- The triangulation processes mentioned above serves to reduce the effect of investigator bias.
- Clear acknowledgement of the researcher's beliefs and assumptions as well as recognition of the researcher's shortcomings and their potential effects will be used in order to meet this criterion.

Conclusion

This chapter discussed the methodological underpinning, data collection and data analysis of the study. The choice of a qualitative research paradigm was discussed along with the implications of this choice on the study. Thematic content analysis as used in the analysis of the interview data was discussed. Finally, the ethical procedures in the study were explained. The next chapter will explore the participants' stories in the form of identified themes and these themes will be compared to the relevant literature as discussed in chapter 2.

Chapter 4

Discovering the Participants' Voices

Simply having children does not make mothers.

John A. Shedd

Introduction

This study focused on mothers' experiences of raising twins when one twin is born with a congenital facial deformity such as a cleft lip and/or palate. In the context of this research the mothers were considered to be the experts as a result of their lived experience. The identified themes are structured in chronological order starting with the discovery of their child's cleft and proceeding through their process of acceptance. The themes conclude with the participants' reflections. Where relevant the themes are compared and integrated with the literature chapter. This integration is vital as it adds to the richness and diversity of the information. Mothers' experiences of raising twins when one twin is born with a congenital facial deformity such as a cleft lip and/or palate are vast and varied. The current study provides only a glimpse of insight into these mothers' experiences.

Although this study focused on mothers' experiences it is important to remember that these experiences cannot be seen in isolation but must be viewed in terms of the patterns of interaction that take place within a family. The various processes within the family system contextualise the mothers' experiences. Chapter 2 described the

way in which the systems perspective focuses on the relationships and interactions of individuals within a system. The information in the participants' stories clearly indicated the existence of mutual interaction and influence between the members of the family. According to Anderson and Goolishian (1992) human life is constructed in personal and family narratives that maintain both the process and meaning in individuals' lives. These narratives and personal stories are thus constructed in social interactions over time. In the context of this study the participants' experiences of raising twins when one twin is born with a congenital facial deformity were viewed as constructed realities within these families.

This chapter explores the information gained from the participants' stories and deals with the three participants' experiences with regard to their family and social environment. Within this research study the participants are referred to as Abigail, Claire and Juliet. A brief description of each participant and their family is provided below.

Background of the Participants

Abigail's story

Abigail and her husband Dirk are in their late thirties. They met in high school and married after the birth of their son Dylan, who is now 19 years old. They have been married for 17 years. Abigail is the mother of twin girls, Zoey and Jayden, who are currently 14 years old. Zoey was born with a bilateral cleft lip and palate. Abigail had an uneventful pregnancy and was shocked to find out that Zoey had a cleft during one of her pre-natal ultrasounds. She recalls being devastated by the news.

Claire's story

Claire and Doug are in their in mid-thirties and have been married for 16 years. Claire is the mother of Joey and James, 15 year old fraternal twin boys. Claire had a miscarriage before the birth of her twins and refers to the boys as her second and third children. James was born with a unilateral cleft lip and palate. Claire had no foreknowledge about James' cleft and was shocked to find out about it when he was born. However, she remembers feeling relieved that his life was not in any danger.

Juliet's story

Juliet and Chris are in their mid-fifties and have been married for 30 years. Juliet fell pregnant with twin boys when she was 37 years old. She has two older sons Austin (29 years old) and Bradley (27 years old). Her twin sons, Justin and Sam, are 16 years old. Juliet discovered that Justin had a cleft early in her pregnancy and recalls that the news was devastating. The boys were born prematurely and required breathing assistance. Justin was born with a unilateral left side cleft lip and palate.

Theme 1 - Stepping on to the Emotional Roller-Coaster

Intense, fluctuating emotional experiences were the key focus of all three participants' stories. At the time of the interviews the participants' children were adolescents and yet all three mothers became extremely emotional when describing their early experiences, especially the first year of their twins' lives. The intervening years and the successful surgeries do not seem to have lessened the impact and intensity of their fluctuating emotional experiences.

The metaphor of a 'roller coaster' ride is often used to describe life experiences. This metaphor seems to have particular relevance in terms of attempting to understand the participants' experiences. When individuals embark on a roller coaster ride they expect to be frightened and challenged and thrilled along the way and they are rarely disappointed. At some point during the ride most people start doubting their decision to begin the ride. However, they realise that they cannot get off so they just have to go with it and ride the ups and downs and twists and turns and lurches and bumps to the finish. The participants' stories contain a lot of information concerning their personal and family struggles in relation to raising and caring for a child with a cleft lip and/or palate. These stories have not ended yet.

The participants' stories are all characterised by the presence of intense and fluctuating emotions from the time of their twins' birth and the news of the child's diagnosis to the present time. The participants began their stories by describing the feelings they experienced when they discovered they were pregnant with twins and the experiences they had when their children were diagnosed with a cleft. The participants then described their experiences of meeting their child for the first time. The participants also went on to explain how some of those feelings remained with them, how some of those feelings went away and came back and how some of those feelings changed over time.

Most parents look ahead to the birth of a child and form fantasies and images of the expected infant (Huber, 1979). Parents' expectations may include achievements such as success in a societal role or in a profession or proficiency at some activity. The way parents react to the discovery that their child has a disability needs to be understood in relation to these normal thoughts and expectations. The discovery of a disability leads to the loss of the fantasized child and the incongruity between

expectations and reality precipitates a crisis reaction that is characterised by feelings of grief and loss (Huber, 1979; Styles, 1986).

The first thing parents want to know following the birth of their child is the sex of the child (Bugental, 2003). Secondly, they want to know if 'everything is okay', which is typically followed by a visual inspection. If anything unusual is observed the parents embark on an active search for information. Initial maternal reactions to a child who is visibly different are enormously variable (Collet & Speltz, 2006). The participants' stories clearly illustrated that the mothers struggled with their own personal responses to a visibly different child. For the participants the realisation that their child has a disability was devastating and initially completely overwhelming.

Research suggests that feelings such as anger, guilt and sadness often accompany the initial discovery that a child has been born with a congenital facial deformity (Van Staden & Gerhardt, 1994). Many parents report experiencing feelings of grief on learning of their child's disability (Allen & Vessey, 2004; Hunt et al., 2005; Rigazio-DiGilio & Cramer-Benjamin, 2000; Patel & Ros, 2003; Van Staden & Gerhardt, 1994). Many parents experience shock, a sense of devastation and intense grief when learning of their child's diagnosis. They associate the diagnosis with the loss of the fantasised child (Fraley, 1990). It is common for these parents to experience varying levels of anxiety, anger and guilt as they try to come to terms with the initial diagnosis (Zeitlin, Williamson, & Rosenblatt, 1987).

These feelings are extremely intense and hurtful and are often regarded as inappropriate and mothers may often not feel comfortable expressing them to other people or even to themselves. This was true for all the participants in the study, who grieved privately and in secret.

Abigail first discovered that Zoey had a cleft during a routine ultrasound: *I remember my heart racing, when I was told but I tried to stay calm. No one can prepare you for a moment like that. Even though the doctor explained that this was something that could be fixed, I was absolutely devastated! No one wants anything to be wrong with their baby. The first thing that went through my minds when I found about the cleft was that it was my fault. I couldn't help myself thinking "How could I do this to my child"?*

Claire only discovered that James had a cleft after his birth. She recalls that she based her response on her husband's response. She describes her husband as appearing happy, sad and disappointed all at the same time. *That was devastating, and I felt that I had yet again let him down. I looked long and hard at James and felt so overwhelmed by what I saw. I was taken completely aback by the cleft.*

Juliet describes the moment she found out about Justin's cleft: *My world came crashing down with one sentence during an ultrasound test. "One of your babies has a cleft." The news was devastating to me. I grieved for months as if the dearest of loved one had died. I never felt such overwhelming sadness, despair, and anger. And guilt, I was convinced that somehow I was responsible.*

Stepping into the Unknown

All three participants placed special significance on the specific moment they discovered they were pregnant with twins and the moment they discovered that one of their babies had a congenital facial deformity. This emphasis is not unusual as the birth of a child is usually seen as a distinctive and memorable moment in the lives of parents and as such the pregnancy and birth story is often told to friends, family and to their children. It is clear from the shared experiences that the participants'

experienced intense emotions when they discovered they were pregnant, when they discovered they were carrying twins and when they discovered that one of the twins had a cleft. Words cannot fully describe the gauntlet of emotions these mothers experienced, ranging from the anticipation of a new life when they discovered they were pregnant, to the peak of joy at the birth of their children and the devastation at being confronted with a child with a deformity. Their stories all display a powerful emotional oscillation between positive and negative emotions.

Abigail recalls that she was very excited when she discovered that she was pregnant but the news that she was pregnant with twins made her think about her three year old son and how he would react to two babies entering his world. She thus realised that the event would have an impact on other family members. *We were very excited and other than the usual morning sickness, my pregnancy was uneventful until my second ultrasound. Preparing for the arrival of any new born baby is stressful enough, but preparing for the arrival of twins has additional preoccupations. I wondered how my son would react to the impending changes the new additions to our family were going bring. How would he adjust to not just one, but two children entering his world and turning it upside down?*

Claire felt shocked by the news that she was pregnant and was not entirely sure she wanted to continue with her pregnancy, as she was afraid that she would miscarry again. She did not trust her body. *Finding out that I was pregnant was a shock, we had not planned it and at the beginning I wasn't entirely sure that I wanted to go through with it after losing my first child.* Claire experienced contrasting emotions of both shock and gratitude when she found out that she was pregnant with twins. *Well I wasn't ready when I found out I was pregnant and felt even less prepared for the news that there were two heartbeats and not one.* The news that she was carrying

twins, made Claire feel even more apprehensive about the pregnancy and more afraid of another miscarriage. Her doctor reassured her that she was fit and healthy and both her husband and her doctor provided much needed support during her pregnancy. She describes the final stages of her pregnancy as: *just a whirlwind of excitement and preparing for the arrival of our babies.*

For Juliet the news that she was pregnant was shocking: *The news that I was pregnant at 37 came as a big shock. The pregnancy was unexpected but not unwanted.* Juliet was fearful and apprehensive that her age would mean that there would be complications with the baby. She found out she was having twins during an ultrasound at six weeks and describes herself as excited by the news.

The Rubicon Moment – Confrontation with Reality

Abigail and Juliet both discovered that one of their twins had a cleft during their pregnancies while Claire only discovered that her son had a cleft after the birth of her twins.

Abigail stated: *No one can prepare you for a moment like that. Even though the doctor explained that this was something that could be fixed, I was absolutely devastated!* Abigail recalls that the birth of her daughters was rather straightforward, but that it was largely overshadowed by Zoey's birth anomaly. When she saw Zoey all she saw was her cleft and she experienced an intense emotional reaction when she was confronted with Zoey's cleft. The reality of the cleft was a painful experience for her. *She seemed so raw, swollen and red. For the first day her face was all I saw. I even wanted to skip her hospital photos. I thought no matter how cute her outfit was, the photos wouldn't be as good as those of the other babies in the hospital that day or that of her sister.*

Juliet's experience was similar to that of Abigail and she recalls that she felt that her world came crashing down with one sentence during an ultrasound test. *"One of your babies has a cleft." The news was devastating to me. I grieved for months as if the dearest of loved ones had died. I never felt such overwhelming sadness, despair, and anger. And guilt.* Juliet then became consumed by the news that one of her children had a cleft. *During the rest of my pregnancy I was unable to think of the growing lives inside me as my babies. My thoughts were only of the cleft and I was consumed by them. How severe will it be? What other problems will he have? How will it affect his hearing, teeth, speech, feeding, and self-esteem? How will it affect us financially? How will I go back to work? What will I tell my family and friends? How will we raise our twins knowing that one will always be a reminder of what we had lost? Most importantly, will his cleft make it difficult for me to bond with him and love him as much as he should be? I had so many unanswered questions. When I first really looked at my child, I was taken completely aback by the cleft. I had never seen a cleft before and I was not ready to look at one then. I had a hard time dealing with this.*

Claire only found out about James' cleft when her twins were born. Claire believes that because she had experienced the loss of a child prior to her twin's birth (through miscarriage) *I wasn't as disappointed as other parents may be when their baby arrives looking different; born with a cleft lip or palate.* She recalls that immediately following the birth she was first given Joey while James was taken away to be examined. This made her more determined to meet him, and she recalls telling the doctor: *I don't care what he looks like, he is a gift, they are my gifts from God.* She then experienced feelings of disappointment and devastation once she saw her husband's response to James' cleft. *He looked happy, sad and disappointed all at*

the same time. I could see that he had a difficult time looking at James and seemed to prefer holding Joey. That was devastating, and I felt that I had yet again let him down. At this point Claire was confronted with the impact and reality of her son's cleft. Claire recalls that when she met James she felt overwhelmed by what she saw. I was taken completely aback by the cleft. I had never seen a cleft before and I was not ready to look at one then. The first thoughts that ran through my head included the following: What happened to my poor baby? How will we ever fix that that hole? Why me? How did this happen? Claire explains that although she initially thought that her experience of losing her first child would help her to better handle life's obstacles this was not the case and she struggled to raise her twins. I wanted two healthy babies. I wanted to take them home and love them and now I couldn't because one had a huge gaping hole where his lip was supposed to be.

The participants' stories clearly express the confrontational nature and impact of a facial deformity. All three mothers were devastated by what they saw. The participants' stories contain evidence of the loss that they experienced. This loss involved the loss of the child they fantasised about in their pre-birth thoughts and dreams and the realisation of the impact of changes to the family's life and their relationships. These experiences and realisations all contributed to a sense of grief. During this initial phase the participants all expressed a wish for things to return to the way they were before. Common feelings expressed by the participants included pain, hurt, emptiness, sorrow, fear, guilt and anger and resentment at the unfairness of the illness and of being cheated and robbed of a perfect child.

The Aftershock - A Lonely Journey of Intense Emotional Discomfort

The participants' feelings clearly reflected emotions typically experienced by individuals beginning the grieving process (Kübler-Ross, 1969). The mothers' feelings included shock, disbelief, denial, and sadness in response to the apparent loss of the longed-for healthy and normally developing child. During pregnancy most parents fear that their child will be born with an abnormality. When these fears are realised the parents are faced with the task of adapting to the care of a child with special needs while at the same time grieving the loss of the expected, perfect and idealised child. Parents of twins have no difficulty imagining the perfect healthy child because the image of the healthy child is constantly present in the unimpaired twin (Sandbank, 1999).

Abigail recalls how she mourned her loss and began to accept her child: *I remember walking to the nursery a couple of hours later, when everyone else had gone home or was sleeping, and I walked right up to the window where she was laying in the bed warmer, all naked and adorable. I had an array of emotions flow through my heart and soul at that moment in my life. She was so different than the other babies. She was very different from her sister. I prayed that I would be able to love her as much as her sister. I kept asking Why me, why us, why her? I spent the next half hour grieving for what I didn't have, what I thought I wanted, and mostly for what I was afraid she would go through the rest of her life.*

Claire elaborates on the theme of mourning and acceptance and recalls the advice that her mother shared with her regarding her husband. *I remember on one particular day after a very long feeding where I sat crying and feeling completely worn out and alone, she reminded me of how understanding and caring he was after*

the miscarriage, how he gave me the time to heal and accept my loss and his own loss. And that perhaps he too was grieving and dealing with the loss of his perfect son. She explained to me that when we prepare ourselves for the birth of our children we fantasize. We speak about our babies to every important person in our lives, and even some who were not so important. We tried out dozens of names until we found the one that perfectly suited our boys that we imagined ourselves to have. We pictured our babies in our arms. We pictured them big and healthy one day, small and vulnerable the next. We pictured heads full of hair. We saw the boys. But we never saw a cleft. That is, not until the morning they were delivered.

Juliet discovered that that her son Justin had a cleft before his birth, but she found it extremely difficult to accept this news. Following the birth Justin was quickly taken to intensive care and she remembers hearing the doctor say: *"It's such a shame that the second baby has a large cleft lip and palate."* Juliet recalls that her heart froze and she did not know what to do. *I tried to visualize what he might look like. I was so worried about both of them being premature and I didn't know how this would impact the prematurity issues. Once Juliet was alone in her room the shock set in for her and she felt overwhelmed and started questioning herself. I think I was in shock ... so many thoughts went through my mind. What are you thinking, God? I can't handle this! What did I do wrong? I was careful! I didn't smoke or drink or do drugs. Why is this happening to me? Why does my baby boy have to go through this? Lord, Lord — how will I do this? The bottles they want me to use ... it seems really hard to feed him ... I don't think I can do it ... and how will I care for him when he has surgery? Oh Lord How !?!* She remembers that during her recovery she cried a lot and thought about the long road ahead. *I knew very little about clefts. I had no idea if he would be alright. As I drifted in and out of sleep, I kept thinking that maybe it*

was really just a dream and that both of my babies were really alright. Juliet also recalls that when *friends and family gathered at the hospital to welcome the boys, the pain and devastation set in.* Justin was on breathing assistance and Juliet was unable to hold him until he was three days old. Juliet was very fearful for him and felt that he would not know his parents and worried that he was in pain or scared.

The participants' stories reflect the difficulties that parents, and specifically mothers, experience in accepting that their child is physically different. The participants' grief-related feelings seemed to revolve around the loss of the imagined child. Many parents and especially mothers experience feelings of guilt and anxiety when their child is born with a deformity (Hunt et al., 2005; Rigazio-DiGilio & Cramer-Benjamin, 2000; Van Staden & Gerhardt, 1994). The participants in this study all acknowledged experiencing feelings of anger and guilt regarding their child's condition. They also experienced a sense of self-blame and felt that they had let people down by having a less than perfect child. The child's disability was seen as a reflection on themselves and their bodies. Allen and Vessey (2004) found that parents of children with a congenital birth defect often feel guilty and believe that they might have caused the problem in some way. These parents are also saddened and frightened by the news that their child will have to undergo corrective surgeries and possibly other forms of treatment. Allen and Vessey's (2004) study found that parents often wish that they could undergo the treatment in their child's place. All three participants in this study initially blamed themselves for their child's cleft. This sense of guilt appears to be related to a sense that they had biologically induced a disability in their child. The mothers also felt guilty about the reduced amount of time they were able to spend with their other children.

Abigail recalls that the first thing that went through her mind when she found out about Zoey's cleft was that it was her fault. She goes on to explain that although she knew that it was not true she continued to think that she was responsible. *I couldn't help myself thinking "How could I do this to my child?" and "Why was only one of my babies affected?" "How could my body do this to my child?"*

Claire recalls that she did not initially react with shock to her son's cleft. However, shock and guilty set in when she saw her husband's reaction to their son's cleft. *The shock set in when I saw my husband's face ... That was devastating, and I felt that I had yet again let him down.*

Juliet was convinced that her age was responsible for son's cleft. She found it extremely difficult to accept the reality of the cleft. *My world came crashing down with one sentence during an ultrasound test. "One of your babies has a cleft." The news was devastating to me. I grieved for months as if the dearest of loved ones had died. I never felt such overwhelming sadness, despair, and anger. And guilt, I was convinced that somehow I was responsible. It was my age.*

The participants' stories clearly show their families and relationships experienced extremely high levels of demands during the first year of the twins' lives. During this time the families had to deal with surgery and care. The participants all experienced contrasting emotions in relation to their child's surgery; they were excited by the prospect of a new baby with a normal lip and palate but were scared and apprehensive about the surgery itself. The participants all seem to have experienced a strong sense of guilt in relation to their children's corrective surgeries.

Abigail describes handing Zoey over for her first surgery as the toughest thing that she has ever done. She experienced the uncertainty and waiting as an almost unbearable ordeal. Abigail explains that she and her husband got through the process by reassuring themselves that it was in Zoey's best interest. *It was hard for my husband and me because we hated putting her through it, but we know that it was for her own good. We knew that the next time we saw Zoey after her surgery she was going to look a lot different than what she did before. We were excited and apprehensive at the same time. We were going to leave the hospital with a different baby.*

Claire recalls that she feared for James' life and was fearful during his operation. *I was terrified that something would go wrong and I would lose my little angel.*

Juliet recalls experiencing extreme uncertainty regarding the outcome of the surgery. She was also acutely aware of the pain her son would have to endure. Juliet explains that *having to take your child into hospital and leave him there is the most painful experience any mother will endure. I felt so guilty. As I reflect back I remember thinking that I am the mother of this child. While it is he who must bear the trauma and the pain, it is I who suffers with him and sometimes truthfully because of him.* Juliet's story clearly illustrates the emotional turmoil that mothers experience when their children have to undergo surgery. Her story also clearly portrays the physical and emotional exhaustion associated with raising a child with a congenital facial deformity such as a cleft lip and/or plate.

The participants experienced the process of surgery as extremely lonely and they felt unable to acknowledge or express their emotions. Although support was available to

the participants (this is discussed later in the chapter) they struggled to express their experiences and intense emotions.

For Abigail the journey was very lonely. She explains that: *in times of crisis, I kept a lot of what I was experiencing to myself. I didn't want to burden him (her husband) with what I was feeling. I tried to share this with my husband as I was sure he was going through a similar experience but I couldn't. We simply put everything aside and kept going. We were too busy surviving.*

Claire also wanted to speak to her husband about her fears and concern but explains that when *we tried speaking to one another, this almost always lead to an argument.* Her inability to speak to her husband was further complicated by her feelings of exhaustion and her husband's absence. *It was so difficult for us to talk to one another, I was exhausted all the time and Doug worked to keep the family afloat.*

Juliet indicates that she too did not discuss her feelings with her husband due to her own feelings of guilt and responsibility. *It was difficult for me to talk to him about what I was feeling because I felt so responsible. I don't recall sharing how I felt with anyone. I preferred not to think and talk about it.*

The participants all struggled to share their painful and intense emotions with their spouses and this had an impact on their relationships. Their spouses responded by fulfilling their role as financial provider in the system. They did not share their feelings regarding their children's cleft with their wives. This in turn impacted the mothers' experiences and added to their negative, painful emotions. This circularity of experience is in keeping with family systems theory's description of the family system.

Stepping into the Light - Regaining Control

The identification of meaningful coping strategies, such as talking with others and allowing themselves to grieve, appears to have been decisive in the participants' attempts to continue functioning in their daily lives. Parents never want their children to be sick, deformed or harmed in any way. The experience of raising a child with a deformity is thus never expected but is always unplanned and difficult to manage. However, the literature review in chapter 2 highlighted research that found that most families are able to find the strength within themselves and their support systems to adapt to and handle the stress and challenges that accompany their child's illness or disability. The type of emotions parents experience, as intense and overwhelming as they may be, are also normal and acceptable. For most families and individuals stability does eventually return.

Uncertainty is the single greatest source of psychosocial stress for people affected by chronic health conditions (Allen & Vessey, 2004). According to Steward and Mishel (2000) parents attempt to manage this uncertainty through information management, which typically takes two forms. The first form involves an intensive pursuit of information concerning the child's health and potential environmental threats, while the second form involves the careful avoidance of social encounters or cues that call to mind the child's condition and draw attention to negative aspects of uncertainty.

It is evident in their stories that the participants felt uneasy, apprehensive, fearful and confused in relation to their experiences. The stories also indicate a desperate need for control. The participants gathered information, looked for reasons and sought answers in order to gain an understanding of what was happening to their children

and their families. They also looked for answers within themselves. The participants obviously initially struggled to assimilate the information that their children had congenital facial deformities. It took the participants some time to understand the full implications of the diagnosis. The participants attempted to deal with their emotions by gathering information about their child's disability. They gathered and examined as much information as they could in order to try and understand their child's condition, feel some form of control, empower themselves and rid themselves of their fear and uncertainty regarding their child's future.

Juliet recalls that she was accustomed to being in control of her life and this was taken away when her son was born with a cleft. Although she knew about the cleft before the birth of her twins and was consumed by thoughts of her child's cleft and was unable to accept the diagnosis. *We began learning a lot about clefts after we took them home. The hospital had been very helpful at giving us information and resources.* Her search for information was an attempt to regain the control that she felt she had lost. *I was determined to learn absolutely everything I could. Somehow being knowledgeable on the subject made me feel more in control, I always tried to keep a cheerful, encouraging face on even though my heart was breaking. Together we struggled through all the challenges.*

Abigail and Claire also felt the need to gather information. Abigail recalls that: *any free time that I did have to myself I spent it researching Zoey's cleft lip and palate and all her upcoming surgeries.* Claire recalls the desperate need she felt: *I was already anxious to gather whatever information I could to ready myself for the task and to help myself prepare to make good decisions for my son.*

All three participants indicated that their attempts to regain control by looking for information provided them with some sense of control and helped them prepare themselves and their families for the long journey ahead of them.

Theme 2 - Disruption of the Family System

The birth of a child with a facial deformity produces disequilibrium within the family system and the system must therefore change and adapt. Van Staden and Gerhardts (1994) study found that families initially respond with family disorganisation and disruption when faced with the birth of a child with a facial cleft deformity. The family system must adjust to new demands and introduce new patterns into the system in order to survive. The systemic perspective views family functioning as profoundly interdependent and changes in one part of the system reverberate in other parts of the system. Research suggests that parents often respond to the birth of a child with a handicap by being overprotective and overindulgent due to their own high levels of stress and anxiety (Barden, 1990). The systems perspective holds that these changes in the parental sub-system will impact on the family in general. However, the literature reviewed in chapter 2 (Bohacahick & Anton, 1990; Donally, 1994; Rehm & Cantazaro, 1998; Sawyer, 1992 cited in Allen & Vessey, 2004) suggests that stability does eventually return, both to the individual and to the family. In order to reach stability parents must begin to search for needed information and adjust their interactional and behavioural patterns and roles to accommodate the special needs of their child.

The mothers' stories indicate that their families were able to adjust to the changes and challenges that are required when a child is born with a cleft lip and/or palate.

The participants' stories show that their families were able to adjust to these internal changes by changing family patterns, rules and boundaries within the parameters of effective family functioning

Many parents and particularly mothers experience a loss of control of their lives when faced with a child with a birth defect. This sense of control can only be regained with sufficient social support (Van Staden & Gerhart, 1994). The participants' stories clearly illustrate that the support they received from external sub-systems was vital in allowing them to adjust to their situation. In general the participants' families were open systems, although the degree of openness did differ from family to family.

A Shifting of Roles

The term family roles refer to the patterns of interaction between family members that ensure family functioning (Becvar & Becvar, 2006). The participants all experienced a significant and sudden role change following the birth of their twins – they became full-time mothers. The changes associated with this role change are discussed in the section below.

Mothers are usually the primary care-givers within a family and as such are key members of family systems (Minuchin, 1996). Regardless of the specific family constellation, mothers are often integrally involved in the developmental transitions of their family as a whole. All the participants recalled their initial denial, depression and shock as well as the extra effort that caring for their child demanded of them and their families. The participants were responsible for all aspects of their children's care and support while their husbands provided financial support. The participants all

had to make several adjustments to their lives in order to be able to devote themselves to caring for their children.

All three participants changed their career goals as a result of the additional demands their children placed on them. The participants all left paid employment to become fulltime mothers to their children, leaving their husbands as the sole financial providers. The mothers' priorities also shifted and they devoted more time and energy to care-giving and less time and energy to socialisation and work. Research has shown that when care-giving for children with specific needs requires that one parent stay at home, the family's financial well-being and the parents' social network and self-identity can be negatively affected (Barnett & Boyce; Turnbull & Turnbull, 1997, cited in Dell Orto & Power, 2007). The participants' stories clearly show that each of the participants responded to their child's needs by becoming the primary care-giver. Although this shift was necessary it was also difficult and tiresome with the mothers experienced feelings of exhaustion and loneliness during the first years of their children's lives

Before the birth of the twins Juliet and her husband shared a sense of responsibility and compatibility. Early in their marriage her husband was retrenched and became a stay at home father to their older children while she supported the family financially. Their roles shifted with the birth of their twins and Juliet admits that this was an enormous adjustment for her. She recalls that *this was an enormous adjustment for the both of us. I was so used to Chris looking after me and now it was my turn.*

Abigail recalls that she took over the responsibility of caring for the girls because she did not believe that her husband could look after Zoey or feed her the correct way or care for her immediately after her surgeries. It was very difficult to speak to her

husband about her concerns because he was *busy working and providing for us as a family and I was too busy looking after our family*. Communication between her and her husband was not easy and she attributes this to her extended stay at home, which put added financial strain on the family and in particular on her husband. *I know that he worried constantly about how we were going to pay for Zoey's extensive medical treatment. He feared that our medical aid would run out, or refuse to pay for some part of her treatment and that he would not be able to provide for this.*

Claire explains that the birth of the twins changed her plans considerably. She mentions that she and Doug discussed having an extended maternity leave before the boys' birth *but the plan was for me to go back to work. Our plans changed and this put added pressure on Doug and in particular on our marriage. We decided that I would stay at home in the beginning and reassess the situation later on whether I would manage working*. Claire believes that this put a lot of stress on her marriage and created distance between her and her husband. *It was so difficult for us to talk to one another, I was exhausted all the time and Doug worked to keep the family afloat. We hardly saw each other. It wasn't an easy time and looking back it is surprising that we stayed together*. The situation improved when her sons went to pre-school and she returned to work. Returning to work gave Claire a sense of purpose. *I eventually felt like I was contributing to our family and taking a lot of financial stress off my husband*. Claire admits that she needed to go back to work for the sake of her marriage. *Most of our arguments were because of the financial stress we were all under. I kept wondering how we would manage with the all the additional costs with James' surgeries and hospital visits and I know this is what drove Doug to work as hard as he did.*

In order to care for their children the participants all adopted clear roles within the family system. The participants' role was to be the primary care-giver for the children while their husbands' role was to be the financial provider. In this way the boundaries between the spouses became quite rigid while the boundaries between the mothers and their children became more diffuse.

Most researchers agree that care-giving responsibilities can cause a great deal of stress for families of children with disabilities (Plant & Sanders, 2007; Seltzer & Heller, 1997). Various aspects of care-giving contribute to parental stress, including the excessive amount of time involved in completing tasks, the complexity of care-giving tasks due to the severity of a child's disability and financial stress placed on parents (Haveman, Van Berkum, Reijnders, & Heller, 1997).

All three participants reacted to their child's facial deformity by becoming overprotective. The participants thus became over involved in their roles as mothers. All their time and energy was devoted to the mothering role. The boundaries between the mothers and their children were thus diffused and they became over involved in their child's care, often to the exclusion of their spouses. The feeding demands of a child with a cleft lip and/or palate seem to have been a major factor in the participants becoming absorbed in the mothering role.

For Abigail learning to feed Zoey was a big challenge. Zoey was born with a cleft lip and palate and she was therefore not able to perform the normal suction around a nipple, although she did try. *I often found it difficult balancing my time to feed both of them but my husband was very supportive and helped me every step of the way. I didn't breastfeed for very long because I was unable to breast feed Zoey while her sister had no difficulty breastfeeding. Initially I was worried that Zoey was missing out*

and I felt guilty when I breastfed her sister. For those reasons and practical reasons both girls were bottle-fed and it worked out perfectly because Zoey's feeding times were time consuming.

Claire recalls: *I expressed milk for James and breastfed Joey. Feeding times were long but once you get used to the teats, you find a way that suits you and then it become part of the routine. In the beginning I was concerned that I wouldn't bond with James as easily as a result but the extending feeding times ensured that we had more than enough time to get to know one another. I do believe that I succeeded in bonding with both my sons and that it was silly to be so concerned about it.* Her story illustrates both the extensive duration of feeding times and her fear of not being able to bond with James because she was unable to breastfeed him.

The exhaustive nature of care-giving is a prominent theme in the mothers' stories. Abigail describes the first year after the birth of her twins a *blur. I was exhausted all the time and barely awake when I was awake. I functioned on autopilot, just doing what needed to be done.* In order to survive Abigail simply had to keep going and this meant that she kept a lot of what she was experiencing to herself. This put added strain on her relationship with her husband. *In times of crisis, I kept a lot of what I was experiencing to myself. I didn't want to burden him with what I was feeling. Talking to him was difficult because he already had so much on his mind. We simply put everything aside and kept going. We were too busy surviving. I don't really remember us ever talking to one another during that first year. We were too busy raising our three children, preparing for surgeries and feeding, feeding and feeding.*

Claire's husband was frequently absent during the first year of James' life due to his need to provide financially for the family. Claire felt that she had to compensate for her husband's physical absence by always being available to her children. She admits that at times she felt resentment at her husband's absence because she was *also tired and overwhelmed by everything that was happening*. She goes on to explain that *having two babies is very difficult and having a child with a cleft lip and palate is extremely demanding. His feeding took so long in the beginning and I was often left feeling exhausted and alone during this time*. Claire's role was clearly defined as that of care-giver: *I would be caring for the boys; I would be there every day. I would have to take James for all his hospital appointments and look after him while he recovered*.

Claire and Doug's relationship also suffered in the first year of James' life due to what Claire perceived as Doug's inability to bond with James. She wanted her husband to treat their children the same but could only see Doug bonding with Joey. *During those early days, it felt like James only had one parent, me. We fought about this constantly; I felt that Doug was being unfair and that he didn't love James*.

Juliet's story indicates that the birth of her twins led to a shift in roles within the family, with her resuming a care-giver role. However, she also indicates that this reversal of roles within the family unit ultimately resulted in a sharing of responsibility. Her story also reflects a change in communication between partners. *It was difficult for me to talk to him (her husband) about what I was feeling because I felt so responsible. I don't recall sharing how I felt with anyone. I preferred to not to think and talk about it*.

Caring for twins is always difficult, but when one twin has a deformity the situation is even more difficult as the child with a deformity is accompanied by multiple services, systems, and care needs. The participants all expressed various degrees of exhaustion or fatigue associated with care-giving. The participants all indicated that it would be difficult for people who do not live with disabilities or some form of deformity to understand the frequently exhausting nature of care-giving. They all felt that nothing could have prepared them for this journey. The participants were also acutely aware of the effect that their constant care-giving had on other immediate family members.

Impact on the Spousal Sub-System

Although it is normally a positive event, becoming a parent can place huge strains on a couple's relationship and on the partners' individual functioning within that relationship. Having a baby can be extremely stressful and, as with any major life change, it entails some degree of risk. This risk is usually related to the challenge of raising children, which can cause new problems or highlight existing vulnerabilities for both parents (Cowan & Cowan 1995). The birth of a child with a deformity raises new issues for parents and creates a serious disruption in the family system. Most individuals are not initially well equipped to handle raising a child with special needs. It takes time to learn how to deal with the confusion, the physical demands, the behavioural challenges, the special expenses and the feelings of embarrassment and loneliness.

The participants' stories clearly illustrate the complexity of the mother-child relationship. This relationship becomes even more complex when the child is born with a deformity. For the participants their children's wellbeing was their first priority

and the care of their child with a cleft became a fulltime responsibility. Their stories highlighted the adjustments they had made in their lives in order to be able to devote themselves to caring for their child.

The participants all indicated that raising a child with a cleft lip and or palate placed strain on their marital relationship. In particular, the participants all stopped communicating with their spouses. Parenting responsibilities were also unequally distributed and the mothers assumed the bulk of the responsibilities. Risdal and Singer (2004) completed a historical review of the literature concerning the impact of children with disabilities on marital and other familial relationships and noted that much of the research concluded that the impact on the marital system was negative.

Prior to the birth of their twins the participants' relationships with their spouses had clearly established boundaries. Following the birth of their twins the family structure shifted and the spousal boundaries became more rigid, specifically during the first year of their twin's lives. The participants and their spouses accepted these new roles and incorporated them into their daily lives. On a practical level this arrangement was effective and helped the spouses execute their responsibilities within their assigned roles. However, on a deeper level the participants felt unsupported and isolated in their roles. They experienced their relationships with their spouses as characterised by a profound lack of togetherness and belonging. Their disconnectedness and disengagement as couples was evident in their lack of support, care and nurturance of one another following the birth of their twins. This perceived lack of support was felt by the mothers in the study; however the researcher felt that it was pertinent to mention that the fathers are likely to have had a different perception of the experience. It is clear that the participants' family systems changed dramatically following the introduction of this unique stressor. As

mentioned previously, the spousal subsystem's boundaries became more rigid in order to handle this challenge.

The exhausting nature of care-giving was a prominent theme for all the participants. The child with a cleft has multiple needs and the mothers found themselves constantly providing care and were thus constantly fatigued. The participants stated that they were frequently unable to pay enough attention to their other children and their spouses. The presence of a child with a disability thus results in a host of difficulties, including parental guilt, marital discord, and family stress.

A positive communication process is important for the healthy functioning of a family system. The family system becomes dysfunctional when individuals within the system do not send each other straightforward messages (Becvar & Becvar, 2006). Good communication skills are essential for a healthy marital relationship (Lauer & Lauer, 1997). However, the participants all recalled that they had avoided sharing their emotions and experiences with their spouses. This decision seems to have been based partly on a sense of guilt in relation to their child's conditions and partly on their acceptance of their role as the child's primary care-giver.

The participants identified financial stress as a result of role changes and the costs of treatment as an additional area of conflict within their relationships. Financial stressors are not uncommon in families of children with disabilities, especially if the disabled child has healthcare needs beyond that of a typically developing child (Jackson, Tsantefski, Goodman, Johnson, & Rosenfeld, 2003). Hospital bills can accumulate quickly and even with good medical aid, families typically have to pay a large portion of the bills out of their own pockets. In addition to the expenses associated with medical and other bills, families also have to take time away from

paying jobs in order to accompany their children to various appointments, including doctors and physical, speech, and/or occupational therapists. Families of children with deformities are more likely to be divided into the traditional roles of a stay-at-home mother and a working father than families of typically developing children. This division of labour is mostly due to the special needs of the disabled child (Vermaes, Janssens, Mullaart, Vinck, & Gerris, 2008).

In most previously dual-income families a decision is taken for one parent to remain home to take care of the child's needs and services, thus cutting the family income in half (Jackson, et al., 2003). This loss of income was a reality for all three participants and they had to contend with the reality of there being a sole family provider.

Abigail's extended stay at home in the early stages of her twin's lives put a lot of financial strain on the family and in particular on her husband. *I know that he worried constantly about how we were going to pay for Zoey's extensive medical treatment. He feared that our medical aid would run out, or refuse to pay for some part of her treatment and that he would not be able to provide this. I also worried about this and it put a bit of strain on our relationship and caused some unnecessary arguments.*

Claire's relationship with her husband during the first year was completely different to their relationship at any other time. She recalls feeling constantly lonely and tired. Claire recalls that during that time *it was so difficult for us to talk to one another, I was exhausted all the time and Doug worked to keep the family afloat.* The couple spoke through Claire's mother and relied on her for emotional support.

Juliet did not speak about any relational difficulties, but did recall that she kept much of what she was experiencing to herself, preferring to deal with it on her own.

Impact on the Siblings

Research indicates that having a child with a disability has a powerful impact on every member of the family. From a systemic perspective this is particularly relevant as the physical, emotional and social functioning of family members is viewed as profoundly interdependent. Changes in one part of the system thus reverberate in other parts of the system, including the child's brothers and sisters. The introduction of a child with a deformity into a family has a profound effect on the other children in the family. Growing up with a sibling with a disability can have both positive and negative effects. Research findings (Cicirelli, 1995; Hunt et al., 2006) are contradictory, with some research indicating that siblings of children with disabilities are more compassionate, knowledgeable about disability issues, and willing to help others than children without a sibling with a disability. However, other research findings suggest that the siblings of children with disabilities experience stress in relation to feeling embarrassed by their brother or sister, not having enough time with their parents and worrying about what the future holds for themselves and their brother or sister (Cicirelli, 1995; Hunt et al., 2006). Despite these contradictory findings most research suggests that the siblings of children with disabilities are likely to adapt and even blossom when their developmental needs are met within the family (Cicirelli, 1995).

Family life can often appear to revolve around the special needs of a child with a disability. The other children within the family may fade into the background, not because they are not loved by their parents but rather because they are seen as not requiring as much time and attention. Bugenthal's (2003) study confirmed these assumptions and found that priorities in the family change when a child is born with some form of deformity or illness.

McHugh's (2002) research found that the impact on siblings varies considerably between individuals and families. For many siblings the experience is a positive, enriching one that teaches them to be accepting of others. The participants in this study indicated that their other children (co-twins as well as siblings) became protectors and supporters of their brother or sister born with a deformity. This finding contrasts with the findings of Lavin's (2001) research, which suggested that many siblings experience feelings of bitterness and resentment towards their parents or the brother or sister with a disability. Lavin (2002) found that these siblings feel jealous, neglected, or rejected as they watch most of their parents' energy, attention, money, and psychological support flow to the child with special needs.

Both Abigail and Claire indicated that prior to their twins' birth they were very aware of their other children and were concerned that they would feel neglected. However, they did not elaborate on this concern.

Abigail recalls that her son was extremely protective of his twin sisters from the very beginning. Jayden, Zoey's twin, developed a fierce protectiveness over her sister. Abigail believes that this protectiveness was the result of her witnessing and experiencing her sister's pain. Abigail's experience thus supports Sandbank's (1999) research, which argues that the development of a close and interconnected relationship in twins is usually attributed to the simultaneous and permanent presence of a same aged sibling.

Abigail adds that *they (the twins) are both extremely protective of each other. They never wanted to be separated; both would become tearful when Zoey had to go for a surgery and overjoyed to be reunited.* Abigail also spoke about her fears and contentment regarding the relationship between her daughters and their upbringing.

We never raised our daughters simply as twins but rather as individuals, each with their own unique personality. Their physical similarities and differences have never been an obstacle. During my pregnancy I used to worry that Zoey's cleft would affect her relationship with her sister, that she may resent her sister for not having one or having to undergo the painful repairs. I couldn't have been more wrong. My daughters are remarkably close and I think the reason for this is because they grew up together. Both are protective of one another and extremely sensitive to each other's needs.

Claire's twin boys have also always been close and supportive of each other. The boys have always been close and very perceptive of each other's needs. I never really had to worry over the boys because they were always there for one another, one minute fighting, and the very next minute laughing and extremely protective of each other.

Juliet also describes her twin sons as exceptionally close and even somewhat overprotective of each other. Juliet's older sons were also very protective and she relied on them for support.

The concept of circularity can be applied to the sibling sub-systems within this study. The mothers felt that all their children, including older siblings and co-twins, have an increased level of empathy for children with disabilities and that this empathy developed as a result of the birth of the twins. The participants' stories suggest that the sibling sub-systems are open and functional. However, they also indicate the presence of another sub-system, that of the twin dyad. The participants all commented extensively on their twins' exceptional closeness to one another.

All families undergo changes. Some of these changes alter the family structure and have lasting effects on the children as they grow and mature. Families may be exposed to various stressors such as divorce, death or the birth of a child with disabilities. A family's degree of cohesion and adaptability has an impact on its ability to cope with these changes. Within a family the term cohesion refers to the bonding relationships among family members on an emotional level. The degree of cohesion results in engaged or disengaged family relationships and varies within and between families. Adaptability refers to a family's ability to change when faced with stress and crises (Goldenberg & Goldenberg, 2004). The participants' stories clearly show that despite the stressors they encountered, the families adapted and maintained a functional level of cohesiveness.

Social Isolation and the Fear of Scrutiny

Research shows that when a child has a highly visible defect parents tend to withdraw from social interaction due to anticipatory shame and discomfort in relation to public scrutiny and questioning (Poznanski, 1973). The participants in this study all reflected to some degree the belief that society still stigmatizes people with disabilities. This belief resulted in intense fears and apprehensiveness about being seen in public.

Claire admits that she worried about how she would explain James' cleft to family and friends. *I admit I had other thoughts and questions racing through my head that I am not too proud of. Those thoughts included: How will I explain this to my family and friends? Can I keep my family and friends from seeing it? How could I take him out in public? Do I have to take him home this way? I admit that I was not prepared for the enormous challenge ahead of me. Claire describes the hospital as a setting*

that was safe, where she felt safe and understood. She describes how she left the hospital attempting to hide her babies and that this failed once people noticed that they had two babies. Doug was there with me and I could see that he was equally as distressed by all the attention that we got because we had two babies. After that first day I really didn't want to go out in public, to subject my babies to people's stares and questions. I was simply protecting myself, I didn't want the stares and the questions and the pity. Claire initially wanted to hide away and stay at home but this was not a possibility, as described in the extract above. After her first solo outing with her sons Claire and her husband started going out as a family.

This fear concerning other people's reaction is further illustrated by Claire's description of the experience of leaving the hospital after James' first surgery. This part of her story provides a clear description of the remarkable change children born with a cleft lip and/or palate undergo following surgery. Claire's story demonstrates the fear she experienced at the thought of other people's reactions to her son's appearance and how this fear shifted once he had surgery. *When I took my eight-month-old son back to the hospital for his surgical repair of his lip I thought how different it was from our original departure. When we left the hospital after his birth I had wrapped both boys like mummies, so terrified of what people would say of the child I had borne. When we came back four months later, I carried him proudly in my arms, returning curious glances with a proud smile!*

Abigail also felt the need to explain Zoey's cleft to her family and friends. She worried about how people would treat her daughters. *When the girls were younger I worried about them making friends. Would people notice Zoey's difference? And if they did, would Jayden's aggressive protectiveness over her sister scare them off. Would it be more difficult for the both of them to make friends?* Abigail recalls that in

the early days it was impossible for us to go out and see friends and take trips with the children, as we were either planning for one of Zoey's operations or caring for her afterwards. Abigail also had to contend with the 'celebrity status' of twin babies. She explains that no matter where we went or what we were doing, people wanted to come up and see the two cute babies, because we all know that two is cuter than one. Then they saw Zoey. Most people were kind, a very few said some not so kind things, but with that kindness came pity and the over used phrase dripping with sadness "you know they can do wonderful things nowadays". We understood that they were trying to lift our spirits, but hearing it over and over again, it really started to grate on our nerves.

Juliet also experienced concerns in relation to the way in which society would treat her son. *One of the biggest uncertainties is perhaps how other people will judge Justin on his appearance. I feared that he would be rejected and teased and that people would never see the Justin that I saw. Juliet also had some negative experiences with society: the stares and the questions that people gave Justin were almost too much for me to handle sometimes. I found myself getting angry at first, but now I realize that most people that whisper and point are just doing so because they are uninformed.* However, Juliet was also able to recognise and share some positive experiences. She points out that *the attention a family gets in these circumstances is unbelievable. Maybe it's because there we two or perhaps it was because of Justin's cleft but I found that people saw us as special, everyone wants to help, and there is a certain amount of glory or martyrdom involved. "How do you manage?" they ask. They could never do it. Well the answer to that is, you do it because you have to. There is no else to do it for you.*

The participants' stories all indicate that they initially had some difficulty engaging in social activities. Immediately following the birth of the twins the cleft lip and/or palate resulted in feelings of social isolation for all of the families. Some of the participants indicated that they lacked the energy to engage in social events. However, they also avoided social situations due to a sense of other people's discomfort, fear, and ignorance. Family outings were never simple and the participants often had to be content with outsiders watching, judging and expressing pity. As a result the participants were initially extremely apprehensive about taking their twins out in public. Their stories clearly demonstrate their concern regarding the way in which the world would treat their children.

Theme 3 - A Helping Hand

A well functioning family system consists of co-existing sub-systems, which interact with other sub-systems in the external environment (Goldenberg & Goldenberg, 2004). The support that family members provide each other, especially in families of children with disabilities, appears to be a major contributor to the adjustment and well-being of the entire family. Support is needed from various sub-systems in order to help mothers and families cope with the challenges of raising twins when one twin has a congenital facial deformity. Extended family members are also impacted by the birth of a child with a facial anomaly. These extended family members have an effect on the child with a facial deformity. The presence of support networks has been shown to be a mediating factor in determining how parents respond and adjust to the potential stressors involved in raising a child with a disability (Hanline, 1991; Trute & Hausch, 1988). The participants all reported receiving valued support from family

and the multidisciplinary team at the Facial Cleft Deformities Clinic. This support helped the families adjust to the unique stressors of having a family member with a cleft lip and/or palate. The participants' stories indicate that their family systems were able to receive support in various ways and to varying degrees. Many parents, and particularly mothers, experience a sense of loss of control of their lives when faced with a child with a birth defect. This sense of control can only be regained with sufficient social support (Van Staden & Gerhart, 1994). The participants clearly indicated that the support they received from external sub-systems was vital in allowing them to adjust to their situation.

Immediate Support in the Form of Family and Close Friends

The participants' stories all indicate various degrees of disengagement in the spousal sub-system, especially during the first year of the children's lives. Despite this disengagement the participants received support from their immediate family, specifically from their spousal systems and their own parents.

Juliet initially received support from her husband and he remained supportive throughout the entire process. *My husband could not bear to leave the hospital, during that time and for that I will always be grateful. He was my rock. All along we prayed to God to give us the strength, courage and wisdom to make the right decisions.* Despite experiencing a lack of support from her extended family, Juliet received a lot of support and assistance from her older children. However, as previously mentioned, despite this support Juliet struggled to speak about her feelings in relation to her child.

Although Abigail's husband was supportive, her primary source of support was her own mother. *Both my family and my husband's family came to our rescue during*

those first couple of weeks. Just making themselves available to look after my son (older child), take him to school and friends and just entertaining him as well as cooking and cleaning my house and just being around. Abigail also relied on her domestic worker who provided practical assistance.

In a similar way Claire experienced her husband as supportive, but described her own mother as her primary source of support. Claire explains that she thought of her mother as their saviour. *She moved in shortly after the boys came home and her presence was both welcome and needed. She didn't intrude on our space but was always available when I needed her. And she spoke to both Doug and I and just listened when we needed to blow off steam. She also made sure that Doug and I had time to ourselves, even if it just to sleep in the same bed together. Her support helped us through that difficult period*

Professional Support

The clinical literature concerning cleft lips and/or palates recognises the resulting distress and disruption to family life and emphasises the need to support and provide care for families. Families need to be heard and their experiences need to be validated and normalised. In addition, families require information about the nature of the illness and its treatment and each family member need to understand his or her role in terms of caring for the child with special needs. The participants described positive experiences with the professionals who provided support to them and their children. The mothers were highly appreciative of the team members who were perceived to have gone above and beyond the routine level of service. All the mothers reported using both formal and informal support to ensure that their children's needs were always met. During the first year of their children's lives the

support and information received from the nurses and team at the Pretoria Cleft Palate and Facial Deformities Clinic at the Oral and Dental Hospital was vital to the mothers' functioning. According to Allen and Vessey (2004), helping families master the treatment regimen and develop a management routine that accommodates other family activities and responsibilities is vital for adaptive family functioning

Abigail recalls that the cleft team at the Facial Deformities Clinic in Pretoria were a huge stress reliever, who never failed to answer any questions we had. Claire explains that except for the hiccup at the birth of the boys the nurses and staff at the hospital were terrific. They were very supportive and positive and within a few short hours after the birth we were already talking to experts about James' repair. A wonderful caring nurse spent hours with me, helping me try to nurse him, and teaching me how to use the specialised teats and bottles. Juliet recalls that the nurses were very helpful and brought much needed comfort during the long weeks we spent in the hospital.

The participants' stories clearly illustrate that their children's medical issues required almost constant attention and energy from the families. During the first year of the twins' lives, the mothers reported that they simply survived. Their lives revolved around caring for their children and in particular learning to care for their child with a cleft lip and/or palate. Their first major challenge was learning to feed their child. They then had to deal with the multiple surgeries their child would have to face. While the participants stated that their extended family and friends did not always understand the ways in which their daily lives and emotions were affected by their children's needs, they always made themselves available and offered assistance.

Theme 4 - Crisis as Opportunity

In the Chinese language, the written character for crisis and opportunity is the same. In other words, Chinese culture recognises that opportunity is inherent in crisis. It all depends entirely on how you look at a given situation (Brockner, & James, 2008).

In 1946, Viktor Frankl theorised that the meaning we attribute to life determines our behaviour. Suffering cannot be avoided but people can choose how to cope with it, find meaning in it and move forward with renewed purpose. The therapeutic modality based on Frankl's theory, known as logotherapy, holds that the primary drive in life is not pleasure, as maintained by Freud, but rather the discovery and pursuit of that which is meaningful (Frankl, 2006).

According to Frankl (2006) meaning in life can be discovered in three different ways:

- by creating a work or doing a deed;
- by experiencing something or encountering someone; and
- by the attitude we take toward unavoidable suffering.

The belief that individuals have the psychological freedom to determine their thoughts and feelings is fundamental to Frankl's philosophy. He emphasises that psychological reactions are not determined for people by any stimuli, no matter how powerful or devastating. Frankl's personal experiences of the horrors of imprisonment in concentration camps reinforce this concept. Frankl's autobiographical account of his experiences illustrates that it is possible to be exposed to a negative environment of death and despair and still find meaning in this suffering. Frankl believes that even when death appears inevitable people still have

the inner ability to reflect positively on the things they have accomplished in their lifetime and to put the current meaning of their suffering in perspective.

Although the birth of a child with a congenital facial deformity is an extreme stressor the intention of this research is not to equate it with the horrific experiences of concentration camps and torture. However, Frankl's ideas regarding the search for meaning are useful in exploring and understanding the participants' search for meaning in a context of having a child with a congenital facial deformity.

The participants' stories detail the enormous challenges that these mothers experienced when they discovered that one of their children had a cleft lip and/or palate. Their stories include the experiences of intense emotions such as pain, sadness and guilt, which were described earlier in this chapter. However, the participants' did not remain stuck in these feelings of hopelessness and helplessness. The literature reviewed in chapter 2 suggested that parents faced with the birth of a child with a congenital facial deformity would initially respond with intense emotions but that these emotions would dissipate as they underwent a grieving process where the loss of their fantasised child was mourned (Patel & Ross, 2003; Rigazio-DiGilio & Cramer-Benjamin, 2000; Van Staden & Gerhardt, 1994). The literature also indicates that parents of children with cleft lips and/or palates are able to make adjustments and live with the reality of their child's disability.

The participants' experiences echo the findings reported in the literature review. In spite of the emotional suffering they experienced these mothers became actively involved in the care and treatment of their affected children and were able to find meaning in their experiences.

The participants began their search for meaning and predictability by researching their child's condition and they relied on the professional team of the Pretoria Cleft Palate and Facial Deformities Clinic at the Oral and Dental Hospital for information regarding their child's condition and treatment. The mothers found the Therapy Protocol (see table 1 on page 14) very useful, as it provided them with some form of structure, control and certainty during a very stressful and uncertain time in their lives. The mothers also looked for ways in which to normalise their children's life experiences. This included agreeing to surgical interventions and ensuring that their twins received the same treatment.

The personal meanings that people attach to events have a significant influence on their coping activities. These personal meanings are affected by life goals, personal values and beliefs (Folkman & Moskowitz, 2000). Every human being has a specific understanding of how the universe works. People create patterns that ascribe order to their worlds and their lives. These patterns help them to understand both positive and negative experiences and to make sense of the world.

The participants' experiences with their children helped them to appreciate life and demonstrate more sensitivity to and tolerance of individual differences. They also became strong advocates for their children. These mothers seemed to respond to their experiences by vowing to be continually grateful for their child's life. Although the participants faced hardships and challenges in relation to raising a child with a congenital facial deformity they also felt that they had gained a lot from the experience. The participants re-framed the event of disability in such a way that it enhanced their own well-being as well as that of their families. In sharing their stories these mothers spoke about their strengths and their ability to cope with many problems within an extremely challenging, difficult situation.

These mothers were able to face the reality of their children's congenital facial deformities and all three mothers made a commitment to care for their child in the best possible way. They became responsibly involved in the parenting of their cleft-affected children. These participants were not discouraged by the loss of their fantasised child and actively engaged with the challenges of raising a child with a cleft lip and/or palate.

Juliet states that *this experience has taught me many valuable lessons. Above all, it has convinced me that human will can overcome obstacles that many consider insurmountable. Justin is a constant inspiration to all those who come in contact with him. There is no doubt in my mind that he will succeed in life. I consider myself lucky and remain grateful to all those who helped me and my family along the way. My experience has indisputably helped make me the person I am today.*

Abigail reflects that it was important for her to remember that although her child had been born with a bilateral cleft lip and palate it was not the end of the world. Instead, she had to *accept it as an opportunity to live and experience things that others will not ever have the pleasure to experience.* She goes on to explain that *raising my children has been a process of coping and adjusting to the challenges, some days were more difficult than others but in the end we all managed. I have three beautiful children who continue to surprise me and show me how wonderful it is to be a mother. Today I think that we are a well adjusted family.*

Claire describes the process as a roller-coaster ride that she handled to the best of her ability. She states that *there is no way that one can prepare oneself.* She is amazed by her *own strength and resilience. I was amazed at the resilience of my family, my husband kept going and my mom was there every step of the way and*

this kept me going. My family and friends were always there, next to us during the entire process, not only the good days but the bad ones as well.

Each person's experience of living with and raising a child with a congenital facial deformity is unique. Human beings handle challenging situations differently, depending on their past experiences, personality characteristics, current relationships and various environmental contexts in which their lives are embedded. These mothers' subjective experiences are therefore not representative of the subjective experiences of all other mothers raising children with congenital facial deformities. However, their stories do provide a glimpse of the unique experiences of mothers raising twins where one twin is born with a cleft lip and/or palate. Mental health care workers can learn from these mothers' stories in order to better help other mothers undergoing similar experiences. Their stories demonstrate an ability to face reality and a strong commitment to their children. These mothers worked hard and diligently to ensure their children's care and well-being in different circumstances related to their physical differences. They also attempted to shield their families from any burden related to their child's facial deformity. The participants were thus able to meet the challenges of being mothers to children with special needs. The challenges and barriers they experienced did not overshadow the joy and fulfilment they derive from motherhood. These mothers were able to affirm life despite suffering the loss of the 'perfect child' and continually being reminded of that loss in the form of the twin without a cleft lip and/or palate.

Conclusion

In this chapter, themes from the written accounts of Abigail, Claire and Juliet were identified. Where relevant these themes were compared to the literature reviewed in chapter 2. The theme of loss and intense suffering was particularly prominent in the participants' stories. The duration of this suffering was evident in that the intensity of these experiences was still felt years later, even though the participants' twins are now adolescents. The mothers' commitment to care was also highlighted. These mothers undertook the responsibility of caring for their children in the best way possible. The participants' stories confirmed the systemic perspective by indicating the reverberating effects of the birth of a child with a congenital facial deformity on all family members.

The participants' stories clearly indicate that these mothers and their families were able to adjust to the challenges. They were able to balance positive and negative feedback and thus ensure the stability of their family systems.

It is possible that a different researcher may have chosen to identify and highlight different themes or may have described the themes highlighted here in a different manner. However, the themes identified in this research appear to be similar to those identified in previous research regarding parents and their experiences of raising children with congenital facial deformities. It should be noted that individual people and families handle similar life circumstances very differently and it would therefore be unwise to make generalisations regarding the ways in which mothers and families experience their lives after a child has been diagnosed with a congenital facial deformity such as a cleft lip and/or palate. Cultural backgrounds and family belief systems (Burden & Thomas, 1986) as well as individual personality

characteristics, experiences with prior losses and life-long expectations of family life (Roos, 2009) can all influence the way in which mothers and families adjust to raising a child with a congenital facial deformity. The themes identified in this chapter thus need to be considered within the distinct context of each participant's story. Through sharing their stories the participants provide the reader with some insight into the emotions and coping strategies of mothers raising twins where one twin is born with a congenital facial deformity such as a cleft lip and/or palate.

The following chapter contains a reflection on the findings as well as a discussion of the strengths and limitations of this study. Finally, areas for further and future research are also highlighted.

Chapter 5

Conclusions and Recommendations

Every end

is a new

Beginning

(Anonymous)

Introduction

In this chapter the present study is evaluated. The strengths and limitations of the study are highlighted. The chapter concludes with suggestions for possible future research.

Reflections of the Study

The researcher aimed to gain an in-depth understanding of mothers' experiences of raising twins where one twin was born with a congenital facial deformity such as a cleft lip and/or palate. The research topic addressed a gap in the literature. It was hoped that this study would provide professionals in the treatment and care of mothers with twins where one twin has a cleft lip and/or palate with a better understanding of the intensity and complexity of those mothers' experiences. These

mothers' experiences are often overshadowed by the needs of the child and this study was designed to present them with the opportunity to comment on their experiences and share their stories. The aims of the study have been successfully accomplished as the participants' accounts all provide rich personal meaning and in-depth insight into the personal experiences of these mothers.

The aim of the study was not to arrive at generalised findings that could be applicable to the general population. Instead, the researcher identified themes within the participants' stories. These themes were then linked to the literature reviewed in chapter 2. This method of data analysis generated rich and complex results.

Through the presentation of thematic discussions the researcher highlighted the participants' emotional experiences. Particular attention was paid to the participants' experience of fluctuating emotions and this was linked to the interdependence of change in families with a child with a cleft lip and/or palate. It was evident from the study that rules and patterns in terms of communication, intimacy, problem solving, access to system resources, conflict and crisis management, role functions and system openness and closedness, were especially pivotal. Relationships, and especially long term intimate relationships, are generally characterised by reciprocal support, nurturing and care-giving, interdependence, and division in terms of responsibilities and work, such as child-care, taking care of household duties as well as responsibilities in terms of providing an income. The participants' relationships, roles and boundaries against the background of a systemic framework, with its circular view of causality illustrated the impact of the birth a child with a congenital facial deformity on the participants and their spouses as well as additional family members. Despite the impact of this unique stressor on the families the researcher

illustrated how the mothers found meaning in parenting a child with a cleft lip and/or palate.

The results of this study reflect the central themes which underlie each participant's unique experience regarding the topic being studied. Together these themes tell the story about the initial reactions to the news of the pregnancy, the discovery of the cleft lip and/or palate, the life changes experienced by the mothers and members of their family systems due to the cleft lip and/or palate, the support in the form of immediate family members and friends as well as professional support provided by the team at the Pretoria Cleft Palate and Facial Deformities Clinic at the Oral and Dental Hospital. Lastly the personal meanings attributed to their experiences of raising twins when one twin is born with a congenital facial deformity such as a cleft lip and/or palate.

Strengths of the Study

This study allowed three mothers an opportunity to share their experiences of raising twins where one twin is born with a congenital facial deformity such as a cleft lip and/or palate. These personal accounts provided a description of a topic area that was previously unexplored. As mentioned in chapter 2, previous research had focused more on the child with the cleft lip and/or palate than on parents' experiences of raising a child with a cleft lip and/or palate.

The social constructionist perspective used in this study allowed a co-constructed reality to emerge between the researcher and the participants. From the co-constructed conversational reality to which the unique lived experiences of the

participant mothers, their understanding of their experiences as well as the researcher's experiences, understanding and questions were brought, emerged new knowledge, meanings, in-depth understanding and themes. These new insights allowed the researcher to come to know and appreciate how the stories of each participant cannot be removed or separated from the context in which it was originally formed and shaped. Becvar and Becvar (2006) argue that reality is not external to any person; rather it is constructed by each individual as they bring their own personal perceptions to bear on it, give meaning to it and give order to it.

Furthermore, the researcher has also realised how each participant's story is based on predetermined beliefs and so does not represent an exact account of reality. Therefore, the manner in which each participant perceives the world and events that occur within it is inevitably coloured by their tinted lenses of previous experience, culture and society that they wear. For this reason, Doan (1997) advocates that we should move away from the belief in a single, objective and universal truth, towards the existence of many possible multiple "truths".

The qualitative research approach used in the study gave the researcher the opportunity to share her aims and the research process with the participants. The participants were thus aware of the nature of the process in which they engaged. They were allowed to tell their stories in their own way and were viewed as experts in their own experiences. This research approach was very different to the approaches used in previous studies on congenital facial deformities such a cleft lip and/or palate and parenting of children with disabilities (Rigazio-DiGilio & Cramer-Benjamin, 2000). Most of the previous studies focusing on parenting made use of survey and questionnaire methodology and were therefore not able to provide rich descriptions of the parents' experiences (see, for example Cameron, Snowdon, &

Orr, 1992). In contrast the theoretical framework chosen for this study allowed for the application of a circular view of causality and provided the researcher with an appropriate lens through which to explore the participants' experiences within the family context.

The researcher also made use of the social constructionist epistemological framework to focus on the participants' unique experiences. From a social constructionist viewpoint the researcher and the participants are seen as interconnected. Thus, within this research the researcher and the participants interacted with one another to create new knowledge and meanings in the form of themes, meanings and understandings. These themes, meanings and understandings emerged from the co-constructed research reality of specific relational contexts and should not be regarded as the ultimate or definite accounts of the participants' experiences. It is possible that these themes will change as the mothers progress in their journeys.

The use of a qualitative research approach also allowed the researcher to fully disclose to the participants the aims and the processes that she intended to follow. Given the painful nature of the topic under investigation it was important that the research approach was respectful and that rapport and trust existed between the researcher and participants. These elements were vital in creating a context in which the participants felt comfortable enough to disclose their personal experiences and stories. The collaborative and interactive nature of the qualitative research approach helped to create a respectful research context in which the participants could be respected as experts in their own lives and experiences and became co-researchers within the context of the research project (Rapmund, 2005). All three participants indicated that they valued the opportunity to share their experiences and to provide

assistance to other mothers and professionals working with families with a child with a cleft lip and/or palate.

Various strategies were employed to ensure the reliability and validity of this study. In particular, reliability was obtained through the clear delineation of this study's overall scope and field of interest. Both the aim and the rationale of this study clearly reflect what this study is about, why it is important and what the study aims to achieve. The orientation of this study is also adequately disclosed in that, as the researcher clearly demarcated her personal interest in the study and her expectations thereof. The nature of the study was also clearly explained.

Within a social constructionist research stance trustworthiness and dependability are considered appropriate alternatives to reliability. These concepts refer to the degree to which the reader is convinced that the findings occurred as stated by the researcher. In this study the principles of trustworthiness and dependability were met through the researcher's disclosure of her research orientation and through the provision of rich descriptions that highlighted the social and cultural contexts of the researcher and the co-researchers. The researcher also remained aware of the possible impact of her own frame of reference and her own worldview. In order to ensure that the findings presented were consistent with the participants' stories, every effort was made to continually refer back to the stories during the interpretation process.

Validity was ensured through the use of triangulation. The methods of triangulation include gathering information from various sources, using multiple methods of data analysis and basing the analysis on multiple theories and interpretations. In order to ensure that information was obtained from multiple sources the researcher

conducted a literature review, which was reported in chapter 2. In addition, the researcher also made use of the participants' individual stories and reflections, her own meta-observations based on the reading and re-reading of the participants' stories and engaged in dialogue with the study's supervisor. Validity was further ensured by clarifying the researcher's interpretations of the participants' experiences with the participants and the study's supervisor. The researcher thus remained constantly aware of the existence of multiple interpretations. These processes allowed the researcher to honour the constructions and perspectives of her participants and supervisor as well as the voices of previous research and to integrate these into the study.

The nature and the aims of this study meant that the participants were asked to share very personal information, which in itself raised ethical concerns. The researcher was thus mindful of the ethical considerations within this research. At times, the researcher had to ensure that she did not lapse into the role of therapist. The researcher clarified her role in the context of this study and limited her enquiry and collection of information to the realm of the study and her areas of expertise. Participants were assured that they could terminate the research process at any point. In addition, the researcher clearly explained the research process and her expectations to the participants. The participants were also informed of the possible impact of the study and were thus able to provide informed consent to participate in the study. The welfare and privacy of the participants were of utmost importance to the researcher and pseudonyms were used throughout the study.

Limitations of the Study

The researcher is aware that her interpretations and re-production of the participants' stories were influenced by her own perceptions, values and worldview. The researcher's involvement with the participants prior to them writing and sharing their stories also had an influence on the ways in which the stories were constructed. The written stories were thus co-constructions between the researcher and the participants. The researcher thus attempted to remain aware of the manner in which she communicated her views and ideas to the participants. In addition, the researcher was also clinically trained in a specific research reality within which a specific relationship between the researcher and the participant is created, therefore the creation of themes and interpretations are viewed as co-constructed between the researcher and the participants and are not absolute truths. It is possible that a different researcher may have highlighted and included different themes. The results of this study cannot be generalised to the larger population. However, the aim of this study was not to arrive at generalisable findings but instead to provide detailed descriptions and interpretations of the participants' personal experiences.

A further limitation of the study is that it focused on a very small group of participants. It is possible that other participants and families may have handled similar life circumstances very differently. Thus, as has been previously mentioned, the results are not generalisable to other contexts. Various factors including cultural backgrounds and family belief systems (Burden & Thomas, 1986), individual personality characteristics, experience with prior losses and life-long expectations of family life (Roos, 2009) impact the ways in which families adjust to difficulties. Future research should focus on the impact of these factors.

A further limitation of the study concerns the homogenous nature of the participants, who were all English speaking, white females with very similar cultural and socioeconomic backgrounds. The sample was therefore not representative of the diverse South African population. It is possible that the experiences and meanings of other cultural groups are very different. This study should thus be seen as a starting point for research and later studies should explore the impact of various cultural factors.

A final limitation of this study involves the exclusion of the fathers from the research study. This could result in the study being seen as one-sided. However, an attempt was made to address this limitation by acknowledging that the mothers' experiences cannot be seen in isolation but must be viewed as part of processes within the family system. The use of family system theory allowed the researcher to acknowledge the roles played by other family members. However, additional information may have been provided if the other members in the family system had been included in the research process.

Further Exploration and Future Research Areas

What stood out throughout the study is the difficulty the participants experienced, expressing themselves. The participants' stories indicated that they kept their painful emotions to themselves and they were not able to discuss these emotions with their husbands and their journeys, especially in the beginning, were quite lonely. Their stories also indicate how very vulnerable they were, as this was also the time when their children placed high demands on them as mothers.

The information shared by the participants in this study serves as a reminder of the importance of listening to the mothers of children with disabilities. These mothers provide a unique perspective and can provide valuable information to health care professionals concerning how to best support families.

This study is a valuable addition to the body of literature concerning the experiences surrounding children with cleft lips and/or palates. Its specific focus on the experiences of mothers who are raising twins where one twin was born with a congenital facial deformity such as a cleft lip and/or palate addressed a gap in the literature. However, the scope of the study was limited and additional studies concerning this topic are indicated. These studies should focus on heterogeneous groups in order to gain in-depth understandings of mothers' experiences in these groups. In addition, studies that include fathers' experiences may provide additional information regarding the experience of parenting children with cleft lips and/or palates. Studies that include both fathers and mothers would also be valuable. Additionally with regard to the systems perspective it would prove useful to include other members of the family system such as children that influence the said system, as well as the professionals that treat these families.

Conclusion

In conclusion, it is important to remember that research into this area is by no means finished. This research represents an attempt to begin addressing the topic and is not intended to be definitive. This work continues to live with the researcher in every revision, in every reflexive thought, in a myriad of conversations and in memories of her own personal experience of growing up with an identical twin.

The researcher believes that this research has given value to the mothers' words, thoughts and insights. Readers were provided with an opportunity to come into contact with these mothers' realities and thus experience things they would otherwise have been unable to experience.

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