THE EFFECT OF A CHILD WITH A CLEFT LIP AND PALATE ON FAMILY FUNCTIONING

by

EILEEN PATRICIA RICH

Submitted in part fulfillment of the requirements
for the degree of

MASTER OF ARTS

in the subject

PSYCHOLOGY

at the

UNIVERSITY OF SOUTH AFRICA

SUPERVISOR: MRS E VISSER

JOINT SUPERVISOR: PROFESSOR JM NIEUWOUDT

OCTOBER 2003

ACKNOWLEGEMENTS

I would like to express sincere appreciation to:

- Professor J.M. Nieuwoudt and Mrs E. Visser for their continual support, guidance and encouragement.
- Professor K.W. Butow of the Facial Cleft Deformity Clinic of the University of Pretoria, Department of Maxillo-facial Oral Surgery, Faculty of Dentistry, University of Pretoria, for permission to carry out this study.
- Mrs I. Benninghof and Mrs D. du Plessis of the Facial Cleft Deformity Clinic of the University of Pretoria, Department of Maxillo-facial Oral Surgery, Faculty of Dentistry, University of Pretoria, for their professional advice and extensive assistance.
- Professor F. Van Staden for his continuing motivation and interest over the last three years
- My husband, Steve and sons, Sean and Craig for their infinite patience, understanding and constant support.
- Gina for her endless patience and practical help without which this document would never have been completed.
- Christa and Sunette for their unvarying encouragement and friendship.
- The families included in this study, for their time and collaboration to make this study possible.

DECLARATION

I declare that 'The Effect of a Child with a Cleft Lip and Palate on Family Functioning' is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

Signed: _____

Eileen Rich

SUMMARY

The present study explored the effect of the birth of a child with a cleft lip and palate on family functioning within the context of family systems theory. Five families, each with a child who was born with a cleft lip and palate, were included in the study. The five couples were all married and they were the biological parents of their children whose ages ranged from two months to five years. All five sets of parents were initially interviewed together and then had separate individual interviews where the Family Assessment Measure-III was administered. The results reflected each family's distinctive patterns of interaction and how they adapted to the birth of a child with an orofacial cleft. Factors found to affect family functioning included: External support systems, individual coping skills, family rules and boundaries, open communication and cohesion among family members.

Key Terms:

Cleft lip and palate; Orofacial cleft; Family functioning; Family structure; Family systems theory; Family Assessment Measure – III (FAM-III); Coping behaviour; Task Accomplishment; Role Performance; Communication; Involvement;

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CHAPTER 1

AN INTRODUCTION TO CLEFT/LIP PALATE

"What is a face really? Its own photo? Its make-up? Or is it a face as painted by such or such painter? That which is in front? Inside? Behind? And the rest? Doesn't anyone look at himself in his own peculiar way? Deformations simply do not exist." Pablo Picasso (1881 – 1973) Quoted in *Picasso on Art (* Ashton, 1972)

BACKGROUND

Unfortunately there are few people who feel as Picasso does that there is no such thing as a facial deformity. Generally lacking the creative eye and sensitivity of the artist, most of us judge people we meet on the physical face they present. When a child is born with a facial deformity such as an orofacial cleft, parents are cruelly aware that others will rarely see the sensitive, hurting human being behind the distorted features.

The birth of such a child has a great impact on the family system as not only do parents have to adjust to the normal demands of parenthood, they have to cope with increased stresses and challenges resulting from the disability (Chow, 2002). What is usually a cause for celebration becomes instead a situation fraught with fear, uncertainty, sadness and apprehension if the child is facially deformed.

Most mothers, whether they have a disabled child or not, have been found to generally experience a higher level of stress regarding their parental role than do fathers and this stress is not only related to a child with a disability (Pelchat, Bisson, Ricard, Perreault, & Bouchard, 1999b). All mothers go through both positive and negative changes after the birth of a child. However, mothers who give birth to a child with a cleft lip or palate report higher levels of negative changes in themselves (Clifford & Crocker, 1971). It is well documented that mothers of disabled children report "higher levels of depression, stress, anxiety and emotional distress than mothers of non-disabled children" (Pelchat, Ricard, Bouchard, Perreault, Saucier, Berthiaume & Bisson, 1999a. p. 378). Although similar findings have been noted in respect to fathers responses, a review of the literature indicates that there has been very little research which has focused specifically on the fathers perspectives, emotions and experiences (Nishimoto, 1999). Kanal (1999) found that the only significant difference in attitude between mothers and fathers towards the birth of a child with a facial cleft deformity was that the fathers'

initial reactions were more negative. There are conflicting findings as to whether the birth of a baby with a cleft lip/palate negatively impacts on the couple's marriage. Some studies suggest that such couples are more at risk to "develop relational and communication problems" (Pelchat *et al.,* 1999b, p. 465), while others found that the incidence of divorce is less than in the general population (Van Staden & Gerhardt, 1994b).

Both parents of a child with an orofacial cleft have been found to "experience more stress and adaptation problems than parents of non-disabled children" (Pelchat e*t al.*, 1999a, p. 378). The severity of the cleft and "the immediate impact and the long-range effects may influence the parent's perceptions, reactions and needs" (MacDonald, 1979, p. 188) and initially they experience many conflicting emotions.

They feel shock, anxiety and revulsion due to the "intolerable appearance of the cleft lip" (Clifford & Crocker, 1971, p. 298). Apart from the practical aspects of coping with their infant's problem, parents may experience feelings of revulsion due to the facial distortion (Clifford & Crocker, 1971). Disfigured faces often arouse fear and are associated with negative traits and the mistaken assumption that "ugly is bad" (Dijker, Tacken, & van den Borne, 2000, p. 414). This view often plays a major role in the initial reactions of others and parents must cope with the fact that their child is likely to receive rejection from others based on appearance. Often it is found that the impact of this initial shock continues to have an effect on both the family and parenting functioning for months and even years. A study to determine the impact of child oral and oro-facial conditions on the family found that nearly 75% of caregivers/parents reported that their child's disability affected their lives 'sometimes' or 'often/ everyday' for the preceding three-month period. Other effects included financial problems, conflict within the family and impact on parental emotions (Locker, Jokovic, Stephens, Kenny, Tompson, & Guyatt, 2002).

They feel confused and anxious. Such emotions are a normal reaction " following the birth of any infant, and may be exacerbated when the child has a problem" (MacDonald, 1979, p. 188). Most parents are often not prepared for the birth of a child with a facial cleft deformity and generally do not have the necessary knowledge to deal with the unexpected deformity. (Van Staden & Gerhardt, 1994b). Chow (2002, p. 4462) described parents in such a situation as "embarking on a journey to reach out to seek information, then moved into decision making". They need time to adjust and be able to discuss their feelings with professionals so that they can get the severity of their child's problem into perspective (Mac Donald, 1979). Support from

relevant professionals combined with correct information serves to reduce the anxiety level and enable parents to cope more effectively with their problem (Van Staden & Gerhardt, 1994a).

They experience feelings of sadness and depression and sometimes feel they will never again feel happiness (Rosenstein & Schulman, 1990) *as they have "lost the perfect baby nurtured in their imagination*" (Tisza & Gumpertz, 1962, p. 86). Most parents need a period of mourning before they can deal with their grief and conflicting emotions (Barden, 1990). During the pregnancy, most parents foster "hopes of perfect offspring" (Van Staden & Gerhardt, 1994a, p. 14.) and therefore often experience the different stages of denial as described by Kűbler-Ross in her research on death and dying. It is common to fluctuate between anger, bargaining and depression before reaching a stage of acceptance (Barden, 1997, cited in Van Staden & Gerhardt, 1994a).

They experience anxiety and helplessness, as they do not know the extent of the problem and how they will deal with it. Initially many mothers and fathers make use of various defenses such as rationalization to enable them to deal with the anxiety they experience. As the shock gradually subsides the "initial subjective and highly emotional thinking is replaced by a more objective and educationally informed opinion" (Van Staden & Gerhardt, 1994b, p. 17). A sense of a loss of control over one's life is a common experience of parents who are suddenly faced with a child with a deformity. If they have access to a strong social support system, which enables them to realistically, assess the problem and aids in development of coping skills, their helplessness will diminish as they gradually reestablish this sense of control. As confidence in their coping abilities increases, the problem appears manageable and less traumatic (Van Staden & Gerhardt, 1994b).

They feel shame and guilt which is often intensified if either parent feels they did something wrong during the pregnancy to damage the baby. Many emotions parents experience are not always acknowledged to professionals or even family members and only in retrospect do parents admit that the first few days after the birth of their child "were some of the most difficult moments they have faced" (Barden, 1990, p. 347). One study found that some mothers who had thought about termination of their pregnancy or who wished they were not pregnant viewed their child's disability as a punishment for their thoughts (Van Staden & Gerhardt, 1994a). Fathers too suffer feelings of guilt and shame. They may blame themselves from not abstaining

from sex during the pregnancy or may feel they must be in someway be responsible for the deformity as “We gave her her genes” (Rosenstein & Schulman, 1990, p. 47). They need to be informed as to the various causes of cleft lip and palate so as to minimize their feelings of guilt and anxiety. According to Nwanze and Sowemimo (1987) “Myth and superstition are reported to accompany the birth of physically defective children in many communities” (cited in Van Staden & Gerhardt, 1994a, p. 14).

A study assessing maternal risk factors in the development of cleft lip and palate found only that more mothers, who gave birth to a child with this anomaly, stated they had some illness early in their pregnancy (Natsume, Kawai, Ogi & Yoshida, 2000). Another study found no association between the incidence of cleft lip and palate and factors such as vitamin consumption, smoking, urinary tract infection and recreational drug use during pregnancy. In fact mothers with children who were born with an orofacial cleft were found to drink less alchohol than mothers of children with no birth defect, which prompted researchers to propose that moderate alchohol consumption could have some protective qualities (Beaty, Wang, Hetmanski, Fan, Zeiger, Liang, Chiu, Vanderkolk, Seifert, Wulfsberg, Raymond, Panny & McIntosh, 2001). Natsume *et al*., (2000) had similar findings regarding alcohol usage during pregnancy and other studies found that no single environmental factor could satisfactorily be associated with the incidence of cleft lip and palate (Steinwachs, Amos, Johnston, Mulliken, Stal, & Hecht, 2000).

They feel resentment and anger as they enter a period of mourning for the loss of “an image of the perfect baby” (Clifford, 1987, p. 51). During a pregnancy most couples have plans and hopes for the future, which have to be postponed or changed while they deal with their child’s disability. This often also involves financial hardship due to medical expenses and a possible loss of income when one parent, usually the mother, has to put her career on hold while she takes on the major aspects of child care (Rosenstein & Schulman, 1990). The treatment of facial cleft deformities involves many medical and surgical interventions, which increase the stress on the whole family unit, but particularly on the mother, who usually has the responsibility of the major part of the caregiving. A strong support system can prevent the primary caregiver from feeling overwhelmed by her responsibilities and decrease the stress level (Van Staden & Gerhardt, 1994b). It has been found that parents who themselves have unsupportive parents struggle to adjust to their child’s disability and many react to societal attitude by attempting to hide their infant’s deformity (Speltz, Endriga, Fisher & Mason, 1997).

Along with feelings of inadequacy and guilt, many individuals also feel anger towards their partner whom they may blame for the deformity: “It’s because of your side of the family” (Rosenstein & Schulman, 1990, p. 47). However, although many parents share similar emotions and reactions in response to the birth of a child with a cleft lip and palate, each experience is “ultimately deeply personal and unique” (Rosentstein & Schulman, 1990. p. 48).

1.1. APPEARANCE AND SOCIAL ATTITUDES

Is appearance really so important and are the fears of the parents of a child with a facial deformity justified?

Research carried out in the past few decades has demonstrated that the way individuals perceive physical attractiveness influences “adult-adult, adult-child, and child-child social relationships” (Hildebrandt, & Fitzgerald, 1981, p. 56). Most studies carried out to investigate the phenomenon of appearance confirms that individuals who do not meet society’s criteria for acceptable beauty experience significant disadvantages. Therefore, when a child is born with a cleft lip and palate parents have very real worries and fears as to how the rest of the world will react.

According to Barden (1990, p. 350), research and theory has focused on the possibility that “facial morphological variables could be so powerful that they may influence important social interactional processes from infancy through adulthood”. The face is therefore of prime importance in the way we regulate social interaction and behaviours. An individual who suffers from an abnormality of the face begins life with enormous disadvantages. Results of many studies have indicated that observers attribute positive qualities and abilities to attractive individuals and negative ones to unattractive individuals (Adams, 1977; Barden, Ford, Wilhelm, Rogers-Salyr & Salyr, 1988; Langlois & Stephan, 1981, cited in Barden, 1990, p. 351).

In 1960 there were many television and radio debates between the then presidential hopefuls, Richard Nixon and John F. Kennedy. It was found that when these debates were watched on television, the viewers generally declared Kennedy the winner. However, those people who only listened to the debate on the radio were not influenced by the appearance of the contenders and focused instead on the content of what was being said. In these cases, Nixon was declared the winner (Krauss, in David & Baran, 1981, cited in Brownlow, 1992). The

physical appearance of the two men therefore had a profound impact on how people viewed their ability and knowledge. The more attractive communicator proved to be more persuasive than his less attractive opponent (Brownlow, 1992). According to Eagly and Chaiken (1984) attractiveness is a highly noticeable trait and may therefore "precipitate a transfer of positive affect. That is, we like attractive people and are happy to be in agreement with them" (cited in Brownlow, 1992, p. 102).

Facial appearance has a profound impact on social attitudes. Dijker *et al*., (2000) found that individuals who possessed facially deviant features were judged more negatively when they displayed negative expressions than individuals who lacked such features. A Dutch national survey found that 47% of respondents indicated that assessment of facial features were one of the ways that they could determine whether an individual suffered from a mental handicap (Dijker *et al.,* 2000). This survey indicated that faces that present as deformed or disfigured induce strong negative reactions from others ranging from fear and repulsion to avoidance. It also demonstrated that negative traits are projected onto such individuals as it is assumed that "ugly-is-bad" (Eagly, Ashmore, Makhijani & Longo, 1991, cited in Dijker *et al.,* 2000, p. 414).

1.2. SELF-ESTEEM AND APPEARANCE

There is a strong association between self-esteem and an individual's satisfaction with his physical appearance. Positive correlations have been found between an individual's perception of his/her own physical attractiveness and his/her self-esteem (Nell & Ashton, 1996). People who assess their facial features in a favourable light "have higher ratings of self-esteem than people who evaluate their facial appearance less favourably" (Kenealy, Gleeson, Fruce & Shaw, 1991 cited in Kwon, 1997, p. 900). More satisfying social interactions have been reported by individuals who perceive themselves to be attractive (Garcia, Khersonsky, Stacey, 1997). Children develop an awareness of self from about the age of eighteen months. Their sense of identity and worth develops and is influenced to a large extent on how others, specifically significant others, respond to and treat them (Cooper, 1993). The response of peers influences how individuals perceive their own level of attractiveness (Garcia *et al.,* 1997). For an individual to grow into a stable, socially well adjusted adult it is vital that a positive self-esteem is developed in the childhood years. One of the factors that interact to produce self-esteem is the physical attractiveness of a child (Cooper, 1993).

Numerous studies have found that a child's physical attractiveness determines how others behave and react to him, which in turn influences how he responds. For example, a child who is perceived as 'ugly' may be treated as an individual who is not as intelligent, friendly or as popular as his more attractive peers by both adults and other children alike. As a reaction to this stereotyping, such a child may perceive himself as less worthy and desirable and develop expected negative responses and lowered self-esteem. This social stereotyping is a grand narrative that needs to be challenged in our society. Teachers, parents and other influential adults must be made aware of the far reaching consequences of such negative interaction on the social development of those children who are less attractive or facially deformed (Cooper, 1993).

1.3. CLEFT LIP AND CLEFT PALATE

Cleft lip describes a congenital fissure or fissures in the upper lip while cleft palate is the term used to refer to a congenital fissure or fissures in either the soft palate or in both the hard and soft palates. A cleft palate may or may not occur with a lip that is clefted. Worldwide, the average incidence rate is 1.49 per 1000 among the Caucasians and 0.44 per 1000 among the black population. In South Africa the "reported incidence rate is 1.38 per 1000 among the Caucasians and 0.42 per 1000 among the Black African population" (Hardy & Butow, 1999). Cleft lip and/or palate occurs in about 1 in 750 births in the United States and the incidence rates vary by gender and ethnic group but not by maternal age or socioeconomic status (Speltz *et al.,* 1997, p. 12).

There is no one cause for this disorder which appears to be due to a number of differing, often interacting factors ranging from malnutrition to drugs to hereditary factors. Both cleft lip and cleft palate occur when there is arrested midline facial development during the first trimester but each has distinct genetic etiologies (Speltz *et al.,* 1997). Cleft lip may involve the bones of the upper jaw and/or gum ridge as well as the lip causing mild to severe nasal distortion. It may by unilateral or bilateral. Clefts may occur in the hard or soft palate or both. A cleft results when normal development of those parts which combine to form palate and lip fails to occur (Morley, 1962).

1.4. RESEARCH CONTEXT

My research originated at the Facial Cleft Deformity Clinic of the University of Pretoria. This institution was founded in 1983 and is one of the fastest growing clinics in the Southern African region. At the beginning of 2002, 1716 patients were registered at this clinic of which 1661 were cleft cases and 55 were craniofacial and other cases (Hardy & Butow, 1999). Patients from all over South Africa and Namibia as well as from countries such as Zimbabwe, Zambia, Congo and Mauritius are referred to this clinic for treatment by a multidisciplinary team consisting of –

- Maxillo-Facial and Oral Surgeons
- A paediatrician
- Speech and language therapists
- An audiologist
- Medical Geneticists
- A Clinical Psychologist
- Paedodontists
- Orthodontists
- Professional Community Nurses
- Prosthodontists
- Oral Hygienists

Depending on the severity of the facial deformity, a child may need the intervention of each of these members of the treatment team at differing stages. The process often continues throughout the childhood years and in some cases minor problems may be dealt with during the adult years as well. The parents of a child with a facial cleft deformity perceive the surgical intervention as anxiety provoking but essential.

At this clinic two registered community nurses with psychiatric training, who have specialised in the area of facial deformities, carry out the initial counselling in the hospital environment. If possible, mothers and babies are seen within the first twelve hours after the birth and are encouraged to attend the clinic for an assessment within twenty-four hours. The information, support and practical advice they provide on how to deal with such problems as the feeding of the baby, enable many parents to adjust to the immediate shock of their child's deformity.

1.5. AIM OF THE STUDY

The main aim of this study is to examine the impact of the birth of a child with a facial cleft deformity on the marital relationship and general family functioning.
The following aspects were explored:

1.5.1. Family Structure and Functioning

- How the birth of a child with an orofacial cleft deformity affects each subsystem of the family.
- Family roles
- Boundaries within the family
- Family rules, values and norms
- Interaction within parental subsystem

1.5.2. Evalutation of the Structure and Functioning of the Family Focused on:

- Effects of the birth of a child with a cleft lip and palate on each subsystem
- Effects on the parental relationship
- Effects on the sibling subsystems
- Effects on family relationship with external subsystems such as extended family and friends
- Positive effects of experience on relationships

1.5.3. Parental attitudes towards the facial appearance of a child with a cleft disability

- Parents' distress at birth of an 'imperfect' child
- Parents' emotions resulting from external feedback

This study is exploratory and descriptive. In any study of this nature it is difficult to determine whether family functioning is specific to the cleft lip and palate deformity, is a result of it or if it precedes the development. Such questions are therefore outside the scope of this study.

CHAPTER 2

FAMILY SYSTEMS PERSPECTIVE

2.1. INTRODUCTION

Bateson (1971), defines a system as “any unit containing feedback structure and therefore competent to process information” (Bateson, 1971, p. 242). Family members influence and are influenced by the system into which they are born. A child born with a facial deformity introduces a stressor into the family system. In this chapter, I discuss the interaction between the child with a cleft lip and palate and the way in which the family functions from the perspective of system’s theory.

2.2. FAMILY LIFE CYCLE

The family life cycle is “a process from birth, through growth to decline and death” in which cyclical and linear changes occur. These changes involve changes in attitudes, relationships, roles and social change (Lauer & Lauer, 1997, p. 338).

All families pass through certain predictable events or stages. A critical transition point such as marriage, birth of a child or retirement marks each stage or phase of the developmental process. Roles and responsibilities change as the family moves through each new stage of the life cycle. Each phase of the family life cycle requires that family members learn new tasks and roles and adapt to developmental challenges. To successfully master the tasks of a new period of development, it is essential that the tasks of the previous stage have been successfully accomplished. For example, a young couple that has not separated from their families of origin will experience conflict when they enter the next developmental phase and become parents (Goldberg & Goldberg, 1985).

Life cycle transitions affect all family members concurrently. Therefore as the young married couple is dealing with the transition to parenthood, their parents are simultaneously adjusting to the role of grandparents. Even though the average Western family has a two generational family unit, all family members still respond to past, present and future relationships within this family system (Carter & McGoldrick, 1989).

A newly married couple has a family structure and roles, which are generally flexible, and it is likely that their lives do not change as much by getting married as it does by having a child. A highly significant transition point in the family life cycle is the decision to have a child. There are new tasks that this couple must now accomplish as they prepare to care for a younger generation and certain adjustments must be made. Both partners must be willing to give up their mobility and free time and develop tolerance and patience. If one partner has to shoulder all the child caring responsibility, feelings of frustration and resentment may develop which will impact on the marital relationship (Lauer & Lauer, 1997). Research has found that family stress increases as the family prepares to move from one developmental stage to the next and "symptoms are likely to appear when there is an interruption or dislocation in the unfolding family life cycle" (Carter & McGoldrick, 1989, p. 5).

Early on in their relationship, a marital dyad must develop mutually satisfying new behavioural patterns, which will eventually become familiar and will be 'their' way of dealing with each other. Each partner enters the marriage with a set of rules and expectations, which he/she brings, from his/her family of origin. These rules must be acknowledged to ensure that each partner retains his/her sense of self, while also being reconciled so both partners can evolve their own unique patterns of interaction. Mutuality occurs when relationships develop in which each member respects the individuality of others while still retaining a separate, unique identity.

The life cycle of most families is disrupted by a minor or major unexpected event at some stage, such as accidents, divorce or the birth of a child. The birth of a child with a facial deformity adds to the stress of this unexpected event and may overload the family's coping mechanisms. Most family groups have developed their own unique techniques, which enables them to successfully cope with most everyday problems. Although certain problems are inevitably more stressful and frustrating than others, members are generally satisfied that these methods allow them to manage most of their problems. A family crisis arises when such an event disrupts the normal functioning of the system and the family's normal problem-solving strategies are inadequate to deal with the situation. When usual coping behaviour is inadequate, the family system must restructure and organize itself to find new ways to deal with the problem. Mobilizing family resources and reorganizing family functioning enables some family systems to cope with their crisis. The interaction of family members and their functional re-organization during this crisis period will determine the success of the outcome (Goldberg & Goldberg, 1985).

As new events occur within a family life cycle it is necessary for roles and rules of relationships to change and evolve. If this modification of roles does not take place when a new event occurs a crisis may result as the system becomes more disorganized (Becvar & Becvar, 1999).

From family systems perspective, dysfunctional behaviour is viewed as a representation of a system that is in disequilibrium and indicates that there are problems with task accomplishment and moving to the next stage of the life cycle. Dysfunctional behaviour is related to both *vertical* and *horizontal* stressors. Vertical stressors include family attitudes, myths and prejudices, which are patterns of interacting and functioning, which are passed down through generations. Horizontal stressors include both transitional developmental crises and unexpected events, which occur throughout the life cycle (Goldberg & Goldberg, 1985).

Family Systems theory developed from the work of many pioneers and resulted in several "orientations to family therapy". These include communications family therapy, intergenerational family therapy, structural family therapy and many more. While each theory has it's own "unique emphasis" (Lastoria, 1990, p. 44) many common elements and similarities do exist. All schools view the family as an engine with interdependent parts and if "one part malfunctions, the total engine is adversely affected" (Thompson & Rudolph, 1988, p. 222). Proponents of these theories emphasise the importance of interpersonal interactions and focus interventions on the "network of relationships within the family organization" (Lastoria, 1990). Families are composed of a set of relationships that evolve and change over time depending on the stage of the life cycle they are experiencing. Change focuses on such aspect as patterns of interaction between individuals, expectations of behaviour and roles. Without change there can be no growth (Lauer & Lauer, 1997).

Salvador Minuchin has been widely credited with developing an understanding of how families function and also in producing interventions which corrected "malfunctions in the family system" (Thompson & Rudolph, 1988, p. 236). While working with delinquent boys at the Wiltwyck School for Boys in New York, he noted that the recidivism rate on release was close to 100% and concluded that the problem lay not with the individuals but within their families of origin. The structural family therapy approach he developed was therefore directed towards changing the family structure in order to modify the behaviour of the family members (Thompson & Rudolph, 1988). Research has consistently linked parent-child interactions to child adjustment in many areas (Sameroff, Lewis & Miller, 2000).

2.2.1. Family Structure

Family structure is " the invisible set of functional demands that organizes the ways in which family members interact" (Minuchin, 1996, p. 51). The concept of boundaries implies a hierarchical structure, which is a characteristic of living systems (Bloch, 1984). Families are evolving organizations and have unique rules and patterns of behaviour necessary for interacting both across and within the various subsystems (Thompson & Rudolph, 1988). As individuals reciprocally influence each other so too do relationships within families influence each other (Bardill, 1997; Bowen, 1978; O'Connor & Lubin, 1984, cited in Jonsson Jones, 2001). Research indicates that the birth of a child with a deformity "extends to involve family functioning" and can be either positive or negative outcome as coping skills are strained" (Van Staden & Gerhardt, 1994c, p. 45).

When two people marry, a spouse subsystem is formed which involves a process of adjustment and role negotiation. Individuals who have successfully attained a degree of autonomy and independence from their families of origin are more likely to adjust to their complementary roles in this new, unique subsystem (Becvar & Becvar, 1996). It has been found that the higher the level of cohesion, flexibility and ability to adapt within families, the better they function. When the spouse subsystem is supportive, has open communication and strong coping strategies, both marital and family satisfaction develops (Greef, 2000).

Minuchin felt that a strong parental coalition determined how stable and effective the family system would be. If the parents share a similar value system and were in agreement as to how to rear a child the outcome is likely to be more favourable (Gerdes *et al*., 1988). Support is defined as "the furnishing of comfort, recognition, approval and encouragement to another person" (Reber, 1985, p. 747). Mutual support between parents suggests healthy adaptation and indicates that the facial anomaly of their child is not viewed as a situation, which is likely to threaten the stability of their relationship. This mutual support also decreases the likelihood that the birth of a child with a cleft lip and palate will result in divorce or separation (Pelchat *et al.,* 1999b).

There are indications that when a mother of a child with a cleft lip is content within her marital relationship, she is more likely to respond to her infant in a sensitive manner (Speltz, Goodell, Endriga & Clarren, 1994). In the context of parenting, mothers experience more stress and

adaptation difficulties due to the restrictions of their role even if they do not have a child with a medical problem (Pelchat *et al.,*1999a).

Contrasting findings have been reported in the literature regarding the effect of the birth of a child with a disability on the spouse subsystem. Some parents experienced a strengthening of their marital relationship due to an increase in maturity, honesty, emotional sharing and support within their relationship (Van Staden & Gerhardt, 1994c). Kazak and Marvin (1984) felt that it is possible that in some cases the birth of a handicapped child may actually strengthen a marital relationship. Results of the FAM-III found that such families scored higher scores than the norm on areas of affective expression and involvement, which indicates strong family cohesion. Consistency of values and norms and satisfaction with extended family support seem to facilitate the coping abilities of these families (cited in Trute & Hauch, 1988). Well functioning families tend to cope with a crisis in a positive manner and grow and develop from the experience (Goldberg & Goldberg, 1985).

Factors which contributed to marital strain included feelings of guilt, blame and resentment, a lessening of emotional closeness and the practical aspect of having less time to do things alone (Van Staden & Gerhardt, 1994c). Results from other studies suggest that parents of disabled children are more likely to "develop relational and communication problems" (Pelchat *et al*, 1999b, p. 465) which may result in separation or divorce. Many parents feel socially isolated and do not enjoy sufficient support from extended subsystems, which increases their feelings of aloneness. When their spouse does also not provide emotional and practical support, feelings of resentment, anxiety and depression may result (Pelchat *et. al*, 1999b).

The day to day care of a physically challenged child often requires parents to rebudget time, energy, finances, career responsibilities and aspirations as they have to "renegotiate parental roles and responsibilities" (Barden, 1990, p. 345). Individuals who communicate in a congruent, healthy manner are more likely to develop efficient coping skills to deal with their problem. By communicating their needs and feelings they will reduce uncertainty and prevent chaos and disorder in their family system. A system, which is open to information exchange, will receive necessary emotional and practical support and emerge stronger from the challenge (Goldberg & Goldberg, 1985). Those families who receive the necessary support and guidance are less likely to suffer from stress related problems (Lavigne & Wills, 1990).

Some parents report an initial negative experience regarding their first interaction with health professionals (Van Staden & Gerhardt, 1994a). Families are part of the larger system of the community in which they live and this includes the health professional team who can support and educate them through the process. (Lavigne & Wills, 1990). This is a period when parents need support and interaction from medical staff and it is crucial that they are not overwhelmed with confusing information but is empowered to make educated decisions (MacDonald, 1979). It was found that counseling and scientifically correct information replaced emotional thinking and enabled parents to develop more objective, educationally informed opinions (Van Staden & Gerhardt, 1994b)

The period immediately after the birth of a child with a facial cleft deformity is when the parents are in most need of social support as they experience many negative emotions such as guilt, anger and resentment and these feelings may negatively affect their marriage (Barden, 1990). It is important that professionals allow them to express their feelings and be reassured that it is normal to feel sadness and fear (MacDonald, 1979). Families who function within a closed family system are more likely to resist external support and information exchange. If their characteristic way of functioning is to keep their feelings to themselves, they will be reluctant to express their feelings to outsiders as they may feel they are being 'disloyal' to the family system (Becvar & Becvar, 1996).

Studies have found that the sibling subsystem plays an important role in the development of the child and that the birth of a child may affect family interaction patterns (Feiring, Lewis & Jaskir, 1983; Lewis & Feiring, 1992, cited in Sameroff *et al.*, 2000). Siblings too feel the stress of the first few months after the birth of a child with a cleft lip/palate and need simple explanations from their parents to help them deal with their own anxieties and fears (MacDonald, 1979). There is a lack of research focusing on the response of the sibling and extended family subsystem to the birth of a child with a cleft lip/palate. Palkes, Marsh and Talent (1986) found no indication that such a birth impacted negatively on the family system although it was felt that "the issue of parental denial remains unaddressed" (cited in Rosenstein & Schulman, 1990, p. 48).

Parents experience ongoing worries about the practical and emotional care of their other children while their attention is focused on surgical procedures and treatment necessary for their child (Rosenstein & Schulman, 1990). Many parents feel saddened that they do not have the

time they feel they should have to give all family members adequate attention (Van Staden & Gerhardt, 1994b).

The larger family system continues to have an influence on the behaviour of members after they have grown to adulthood (Fingerman & Bermann, 2000). Friends and family members can provide both information and emotional support which results in decreased levels of stress and an increase in coping abilities (Trute & Hauch, 1988). Good relationships with extended family members and friends have been found to be important for well functioning families (Greef, 2000). Families who cope well with the birth of a physically challenged child were found to have a strong system of social support and admitted to a high level of satisfaction with the interaction, support and involvement experienced from extended family members (Pelchat *et al*., 1999b). An open system, which permits an optimal level of information into the system, aids the development of coping mechanisms in such families.

Information received from outside systems has an impact on the functioning of a family after the birth of a child with a facial deformity. Negative and even implied criticism will affect parental interaction. It has been suggested that a "less than optimal caregiving" (Barden, 1990, p. 357) may be the cause of emotional and behavioural problems in children with a facial deformity. Some studies indicate that these children may experience a less nurturing relationship with the mother and possible peer rejection during the school years (Barden, 1990).

A child's self esteem develops mainly in his social interactions with others and it is important that professionals help parents to cope with both their own frustration and help their child to develop a sense of his own self-worth (Mac Donald, 1979). An inappropriate parental response to dealing with a child with a disability has been found to negatively impact on developmental processes. Overprotective parents who attempt to shield their child from social interactions may prevent them from learning necessary social skills necessary for peer interaction (Barden, 1990).

2.3. THE INTERACTING SYSTEM

The field of cybernetics which dates from 1942, had a profound influence on the development of family systems theory and was a radical move away from traditional thinking as it focused on "organization, pattern and process rather than with material and content" (Becvar & Becvar,

1996, p. 16). Early pioneers who contributed to this way of thinking included mathematicians, physicians, economists, psychologists and engineers. The focus of these thinkers was on feedback mechanisms, information processing and communication patterns. The terms *simple cybernetics* and *systems theory* are often used synonymously as they share the same basic concepts and fundamental assumptions and the role of the researcher or therapist is likened to an observer outside of the system who is not actually part of the system itself (Becvar & Becvar, 1996).

Systems theory maintains that the family must be studied as a whole and is composed of individuals who interact and influence each other in such a way as to maintain the functioning of the system (Lauer & Lauer, 1997). A family is an open system with a flow of elements continuously entering and leaving it and consists of family members and their relationships with each other. The focus is not on *wh*y the family is behaving in a certain manner but *what* is happening between the parts and *how* they interact. Attention is shifted away from the individual to the interaction between family members. If the therapist can understand the patterns of interaction between family members, it is possible to instigate change (Corsini, 1984).

A system consists of interconnected and interdependent parts that are related to each other in a stable manner. The principle of *nonsummativity* is a fundamental concept of systems theory and states that a system is greater than the sum of its parts and includes the interaction between all components. An event at any one level of the system has a reciprocal effect on all other levels (Corsini, 1984).

The components of a system interact in such a way that each part influences and is reciprocally influenced by the other parts. These elements interact in a constant relationship with each other and the system is therefore organized around these relationships in a predictable manner. The unifying principles of a system are its organization and the relationship between the component parts (Goldberg & Goldberg, 1985).

To understand family functioning it is necessary to see the organization of the whole as well as the interaction between all members. Behaviour of any one individual can only be understood in the context of the whole. From systems perspective, two people relating to each other are not independent but mutually interacting and the intricacy of the system increases as the number of

members increase. Therefore, a marital dyad consists of two individuals plus the relationship between them. Or 1+1=3 and the relationship dynamic is the three. When a child is born the system increases by one member and now comprises three members and six relationships. As all components are so interrelated, any change in one part impacts on the whole (Becvar & Becvar, 1999).

The well functioning family is viewed as a system consisting of "interlocking triangles, maintained or changed by means of feedback." (Corsini, 1984, p. 447). According to Shapiro, (1983) professionals should develop an awareness of the whole family in order to implement interventions on a larger scale. Instead of blaming one individual for family pathology it is necessary to see each person as part of a system, which as a whole was functioning badly (Bateson, 1971). A decreased focus on the identified patient would enhance family functioning at all levels (Van Staden & Gerhardt, 1994c).

Systems theory studies people in relationships and each family member is seen in relation to other members and how each affects and is affected by others. Consistent with systems perspective, the family is seen as a subsystem of a larger network or systems. To understand each family it is therefore necessary to study them in relation to other families within their environment (Becvar & Becvar, 1999).

2.3.1. Systemic Versus Linear Thinking

Systems theory does not accept the notion of linear causality and focuses on relationships between individuals instead of concentrating on the individual and his/her problems in isolation (Becvar & Becvar, 1996). According to the linear model, a particular action "A" is the cause of effect "B" and it is possible to solve any problem if we can answer the question *Why?* Therefore from this viewpoint it may be argued that the birth of a child with a cleft lip and palate *caused* the mother's depression. Systemic theorists do not ask *why* something happened but rather concentrate on *what* is going on in an effort to describe relationship patterns of interaction (Becvar & Becvar, 1996).

Traditional linear thinking ascribed labels to an individual with the underlying assumption that the individual was "the site of pathology" (Keeney, 1979, p. 118). Followers of this approach felt that to understand human behaviour and find solutions to problems, it was necessary to

concentrate on history and past events that 'caused' the problem. Thus the individual and his specific behaviour were studied in isolation (Becvar & Becvar, 1996).

According to Keeney, (1979) such a perspective prevented the process of change in relationship systems. While systems theorists acknowledge history and past events as the context of a system, the focus is on the present and on the processes that give meaning to events. Systems theory is therefore not concerned with *why* individuals act as they do but emphasises relationships and how individuals mutually influence each other (Becvar & Becvar, 1996).

Family systems perspective maintains that behaviour is interactive and must be viewed in relation to the behaviour of others. This model of circular causality explains behaviour "in terms of ongoing circular loops capable of giving and receiving feedback" (Lastoria, 1990, p. 45) and suggests that each individual's behaviour "affects and is affected by the behaviour of the other" (Gerdes, Moore, Ochse & van Ede, 1988, p. 202). It has been found that infants with a cranio-facial anomaly and their mothers engage in less frequent interactive behaviours such as smiling and vocalizing than dyads with no facial anomaly. It is unclear if the decreased social behaviour of the infants influenced a similar response in their mother's behaviour (Field & Vega-Lahr, 1984).

The idea of triangles was introduced to explain interactive behaviour. So the depression of the mother after the birth of a child with a cleft lip/palate could be explained as interactive with her difficulty in accepting her child's facial anomaly, which is interactive with her husband's rejection of his child's orofacial cleft and his behaviour towards his wife, which she interprets as rejection. To assign blame and to try and determine 'who started it all' is detrimental for effective intervention as once in motion, feedback loops tend to be self-perpetuating (Lastoria, 1990).

2.3.2. Circularity

"Circularity is the reciprocal patterns of interaction in which an event can be both the effect of an earlier event and the cause of a later event." (Keeney, 1979, cited in Jonsson Jones, 2001, p. 98). For example, parents of a child born with a facial deformity may experience heightened levels of stress. This increased stress may result in less time and effort being spent on the marital relationship, which results in feelings of discord and resentment. So as time goes by,

the original stressful problem can cause the marriage to disintegrate which causes increased stress and therefore further disintegration. It is possible that children with a facial cleft deformity experience negative interactions with their parents, which may contribute to the development of long-term anxiety and social inhibition (Lavigne & Wills, 1990). Mothers of children with a cleft lip and palate deformity were found to be more worried about their children than mothers of children who had no anomaly and the children were aware of this anxiety and responded accordingly (Brantley & Clifford, 1979). This anxiety may be due to the appearance of the child, which is caused by the facial cleft deformity or the surgical procedures or both (Lavigne & Wills, 1990).

To understand the difference between linear thinking and the systemic concepts of circularity is to understand "the difference between a line and a circle" (Penn, 1982, p. 270). Linear thinking states that A leads to B and is caused by A. In contrast the circular process is viewed as feedback and evident in so-called 'feedback loops'. Feedback meant that part of the system's output comes back into the system with new information related to this output (Penn, 1982). In other words, B loops back to A and it cannot happen in a continuous line as this is an active feedback process in which B circles back to A and also has an effect on A which includes information from B which is part of the loop. Therefore A both affects and is affected by all the components of the system of which it is a part (Penn, 1982). "The behaviour of each part is determined by the behaviour of other parts as well as its own previous behaviour" (Penn, 1982, p. 270).

From the systemic perspective, A does not cause B and B does not cause A, rather they both impact on each other and the interaction is circular. The mother may perceive her husband as distant and he may perceive her as rejecting. It does not matter whether his distant response caused her to feel depressed or whether her rejecting response caused him to become distant. The birth of their child with a cleft can be seen as both the cause and the effect of the affective quality of their marital and parental relationships (Jonsson Jones, 2001). "Interaction and communication become organized into patterns and sequences which tend to be repeated" (Gerdes *et al.,* 1988, p. 202).

Circularity implies that everything within the loop has the potential to change or restructure when new information is introduced (Penn, 1982). A recursive perspective views each system as influencing and being influenced by every other system and there are "patterns of connection at

every level of the system" (Becvar & Becvar, 1996, p. 64). All family members perceive their family interactions from their own unique perspective and can be helped to "experience the circularity of their family system" so that they can co-evolve and form a new context where they can be more aware of the perspectives of other members (Penn, 1982, p. 271).

Many studies have shown that attractive facial features and facial anomalies do influence social interaction. It therefore raises the question as to how such facial anomalies influence interaction in family relationships and the "subsequent acquisition of social competencies and self-control systems influenced by such relationships" (Barden, 1990. p. 355). Most research of this nature has been focused on patients with cleft lip/palate and findings indicate that patients with such facial anomalies suffer few deficits probably due to the fact that surgical procedures improve the appearance of these patients when they are young which obviously reduces the negative social reactions and stresses experienced by individuals with chronic facial deformities (Barden, 1990).

2.4. CHARACTERISTICS OF A SYSTEM

2.4.1. Boundaries

The family can be described as a living system which "is an organized, durable, self-reproducing, slowly evolving pattern of human behaviours grouped together as roles, structures and functions" (Bloch, 1984, p. 190). Healthy families are open systems with selectively permeable boundaries, which allow a constant exchange of information to and from the system. Well functioning families are characterized by flexible boundaries where information that is exchanged is neither too rigid nor fluid to threaten the wholeness of the system (Sameroff *et al.,* 2000).

All families are classified as open in that at least minimal interaction with the environment is essential for survival. However families vary in the amount of information they permit on or out of their system. Systems that are more open respond to input by increased differentiation of functions and roles within the family and are characterized by a balance between *morphostasis* and *morphogenesis* (Alexander, 1985). Healthy families change over time as both the parents and children get older. Therefore what may be a relatively closed system when the children are young develops into a more open system as the children approach adolescence. Functional

families encourage this growth and development and accommodate necessary changes in their system (Gerdes *et al*., 1988).

The system is said to be in a state of *entropy* when it is too open or too closed and in a state of *negentropy* when an appropriate balance and order is maintained. Such a system is therefore permitting appropriate information and change but resisting that which may threaten its survival. (Becvar & Becvar, 1999). All family members constantly readjust their behaviour in response to the behaviour of others and information received. This is a continuous process involving constant feedback loops (Bloch, 1984). An open system will both permit and benefit from external support, which is essential for the family experiencing a crisis such as the birth of a child with a facial cleft deformity.

According to Satir, emotional disturbances result when an individual is caught in a closed family system, which does not encourage opinions, and feelings, which differ from those which are already in place. In contrast, an open family system encourages honest expression and differences and resolves such differences by negotiation (Thompson & Rudolph, 1988). A system is described as closed if not enough change is allowed in response to pressure from within the family and from other systems. The survival and identity of a system is threatened if too little or too much information is permitted (Becvar & Becvar, 1999).

All family systems coexist with various other subsystems and boundaries are the means by which information is accepted or rejected. These include the marital, parental and sibling subsystems which interact with and influence each other while still maintaining a unique, distinct quality. (Sameroff *et al.,* 2000). As all parts of the system are interconnected, a change in one component results in change in the others (Bloch, 1984). For effective family functioning, subsystems must interact with each other in such a way as to permit members to successfully fulfill designated roles and responsibilities. Differentiation is effected by the clarity of boundaries, which separate the various subsystems. Well functioning families exhibit clear, well-defined boundaries, which encourage individuality while still ensuring members, have a sense of belonging (Goldberg & Goldberg, 1985).

The tenet that the marital dyad was central to the well being of the family is central to early family systems theory (Pinshof, 2002). Minuchin highlighted two dysfunctional styles of family interactions – enmeshed and disengaged families. Members of an enmeshed family are

generally undifferentiated from each other and change is resisted as it is viewed as a threat to the system. Enmeshment results when boundaries are blurred and poorly differentiated and family members are over-involved in each other's lives. A lack of privacy, excessive togetherness and loss of autonomy is typical of enmeshed families whose members encourage a high level of cohesion. Individuality is discouraged and members may battle to establish a separate identity. Separation, which occurs in the adolescent stage of the life cycle, is often viewed as threatening as the family functioning style tends to discourage interaction with the external subsystems (Goldberg & Goldberg, 1985).

In contrast, the disengaged family experience very little support and cohesion from each other and have difficulty in affective expression (Gerdes et al., 1988). However, boundaries that are too rigid prevent the effective process of environmental information. Disengagement results when boundaries are inflexible and impermeable and family members tend to go their own way. Such individuals tend to seek gratification from outside of the family and distance themselves from family interactions. (Goldberg & Goldberg, 1985).

2.4.2. Family Rules and Roles

Families are governed by rules, which control the boundaries between the family system and its environment and determine the way interactions are patterned. The rules of a family system permit the members to interact in organized, established patterns and also define their relationships and roles. Each member's role describes patterns of behaviour, which are both accepted and taboo. For example, a mother defines the boundaries of the parental subsystem by telling her mother that it is not a grandmother's decision to permit the children to spend a weekend with their grandparents. However, she redefines that boundary to include her mother in the parental subsystem by telling the children they must obey their grandmother when she is away from home.

The family functions as an interdependent unit with "certain rules, expectations and emotions" (Thompson & Rudolph, 1988, p. 226). If stress is applied to one family member all other members will feel it in varying degrees and a healthy family system deals with it in a positive, open manner. In contrast, a dysfunctional family tends to close the communication process by focusing blame on one member (Thompson & Rudolph, 1988). In all systems there are two opposing tendencies – to both adjust to change while also resisting it. And this ambivalence is

particularly marked during periods of transition such as the transition to parenthood (Gerdes *et al*., 1988).

Rules within a family are both overt and covert. Overt rules concern expected patterns of behaviour between the various subsystems. For example, children must obey their parent's decisions regarding friends they interact with, clothes they may wear and behaviour that is deemed acceptable. Covert rules are 'unwritten' and usually unstated but are inferred by all family members in their observations of repetitive patterns of behaviour within the family. For example, "Do not bother dad with problems till he has had time to relax after work". All family members have a right to a different opinion regarding education or religion but the deciding opinion rests with the parents. For example, sex is not a topic for open discussion. Well functioning families have rules that are appropriate and relevant for growth and development (Goldberg & Goldberg, 1985).

Rules are "compromised of the characteristic relationship patterns within the system" (Becvar & Becvar, 1996, p. 67). They express the values of the family and the roles for appropriate behaviour and distinguish a family system from others. Boundaries are formed from these rules, which are inferred from repetitive patterns of behaviour unique to this system. For example, family A expects all members to attend church every Sunday and to be present for supper every evening. Family B only attends church on special holidays and have a flexible attitude to meal attendance (Becvar & Becvar , 1996).

A key concept of Bowen's family system's theory is that of "differentiation of self" (Becvar & Becvar, 1996, p. 149). Individuals, who are differentiated, while retaining the ability to empathise with the feelings of others, are more flexible and self-sufficient and less dependent on others for their personal fulfillment. Mutuality refers to relationships in which members respect the individuality of others while forming and maintaining a separate, distinct identity (Goldberg & Goldberg, 1985). Couples who are differentiated have been shown to exhibit more marital satisfaction than those who are not and couples that differ in differentiation are more likely to have marital problems (Racite, 2001).

Highly functional families have been found to encourage individuality and respect the autonomy of family members. Autonomy resides within the parental subsystem but is not exercised in an authoritarian way and children are encouraged to voice their opinions even if it leads to conflict.

As negotiation is encouraged, power struggles are not necessary. In contrast, dysfunctional families tend to respond to each other in a passive, controlling manner while interacting in a detached manner (Goldberg & Goldberg, 1985).

Individuals who are unable to differentiate from their family of origin exhibit unresolved emotional attachment and have difficulties in maintaining intimate relationships (Goncalves, 2001). One of the tasks a new marital couple must accomplish is to negotiate their relationship with the families of origin. These subsystems must also adjust their family structure to include a new member and accommodate partial separation of one of its members to allow the formation of a new family unit (Minuchin, 1996).

According to Satir, individuals with low self-esteem view their partners as extensions of themselves and are dependent on their partner to provide what they feel is lacking in their self. However, the resulting relationship tends to result in an even lowering of feelings of self worth. The birth of a child to such parents is often viewed as a compensation for feelings of inferiority and they may use the child to demonstrate their worth both as parents and to the community at large (Thompson & Rudolph, 1988).

Individuals who fail to achieve emotional separation from their families, present as needy and dependent. To differentiate and achieve individuality does not necessitate forgoing emotional closeness with others. Instead it is the attainment of independence and a lessening of a need for the support and acceptance of others. An individual who has complete differentiation has resolved emotional attachment to the family of origin and accepts responsibility for his/her life and actions. A well functioning family permits a developing child to think and act for himself with a low intensity of emotional pressure. His/her self-image is not a result of the anxieties of others. Intense emotions and subjectivity dominates the relationships in poorly differentiated families and prevents the formation of consistent values and beliefs (Kerr & Bowen, 1978).

2.4.3. Communication

Information flow is the basic process of social systems. Successful communication depends on the manner in which this information is shared and impacts on the relationships between subsystems and the family system as a whole. (Sameroff *et al.,* 2000).

Effective communication is a characteristic of healthy family functioning and can be described as the achievement of mutual understanding and shared meaning. It enables individuals to successfully achieve task accomplishment and role performance. The manner in which individuals communicate and share information impacts on all aspects of their relationships. While verbal communication is the means by which factual information is exchanged, nonverbal messages tends to express emotional interaction (Goldberg & Goldberg, 1985).

Communication is a vital part of systems and effective family functioning and defines the nature of relationships within a system. There are two levels of communication and congruency is achieved when these two levels match. (Becvar & Becvar, 1996). According to systems theory three modes of communication have been identified:

- verbal or digital
- non-verbal
- context

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, if a wife says to her husband, "You really work too hard", his response will be dependent on her nonverbal cues such as her tone of voice and facial expressions and also on the context in which the message is spoken. If she is smiling and standing in a neat kitchen the verbal message is likely to affirm her words, but if she is frowning and slamming dishes around the sink as he sits and watches TV he will receive a totally different message.

According to Becvar & Becvar (1999), there are three main principles of communication, which are essential to the understanding of information processing:

- *One cannot not behave*
  Even when an individual says, "I am doing nothing", they are actually doing something. Sitting still and not moving is behaviour and therefore negates the verbal message.

- *One cannot not communicate*
  Even silence is communicative behaviour and conveys a meaning to others who will interpret this behaviour in relation to their relationship with the individual.

- *The meaning of a given behaviour is not the 'true' meaning of the behaviour; it is, however, that individual's personal truth.*

  Many different meanings can be applied to behaviour but most people define a behaviour according to their own experiences in a similar situation. Thus the meaning for them is the only meaning and not one among possible others.

In a healthy family, participants send and receive open, congruent messages and communicate in an open, authentic manner, communicate positive feelings to others and take responsibility for their own behaviour. Satir maintained that improved communication skills led to improved problem solving and conflict resolution within families. (Thompson & Rudolph, 1988). Couples, who share feelings, have positive affective expression and open communications have been found to be more satisfied with marital and family relationships (Greef, 2000).

In contrast, a dysfunctional family attempts to relieve anxiety and stress by distorting the communication process. They tend to habitually avoid eye contact, turn away during conversation or replace conversation with 'speeches' (Goldberg & Goldberg, 1985). Family members may also block communication to protect their own self-esteem. According to Satir, families with 'phony' or 'hidden' communication patterns tend to have members with behavioural problems. Problems can only be solved efficiently when individuals learn to "recognize harmful communication patterns and learn to level with their family members" (Thompson & Rudolph, 1988, p. 226).

According to Goldberg and Goldberg (1985) there are many dysfunctional patterns of communication and these include:

- *A paradoxical communication*

  This form of communication moves in both opposite and internally inconsistent directions at the same time and can lead to dysfunctional interactions if used at a time of crisis. For example, a husband may say he is listening to his wife while he continues to watch the television and neglects to make eye contact.

- *The 'double-bind' message*

This is another circular pattern of communication that is common in unstable family interactions. In such interactions confusion results when the message sent contains messages that are inconsistent and contradictory. For example, the wife rejects her husband's advances but when he withdraws, changes her behaviour and asks him why he is rejecting her. Such patterns of communication are indicative of underlying relationship inconsistencies.

- *Mystification*

  This is an interaction pattern used by dysfunctional families to deal with conflict by masking what is really going on between family members and allows them to temporarily avoid dealing with the real issues. For example, when parents negate a child's feelings by responding that they are not real. "Nonsense, of course you are happy!" (Goldberg & Goldberg, 1985).

As the verbal content is only a small part of the communication process, it is equally important to determine how individuals define their relationships. According to Becvar and Becvar (1999) there are three main relationship styles and communication patterns:

- *Symmetrical relationships*

  Similar behaviour and communication patterns are exchanged and both participants mirror the behaviour of the other. For example, if one participant shouts the other shouts also and such exchanges might escalate in intensity.

- *Complementary relationships*

  Unlike behaviour and communication patterns are exchanged as one participant's behaviour complements that of the other. For example, if one individual is assertive the other will respond with more submissive behaviour.

- *Parallel relationships*

  Each participant alternates in the one-up/one-down position and there is evidence of symmetrical and complementary behaviours. Effective relationships generally make use of this style of interacting and both participants take responsibility for the relationship (Becvar & Becvar, 1999).

As both members within this subsystem ensure that this pattern of interaction is maintained, relationships are viewed as reciprocal. This notion of reciprocity has been criticized for implying that therefore both participants are mutually and equally involved in maintaining this interaction without considering the "reality of socially structured inequality" (Mackinnon & Miller, 1987, p. 145). Systems theory does not accept the explanation of a complementary relationship as one person being dominant and the other being in a powerless position. Submission 'caused' by assertiveness may appear to be control from a linear perspective but from a systems perspective, this submission seeks to change or alter the assertive behaviour of the other participant so is therefore not a powerless act. Instead a complementary relationship is explained as "unilateral efforts to regulate a relationship" (Becvar & Becvar, 1999, p. 30). However as all relationships are necessarily bilateral, it is inevitable that these regulatory efforts will fail.

2.4.4. Feedback Processes in Family Systems

Feedback keeps a system functioning and is "the aspect of recursion involving self-correction" (Becvar & Becvar, 1996, p. 64). *Recursion* is the shared responsibility of members of a system and their continual mutual influence. This idea of circularity implies that all behaviour within a system is preceded by other behaviour and results in a process, which is shared and contributed to by all participants. Systems theory is not concerned with *why* the situation is at is but strives to understand *what* is going on in the present.

Feedback is indicative of and responsive to fluctuations within the system and is a process, which serves as a mechanism to regulate the stability. It is an important criterion of cybernetic systems and is defined as "the process whereby information about past behaviours is fed back into the system in a circular manner" (Becvar & Becvar, 1996, p. 64).

All family members desire other members to behave according to the feedback they give each other. Therefore "mutual influence and feedback occur in an ongoing pattern of reciprocal interaction" (Becvar & Becvar, 1999, p. 24). From family system's perspective we are focused on relationships between individuals within a system and how they mutually interact and influence each other's behaviour. (Becvar & Becvar, 1996). The behaviour of a system is the result of many interactions between its components and the ultimate goal is to maintain the systems organization (Griffith, Griffith, & Slovik, 1990).

All family systems strive for a level of stability, which is promoted by positive and negative feedback. Systems theory does not make value judgements and the terms 'negative' and 'positive' do not indicate 'good' or 'bad' but only describes the process (Becvar & Becvar, 1996). For example, a blood test, which indicated that an individual was HIV negative, would be 'good' feedback for that individual as this would indicate there were no changes in the body and the status quo is being maintained. A 'positive' pregnancy test would be a 'bad' feedback for a thirteen-year-old girl, as this would indicate unwelcome changes in her body functioning.

Positive feedback implies that change has taken place and been accepted by the family system. *Negative feedback* performs a homeostatic function and indicates that the status quo is being maintained. For example, a couple may indicate that their child with a facial deformity is the cause of stress within their relationship. During therapy the therapist suggests that the problem lies in the marital relationship, which initially may worsen, as more issues are uncovered. Reluctant to deal with these issues the parents renew their focus on their child's condition and their marital problems remain hidden once more. Both change and stability are necessary for the continued existence of a system. Feedback processes are mechanisms that increase the probability of survival (Becvar & Becvar, 1996).

Both functional and dysfunctional families make use of positive and negative feedback loops to maintain the stability of the family. *Positive feedback* is a process whereby information about a deviation from a previously accepted and established norm is fed back into the system and the response is such that the divergence is accepted. For example, when a couple is newly married they may be in agreement that they spend their leisure time as they choose. However, the birth of their first child necessitates a change in this point of their life cycle to accommodate their new parenting responsibilities. This new behaviour indicates that change in their normal patterns of behaviour is necessary to allow the system to continue to function in a stable way (Becvar & Becvar, 1996).

The initial response to new behaviour is crucial as a positive feedback loop has the potential to amplify deviation to the point that the system may self-destruct if it eventually droves the system beyond the limit within which it can function. Conflict may occur if the spouse subsystem is unable to accept the necessary change and separate parent and spouse functioning and responsibilities (Minuchin, 1996).

For example, parents who respond appropriately to their adolescents need for autonomy will avoid potential problems and crises by providing a context for family and individual development. Parents who allow too much freedom and a lack of rules may find themselves facing a series of crises, which may introduce stress into the system that may affect the coping capacity. All systems offer resistance to change beyond a certain level of tolerance and any deviation, which goes beyond this threshold results in the elicitation of mechanisms to re-establish the acceptable range. For example, members will make use of guilt-inducing mechanisms to force other members to comply. (Minuchin, 1996).

Feedback is therefore a process whereby a system balances its need to maintain stability and organization and to also adapt to external demands for change (Jonsson Jones, 2001). Positive feedback indicates that the system has accepted a change and negative feedback is the process whereby deviation is corrected and "equilibrium is restored" (Corsini, 1984, p. 449).

2.4.5. Homeostasis, Morphostasis and Morphogenisis

Homeostasis is a state of dynamic equilibrium, which is indicated by negative feedback. While a system strives for stability it must also have the capacity for change and growth if it is to function in a healthy manner. *Morphostasis* refers to the ability of the system to remain stable while undergoing change and m*orphogenesis* describes behaviour that encourages growth and change. Dynamic equilibrium describes, "the constantly fluctuating interaction of equilibrating and disequilibrating forces that, through their dance, generate the patterns we call equilibrium or stability" (Bloch, 1984, p. 392).

Each system has homeostatic mechanisms, which allow change to occur in a controlled manner. Feedback loops serve to feed both negative and positive information back through the system and thereby triggering any necessary changes to maintain the balance. (Goldberg & Goldberg, 1985). The stability of the system may be threatened if too much change is permitted but for healthy functioning it is essential that the family system changes to meet the developmental requirements of it's members. For example, the parenting style will not be the same for a toddler as it will be for a teenager. (Becvar & Becvar, 1999).

The birth of a child with a cleft lip/palate can be viewed as a disequilibrator within the family system, which must then adjust to the new set of conditions (Bloch, 1984). Shock, denial,

resentment and disbelief are normal parental reactions to the birth of a child with a deformity and aid in the adjustment process. Despite the difficulties involved in dealing with a physically challenged child, it has been found that most families do adjust. Studies indicate that parents dealing with these problems have no less stable marriages than those who do not have a child with a similar condition. It is essential that medical health professionals allow such parents the necessary time to adjust to their new situation until they can fully understand and comprehend the situation (Barden, 1990). Research has found that professionals who actively involve the father in the adaptation process facilitate harmony within the family and may prevent possible marital problems. (Pelchat *et al.,* 1999b).

The principle of homeostatic balance underlies crisis theory, which assumes that families function in a state of relative equilibrium and have certain coping techniques to solve everyday problems. However, when problems persist or are overwhelming, as in the birth of a child with a disability, a crisis situation may evolve which necessitates the development of new coping skills (Goldberg & Goldberg, 1985).

Parents of a child with a cleft lip and palate were found to experience less parenting stress than parents of a child with more chronic conditions such as Down's syndrome or congenital heart disease. This was thought to be due to the fact that the children with a cleft deformity were not at risk for developmental problems and once the initial feeding problems were overcome the parents could cope with the future as the surgery improved the appearance and they felt they could cope and were reassured. Although the levels of stress appear to be dramatically reduced following lip surgery, there are often future adaptation difficulties connected to the condition. It should therefore not be implied that such parents do not experience high levels of stress in the first few months of their child's life as they do undergo "adaptation challenges" (Pelchat *et al*, 1999a, p. 393).

While many families do adjust well to the birth of a child with a physical anomaly many others find that the situation is too much for their adaptive capacities and the resulting crisis situation impacts negatively on the whole family (Pelchat *et al*, 1999b). Trute and Hauch (1988) maintain that the birth of a physically challenged child does not necessarily have negative long-term effects on a family system. However, they acknowledge that the birth of such a child initially increases the stress levels and coping demands of the system (Trute & Hauch.1988).

2.5. HEALTHY VERSUS DYSFUNCTIONAL FAMILIES

Definitions, which imply 'goodness' or 'badness', are inconsistent with family systems theory. Therefore to state that a family is 'functional' or 'dysfunctional' is to do a disservice to family members as a system is only pathological if we define it's variants as such (Becvar & Bevar, 1996). Consistent with family systems it is preferable to determine the health of a family by "success in functioning to achieve its own goals" (Becvar & Becvar, 1996, p. 124). According to Becvar and Becvar (1996, p. 140), the following characteristics exist in well functioning families:

- A hierarchical structure with a strong parental/ marital coalition and appropriate boundaries
- A caring and nurturing atmosphere supportive of both individual differences and family growth and development
- Flexibility and adaptability within a context of predictability and stability
- Initiative, reciprocity, cooperation and negotiation
- Effective communication
- A congruent mythology
- Openness in the expression of feelings
- A system orientation
- Optimism and a sense of humour
- A transcendental value system and shared goals and beliefs
- Rituals, traditions and celebrations
- A viable network of support

The level of family satisfaction appears to indicate adequate family functioning and communication is a vital factor for healthy functioning. The style of decision making within families is closely linked to effective communication and two styles associated with healthy family functioning are negotiation and compromise. In satisfied families, parents share a similar perception regarding communication and tend to "represent a united front that acts in a coherent way with respect to their children" (Scabini, Lanz & Marta, 1999, p. 640).

Healthy families have members who are satisfied with the level of cohesion and adaptability and marital subsystems acknowledge conflict but have the ability to solve problems in a mutually satisfying manner (Greef, 2000). In a study designed to identify those qualities laypeople

considered essential for optimal family functioning, it was found that emotional bondedness was the most frequently chosen category. Commonness and mutuality was also considered an important factor with expressive communication, commonly shared faith and time spent together also ranked as highly important through all family subsystems (Quatman, 1997).

The security of a nurturing family allows the children to experiment with differing levels of independence and responsibility appropriate to their developmental level and learn appropriate skills to deal with life beyond their family unit. According to Minuchin, the ideal family "accommodates, nurtures and supports the uniqueness of the other" (Becvar & Becvar, 1996, p. 198). From early infancy, the manner in which family members interact has an important effect on development and behaviour and parent-child interaction "have been consistently linked to child adjustment in a variety of domains" (Sameroff *et al.*, 2000, p. 117). Families who are satisfied with their interaction and functioning have been found to communicate effectively and base their decision-making on sharing and support (Scabini *et al.*, 1999).

There is a scarcity of literature on the family environment and social context of cleft-lip and/or cleft palate infants (Speltz *et al*., 1997). In fact "the family context remains an understudied area for developmental psychopathology" (Sameroff *et al*, 2000, p. 129). This should be rectified as attachment security in infants without clefts has shown strong positive relations to parents' positive marital relations (Isabella & Belsky, 1991). Giving birth to a child with a cleft lip/palate appears to have definite effects on mothers and they report more negative changes in themselves after the birth. However, in line with the comparable group, it does not seem to have an affect on their sexual behaviour in terms of frequency or adjustment and they report a high degree of marital satisfaction (Clifford & Crocker, 1971).

Families who cope well with a child with a physical deformity appear to have a positive attitude to the anomaly and share a philosophy that incorporates "life's difficulties into a coherent framework of productive beliefs" (Barden, 1990, p. 366). A longitudinal study of normative development of attachment behaviours in children with cleft-lip and/or cleft palate and those without, found no difference between the two groups (Hoeksma & Koomen, 1996). Bretherton, Ridgeway and Cassidy found that attachment security in infants without clefts is also related to family cohesion and adaptability (cited in Speltz *et al., 1997).* This appears to confirm other attachment research findings, which maintain there is no apparent differences between atypical, and normal infants pattern of attachments (cited in Hoeksma, Koomen & Van den Boom, 1996).

Healthy family functioning was thought to be associated with a strong parental subsystem that evidenced a high level of cohesion and a lower level of consensus. These findings suggest that such couples have a strong commitment to their marriage but were flexible enough to allow negotiation and compromise when dealing with family activities and issues (Trute & Hauch, 1988). Well functioning couples are satisfied with the manner in which they mutually express effect and communicate information and they enjoy the time spent both with friends and family members. They have a sense of pride and trust in their family members and are able to handle developmental changes or crises in a positive manner. (Greef, 2000).

2.6. CONCLUSION

To gain insight into the effects of the birth of a child with a facial deformity on a family system, it is necessary to study the complexity of the systems in which they function. How family subsystems adjust to the stressors involved in caring for a child with a facial deformity will have a profound and lasting influence on individual members. Support both within the family system as well as support from external systems appears to be a crucial element in healthy adjustment. Children who experience caregiving, which is warm and responsive, develop into confident individuals who perceive themselves as worthy of love and affection (Sameroff *et al.*, 2000).

When a child with an orofacial cleft is born, the manner in which the parents are informed of the situation plays a vital role in the lessening of their stress and their future adaptation to the circumstances. The first few months following such a birth are when the parents are in need of support to aid their adjustment and to allow them "to grieve their dream" (Pelchat *et al.*, 1999b, p. 466). Counseling helps the parents to adapt to the situation and genetic counseling may allow them to plan for the future and help dispel feelings of guilt as they struggle to deal with a variety of sensitive and confusing issues and information (Barden, 1990, p. 365)

Couples who underwent a family intervention programme aimed at the optimal actualization of the internal and external resources of the family experienced less emotional distress and anxiety and were confident in the support they could receive from both their spouse and others (Pelchat *et al.*,1999b). Trute and Hauch (1988. p. 190) found that families who coped well with the birth of a child with a physical anomaly were "strong, well organized units" and the strength of these families was not influenced by the severity of the condition.

Once the initial shock of the birth of the child with a cleft lip/ palate deformity has dissipated and they have accepted and understood the necessary information, most parents find that as they become used to dealing with their baby, the familiarity makes it “look not quite so bad” (Rosenstein & Schulman, 1990, p. 49). Parents who manage to effectively adapt to their situation have a positive effect on the development of the child (Pelchat *et al.*, 1999b). Researchers found that children with varying degrees of physical disorders ranging from cerebral palsy to mild orofacial deformities did not differ widely in their level of adaptation. Their emotional well-being was found to be not due to their physical status but to the family functioning, religious attitude and social support (Hurtig, Koepke & Park, 1989, cited in Barden, 1990).

CHAPTER 3

RESEARCH METHODOLOGY

3.1. INTRODUCTION

The purpose of my study is to explore the experiences of parents of children with a facial cleft deformity and to gain an insight into their experiences. This research problem lends itself well to a qualitative study as it allows each parent's unique story to be heard and challenges the grand narrative that maintains that 'beauty equals goodness'. A detailed, in-depth exploration of a parent's experiences, reactions and feelings as they cope with the inevitable challenges will hopefully result in a more comprehensive assessment of the problems. My focus also includes the impact the birth and coping problems has on the marital relationship. An individual is embedded in a very real structure of the family or social network (Becvar & Becvar, 1996). It will not be possible to truly understand the significance of these individuals' experiences without looking at broader aspects of family life.

In this chapter qualitative research will be discussed in general followed by an explanation of the methodology of my study.

3.2. QUALITATIVE RESEARCH

Cresswell (1998, p. 15) defines qualitative research as " an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants and conducts the study in a natural setting". Qualitative research is a "holistic and encompassing approach towards the researched object, situation or relationship" (Myburgh & Poggenpoel, 1995, p. 5). The researcher seeks to identify different themes that are inter-related to gain an in-depth picture of the different aspects of a problem. This approach attempts "to understand the meaning of naturally occurring complex events, actions and interactions in context, from the point of view of the participants involved" (Moon, Dillon & Sprenkle, 1990, p. 357).

Unlike quantitative research, qualitative research "considers meanings to be negotiable and variable rather than fixed" (Breakwell, Hammond & Fife-Schaw, 2000, p. 269). This paradigm

emphasises social contexts and the main object of study is the person within his or her unique, subjective situation and environment. It is informed by theory and uses methods such as participant observation, unstructured interviews, questionnaires and the recording of life histories.

Cresswell (1998, p. 13) likens qualitative research to “an intricate fabric composed of minute threads, many colours, different textures, and various blends of material”. As a loom holds the fabric together so do general frameworks and theories hold qualitative research together.

Dissatisfaction with the positivist approach has motivated many researchers to seek an alternative with a more “humanistic value base” (Pugh, 1998, p. 258) where the focus is on the individual and his uniqueness. The ongoing debates between researchers as regards the “appropriateness of qualitative research” (Franklin, 1996, p. 243) has led to attitudes of disinterest from many academics who often do not understand the unique benefits of this method. While there is evidence of increasing receptivity to the use of qualitative research methods, many psychologists who are generally trained in quantitative methods still underutilize this form of research (Chawlisz, Wiersma & Stark-Wroblewski, 1996).

According to Fuks (1998, p. 247) “the community is composed of social networks and families represent socially generated constructs”. The Parsonian view of social systems maintains that the individual is “encircled by his family, the family by the larger system, the larger system by the community and so on” (Anderson & Goolishian, 1988, p. 376). However an alternative to this theory views human systems as existing only in the domain of meaning. To truly gain insight into the worlds of the participants in my study it was necessary for me not to take the stance of an objective observer but rather enter into a partnership (Fuks, 1998,). Circularity is the ability of the researcher “to conduct his investigation on the basis of feedback from the family in response to the information he solicits” (Selvini, Boscolo, Cecchin, & Prata, 1980, p. 8).

The roots of qualitative research are found in such disciplines as sociology and anthropology where the starting point is “the context in which study participants are embedded" (Fiese & Bickham, 1998, p. 79). By focusing on the meaning of individual experiences, researchers gain a deeper, richer understanding of phenomena that is not possible with traditional quantitative methods alone. The contextual data obtained from qualitative studies can “enrich the interpretation of quantitative outcome studies” (Moon *et al.,* 1990, p. 365). It is important

therefore that the two approaches should not be viewed as incompatible as each serves a specific purpose and informs and compliments the other. (Brannen, 1992, cited in Fiese & Bickham, 1998).

Banyard and Miller (1998, p. 489) view qualitative research as a "powerful set of tools for understanding the "why" of human behaviour – the subjective meanings people make of their experiences and that give rise to specific behaviours". The main goal of qualitative research is to determine how individuals make sense of their experiences. This form of inquiry involves more than the collection of written or verbal material as researchers need to "get inside the heads" (Fiese & Bickham, 1998, p. 80) of their study participants. In my present study my goal was to gain insight into how parents of children born with a cleft lip and palate make sense of their experiences.

Clarkson (1996) argues that one of the reasons current qualitative research is so confusing and uncertain is due to the fact that it attempts to model itself to the quantitative methods and paradigms of the physical sciences. She feels that these traditional methods cannot capture the human relationship and likens it to "trying to catch butterflies with a tractor" (Clarkson, 1996, p. 146).

A qualitative investigation offers greater depth and "reflect the interest, involvement and personal commitment of the researcher… viewing experience and behaviour as an integrated and inseparable relationship of subject and object and of parts and whole" (Moustakas, 1994, cited in Clarkson, 1996, p. 144). The richness of qualitative methods enables us to "understand diverse experiences through hearing many-sided perspectives and voices" (Banyard & Miller, 1998, p. 491). The differing viewpoints add to the depth of our understanding of the phenomenon we are studying. According to Padula and Miller (1999) the use of the words of participants in a qualitative case study contributes to its richness.

Traditional methods of inquiry which focuses on defined and specified variables often produce studies which "usually bear little resemblance to the complexities and continually changing nature of "real life'" (Anzul, Evans, King & Tellier-Robinson, 2001, p. 236). Qualitative research in contrast often reveals a depth of unexpected and diverse findings that extend beyond the original focus of the study. By placing too much emphasis on traditional scientific methods of

inquiry, Sandelowski (1996) maintains that qualitative researchers may lose sight of their primary goal, which is to make sense of individual cases.

A fundamental reason for choosing a qualitative method is "to grab the nuances and contradictions of real life experiences" (Sandelowski, 1996, p. 527). The current body of research on the experiences of parents of children with cleft lip and palate deformities is mainly limited to quantitative studies. While these studies have provided valuable information on this phenomenon the depth of this knowledge is limited. Qualitative studies would provide an in-depth understanding of their world. If we can better understand the experiences of these parents we will be more able to meet the specific needs of others.

3.3. GENERAL CHARACTERISTICS OF QUALITATIVE RESEARCH

According to Moon *et al*, (1990) all qualitative research shares certain essential characteristics that will be discussed and applied to my study.

- *The purpose of the research is clearly stated at the beginning of the study.*

  The purpose of my study is to explore the experiences of parents who have a child with a cleft lip and palate.

- *Research questions that are open and exploratory are developed to guide and focus the collection and analysis of the data.*

  I began my discussions with general or grand tour questions that were designed to elicit a general and broad picture of each parent's experiences. For example, " Tell me about your experiences in coping with a child with a cleft-lip?" More specific ones then followed these broad questions. For example, "How did you experience the support you received from medical personnel?"

- *Qualitative researchers do not develop prior assumptions and attempt to see events in a new way. The aim is to explore events in a "holistic rather than a reductionistic manner" (Moon et al, 1990, p. 360).*

I did not to enter into my study with prior assumptions as to how a child's facial deformity affects his/her parent's marital relationship. Instead I aimed for a holistic perspective of the experience.

- *Qualitative research attempts to understand the phenomenon under study from the participant's perspective. This understanding is of value to the researcher, the readers and the participants themselves.*

  When the parents of the facially deformed child read the study it should "make sense to them by being real, valid and reliable" (Papaikonomou, 2001, p. 21). The inside perspective of the participant is vitally important. I attempted to understand the experiences of parents from the time they learned of their child's disability to the present.

- *The primary data collection instrument in qualitative research is the researcher so it is important to define the role clearly and acknowledge any personal biases, which may affect the interpretation of the data.*

  My role was that of an individual who was trying to understand the experiences of others and attempted to achieve this through our mutual interaction. According to Holliday (2002, p. 194), the qualitative researcher is "one person amongst others in the social setting where she is carrying out her research".

3.4. RESEARCH DESIGN

Quantitative researchers define a research design as "a set of rules for how to collect data" (Franklin, 1996, p. 251) and believe that internal and external validity will be achieved if data is collected in a certain manner. Qualitative researchers also place importance on the manner in which their data is collected and have comparable procedures to ensure consistency and credibility. A qualitative design differs from a quantitative one in its flexibility and data gathering and analysis processes, which are not linear but reflexive and circular in nature. This recursive process forces the researcher to reflect and analyze constantly throughout the data gathering process in order to discover any gaps before planning the next step. Qualitative research does not allow a researcher to plan a "predetermined sequence of observations" (Evans, 1998, p. 252).

3.5. THE EXPLORATORY CASE STUDY METHOD

A collective case study was my chosen form of study as it has clearly defined boundaries and the available information should enable me to provide an in-depth picture of the experiences of parents of a facially deformed child. This method was used in this study and the data was collected via in-depth face-to-face interviews with parents who had a child with a cleft lip and palate. The case study is generally associated with qualitative research although it is a strategy that may be used in both qualitative and quantitative studies. Case study refers to "both a process of inquiry and its end product" (Sandelowski, 1996, p. 526).

The qualitative case study is defined by Merriam (1998) as "an intensive, holistic description and analysis of a single entity, phenomenon or social unit" (cited in Hebert, 2000, p. 95). Case studies place emphasis on understanding the meaning the environment has on individuals and how they interpret their unique experiences.

According to Yin (1989), the difficult part of doing case studies is the development of an appropriate research design. He maintains that there are five important components of a case study research design (Yin, 1989, p. 29). These are –

- The study's questions
- It's propositions
- It's units of analysis
- Logic linking the data to the propositions
- Criteria for interpreting findings

Reinharz (1992) maintains that the case study is a powerful tool to "convey vividly the dimensions of a social phenomenon" (cited in Padula & Miller, 1999, p. 330). There are certain characteristics common to most case studies that I will discuss and apply to my study.

- *The goal of case study research is to gain insight and understanding of the case (Padula & Miller, 1999).*

  My goal was to gain understanding of the experiences of parents who have a child with a facial deformity.

- *Case studies focus on one specific phenomenon and study it in depth.*

  I selected five couples to participate in my study and attempted to elicit their perceptions of their experiences of coping with a child with a facial deformity.

- *Case studies are particularly useful when there is a need to "understand some specific group of people, a particular problem, or a unique situation in great depth" (*Hebert, 2000, p. 95).

- In my study I felt there was a need to gain in-depth understanding of the experiences of these parents.
- *Case studies are the design of choice when 'how' or 'why' questions are being explored, the researcher has little control over events and when the focus of the study is a phenomenon with real-life context (*Yin, 1989, cited in Padula & Miller, 1999).

  I explored the real-life experiences of my participants and focused specifically on their perceptions and interpretations of events.

- *The case study is a "bounded system" (*Merriam, 1988, cited in Padula & Miller, *1999, p.* 330).

  This study is bounded by:
  - the unit of analysis - the participants
  - the context - which is the experience of coping with a child with a facial deformity,
  - the sampling criteria - which specifies parents of cleft-palate or cleft-lip children.

3.6. RESEARCHER AS INSTRUMENT

The researcher is the main data-gathering instrument in qualitative research and must therefore have a "constant awareness of ourselves as research instruments" (Evans, 1998, p. 247). Researchers using this paradigm look at experiences as a whole and maintain that events can only be understood within their contexts. Evans (1998) argues that findings of a qualitative study, the method by which they were obtained and the researcher who conducts the research cannot be separated, as they are all interrelated. It is therefore essential that the researcher is

aware of him or herself as various aspects such as knowledge, skills and disposition "will shape the biases we bring to our research" (Evans, 1998, p. 247).

It was necessary to build up a relationship of trust with my participants. Hennings, Williams and Haque, (1996) state that research cannot be carried out only on the researcher's terms and must be a negotiated process if the co-operation of the participants is to be achieved. I strived to achieve this relationship by respecting the confidentiality, family responsibilities and time of my participants.

3.7. SUBJECTS

Sampling in qualitative research is geared to "identify subjects who fit the needs and qualities of a specific study" (Papaikonomou, 2001, p. 27). I used maximum variation sampling to choose five couples to participate in my study. This type of sampling is nonrandom and is chosen so that I could study diverse cases and therefore have access to a variety of differing perspectives. I hoped to be able to explore manifestations that are both common and specific to my participants. The only criterion was that each participant is the parent of a child who was born with a cleft lip or cleft palate deformity.

3.8. DATA ANALYSIS

My choice of analysis strategy was content analysis, which is defined by Altheide (1987) and Morgan (1993) as "a dynamic form of analysis of verbal and visual data that is orientated toward summarizing the informational content of that data" (cited in Sandelowski, 2000, p. 338). It is recognized as an appropriate research technique, which is a method in itself and is reliably used for differing types of research (Sinha, 1980).

Content analysis enables a researcher to determine the content of various forms of communication by creating a system to record certain aspects of it. For example, this system may include counting how often certain words or themes occur (Neuman, 1994).

The counting of responses and the number of participants in each response category is a characteristic of both quantitative and qualitative research. However, even if the results of the qualitative study are presented in a numerical summary with descriptive statistics as occurs with quantitative data, this is not the final step in the analysis for qualitative researchers. The next

stage entails " a description of the patterns or regularities in the data that have, in part, been discovered and then confirmed by counting" (Sandelowski, 2000, p. 338). An important aspect of qualitative content analysis is that there is an effort to understand and interpret the concealed, latent data content.

In qualitative research, data collection and analysis are usually carried out simultaneously and each process shapes the other. Throughout the study researchers must constantly accommodate new data and insights that results in a need to modify their treatment of existing data. It is an interactive and reflexive process. (Sandelowski, 2000).

3.9. RELIABILITY AND VALIDITY

In qualitative research reliability refers to the trustworthiness of the data and validity refers to the trustworthiness of the interpretations. (Stiles, 1993).

"A major strength of case study data collection is the opportunity to use many different sources of evidence" (Yin, 1989, p. 96). The rationale is that the use of different sources of information ensures more accurate results (Richardson, 1996, p. 192). In my study I attempted to ensure reliability by having multiple interviews with my participants and cross checking their stories on separate occasions.

I attempted to ensure validity by the following methods:

- Triangulation – by seeking information from my multiple sources
- Coherence – I endeavoured to ensure there are no 'loose ends' and the narrative 'hangs together'.
- Testimonial validity – I checked with my participants that my interpretation matched theirs.
- Catalytic validity – I aimed to conduct a study that encouraged growth and change in the participants.
- Reflexive validity – I too would hope to have changed and grown in the process of this research.

3.10. ETHICAL ISSUES

Research ethics is concerned with doing what is right and good for the participants of a study. Apart from moral and legal reasons, the upholding of ethical principals enhances the credibility and trustworthiness of data and demonstrates the authenticity of the researcher.

The participants in the study were fully informed as to the purpose of the study, the time necessary to carry out the interviews, and the possible results of intense questioning. They were assured of confidentiality and informed that they could withdraw from the study at any time should they so wish.

In a qualitative study of this nature, the feelings of the participants are of prime importance. Each participant has a right not to be harmed in any way during the course of the study and this includes such issues as an increase of stress or anxiety. I attempted to be sensitive to their pain at all times and not seek answers just for the sake of answers to add to my data collection. The dignity of each individual was always respected.

There is a fine balance between being a therapist and researcher in this type of research. When I found that my participants did react to certain aspects of the process with a high level of stress and anxiety, I referred them to an appropriate psychologist who is available for consultation for therapy for which I am not qualified to provide.

3.11. PROCEDURE

The methods of data collection consisted of interviews, observations and administration of the Family Assessment Measure III (FAM-III).

The majority of the interviews took place in the respondents' homes and the follow-up interviews took place in their homes, offices or in my home. This enabled me to get an indication of some of the behavioural interactions that existed within the home environment. I hoped that an interview in the "safe environment" (Hennings *et al.,* 1996, p. 17) of the home or venue of their choice, would produce data of increased depth and quality and would ensure that the participants in my study would feel free to express themselves on their own terms in a safe, non-threatening environment.

The first interviews consisted of a combined meeting with both parents and were conducted in a relaxed manner. Generally they lasted between one and two hours and took place in the evenings. Couples were interviewed together and the interviews were tape-recorded and later transcribed for analysis.

The follow-up interviews entailed a separate meeting with each parent. It consisted of two parts. Initially I clarified any issues that arose in the initial interview and I then administered the Family Assessment Measure–III (FAM-III). All the couples interviewed were the biological parents of the child born with a cleft lip and palate. The names of the respondents are not their real names and pseudonyms have been used.

These interviews were my primary data collection tool as they allowed me to gain access into the feelings, thoughts and experiences of the participants. (Padula & Miller, 1999). Grand-tour questions were initially asked. Creswell (1998, p. 70) states that a grand tour question is " a statement of the question being examined in the study in its most general form". An example of a grand-tour question would be, " Describe your experience of being the parent of a child with a cleft-palate". The responses of the participants guided the direction of the interview.

When I discovered a significant category through my grand tour questions I would then proceed with specific questions, which I hoped would elicit information of each parent's perspective of his/her situation and experience. An example of a specific question would be –"How did the reactions of your family and community to your child's appearance influence your ability to cope with the situation?"

Fifteen interviews were conducted. All children in this study were born with a cleft lip and cleft palate deformity. Their ages ranged from two months to five years. Three children were boys and two were girls.

The initial combined interview was in-depth and allowed the parents to tell of their experiences from the minute they were told of their child's cleft lip and palate, up till the present. Transcriptions of all interviews are available on request.

3.12. INSTRUMENTS

In order to fully understand the impact of the birth of a child with a facial deformity on family functioning the following instruments were used: in-depth face-to-face interviews with parents who have a child with an orofacial cleft (see Addendum A for a copy of the discussion guide); direct observation; and the Family Assessment Measure-III (FAM-III).

3.12.1. The Interviews

The discussion guide focused on a number of issues that the literature indicated were of importance to the family of a child born with a facial deformity. Parents were asked about:

- *Family structure and functioning*

  The way in which the family is structured and functions was discussed and included:
  - The individual members comprising the family unit and how the birth of a child with a cleft lip and palate affects each subsystem
  - Family roles
  - Boundaries within the families
  - Family rules, values and norms
  - Interaction between parental subsystem
  - Support from extended family members and friends
  - Coping mechanisms
  - Adjustment to the situation

- *The effect of the birth of a child with a cleft lip and palate on family functioning*

  The effects discussed included:
  - Stress experienced within the family as a result of the child's cleft lip and palate
  - Effects on the parental relationship
  - Effects on the sibling subsystems
  - Effects on family relationship with external subsystems such as extended family and friends
  - Positive effects of experience on relationships
  - Negative effects of experience on relationships

- *Parental attitudes towards the facial appearance*

  These attitudes explored included:

  - Parents' emotions resulting from external feedback
  - Parents' distress at birth of an 'imperfect' child
  - Perceived perceptions of response and attitudes of spouse

3.12.2. Direct Observation

"Observational evidence is often useful in providing additional information about the topic being studied" (Yin, 1989, p. 91). During the combined interview, I was able to observe the interaction between both parents, the interaction between the parents and their children and the family's nonverbal behaviour. I hope that information gained from direct observation will add new dimensions to my understanding of the experience of my participants.

3.12.3. The Family Assessment Measure -III

Skinner, Steinhauer and Santa-Barbara (1995) devised the Family Assessment Measure – III (FAM – III). It is a self-report test derived from the Process Model that aids in the assessment and understanding of family functioning (Skinner *et al.,* 1995). This multidimensional questionnaire provides the therapist or researcher with information as to how each family member "perceives family functioning within each parameter of the model, and how each is seen as functioning within these same parameters by all other family members" (Steinhauer, Santa-Barbara & Skinner, 1984).

3.13. PROCESS MODEL OF FAMILY FUNCTIONING

The Process Model of Family Functioning is a useful framework to assess family functioning and focuses on family strengths and weaknesses in each dimension (Steinhauer *et al.,* 1984). It attempts to integrate the theories of psychological and family systems in order to gain a more comprehensive perspective. The emphasis is not on family structure but on family process and the focus is on the interaction between the major dimensions of family functioning (Steinhauer *et al.,* 1984).

3.14. FAMILY ASSESSMENT MEASURE - III

The FAM–III consists of three scales: a *Self-Rating Scale*, a *Dyadic-Rating* S*cale* and a *General-rating scale*. The *Self-Rating Scale* is designed to tap into an individual's perception of his or her personal functioning in the family. The *Dyadic-Rating Scale* is a measure of relationships between specific pairs of individuals in a family. *The General-rating scale* "focuses on the family as a system" (Skinner *et al.,* 1995, p. 1). These scales are all scored on a 4-point Likert-type scale, which ranges from Strongly Agree, *Agree, Disagree* to *Strongly Disagree.*

The FAM–III, offers seven subscales, which relate to major areas of family functioning. This instrument also assesses two response styles: *Denial* and *Social Desirability*, (Trute & Hauch, 1988). The FAM-III has been widely used in research literature, focuses on whole family functioning and has the ability to identify both healthy and pathological family functioning (Jacob & Windle, 1999). The process of completing the FAM-III often stimulates family members to perceive their family interactions and relationships and their new awareness of the viewpoints of others enables them to " conceptualise family difficulties" (Steinhauer *et al.*, 1984, p. 109).

The Family Assessment Measure was originally developed to evaluate whole family functioning but it is a valuable tool for assessing marital and parent-child relationships as well (Jacob & Windle, 1999). The *Dyadic scale* allows the researcher or therapist to detect areas of conflict between partners. Systems theory maintains that the quality of the dyadic relationships within a family is closely related to the functioning of the family as a whole and positive parent-child relationships are related to positive family functioning (Shek, 2001).

The majority of scores should fall between 40 and 60. Scores below 40 indicate very effective family functioning and scores above 60 suggests disturbances. While the FAM-III indicates family members perceptions of strength and weakness in various areas it is unable to define the problem. For example, a high elevation on the scale for *Affective Involvement* only suggests difficulties. A clinical assessment is essential to determine if these perceived difficulties are indicative of enmeshment or disengagement (Steinhauer, 1984). The FAM-III complements and assists other assessment approaches but is not a substitute for a clinical assessment (Skinner *et al*., 1995).

There is a high probability that that there are problems in a certain area if a respondents' score is elevated above 60. A discrepancy between the profiles of spouses is suggestive of covert marital discord, even if these scores are not significantly elevated (Skinner *et.al.*, 1995). It is essential to determine which aspects of family functioning are characterised by member discrepancies and which aspects they are in agreement on. However, even if the profiles *are* congruent this does not necessarily mean that there is no dysfunction present (Steinhauer *et al.,* 1995).

The FAM-III scale was used in this study and the following dimensions of family functioning were explored. All these dimensions are "subject to the values and norms of the particular family, and the society" ((Steinhauer, *et al.,* 1984).

3.14.1. Task Accomplishment

According to the Process model, the goal of the family is the successful accomplishment of certain superordinate, and unique tasks or goals. The superordinate tasks are to "…provide for the biological, psychological and social development and maintenance of family members, thus ensuring the survival of both the family and the species." (Steinhauer, *et al*., 1984, p. 77). T*ask Accomplishment* refers to the ability of the family to successfully identify and resolve problems. Statements on this scale relate to practical problems faced by all families (e.g." When problems come up we try different ways of solving them") as well as emotional issues related to problem solving (e.g "When problems come up between us, this person is all talk and no action").

3.14.2. Role performance

To successfully accomplish both its' basic and developmental tasks, a family must negotiate certain common roles and objectives (Steinhauer, *et al*., 1984, p. 79). "Roles are prescribed and repetitive behaviours involving a set of reciprocal activities with other family members" and can either hinder or aid task accomplishment.

This subscale focuses on the established behavioural patterns within a family, which are necessary to accomplish its relevant tasks. Items deal with aspects such as role differentiation (e.g. "Family duties are fairly shared"), emotions related to roles (e.g. "My family expects me to do more than my share") and support within the system (e.g. "We can't rely on family members to do their part").

Roles can only be successfully performed if there is effective communication between family members, strong family involvement and affective expression (Bernstein & Borchardt, 1996).

3.14.3. Communication

Good communication between family members is a characteristic of functional families (Scabini *et al.,* 1999). To successfully accomplish basic tasks and attain mutual understanding, there has to be an effective communication system between family members (Skinner *et al.,* 1995). Family satisfaction is related to the quality of communication that exists between parents and children (Scabini *et al.,* 1999). The items dealing with this subscale focus on both the content (e.g. "I know what this person means when he/she says something") and the process (e.g. "If I'm upset with another family member, I let someone else tell them about it") of communication.

3.14.4. Affective Expression

Affective Expression is defined as "the appropriateness, intensity, timing and inhibition of affective communication" (Bernstein & Borchardt, 1996, p. 5). Various factors, such as age, sex, culture, values and norms interact and determine what different individuals will regard as 'appropriate' affective expression. From an early age infants communicate their needs to their primary caregiver. If they find these needs are met and they receive an 'appropriate' response, they experience positive emotions and are encouraged to further interact. If however the caregiver does not respond correctly to his communication signals the child experiences negative emotions such as anger and frustration which he attempts to control by withdrawing from the interaction (Tronick, 1989).

Affective expression is an important aspect of the communication process and implies the ability to communicate one's emotions and feelings (Skinner *et al.*, 1995). The items on this scale evaluate the extent to which family members can communicate their feelings to each other and focuses on three elements of feelings: the content (e.g."We tell each other about things that bother us"), the intensity (e.g."When this person is upset, he/she tries to get me to take sides") and the timing (e.g. "When our family gets upset we take too long to get over it").

3.14.5. Involvement

A study by Trute & Hauch (1988) found that families who adapted positively to the birth of a disabled child scored significantly higher on the subscales of the FAM-III relating to strong family involvement and affective expression. Well functioning families have neither too little nor too much involvement with each other (Epstein, Baldwin, & Bishop, 1983). Affective ties between members are strengthened by shared activities and value systems (Jacob & Windle, 1999, p. 353).

Affective Involvement between family members refers to the extent to which members meet each other's emotional needs and thus contribute to the development of a positive self-image and feelings of security (Steinhauer *et al.*, 1984). Items on this scale assess both the intensity (e.g. "When I'm upset I know this person really cares") and quality (e.g."This person gets too involved in my affairs") of family involvement.

3.14.6. Control

Control is the manner in which the family system maintains ongoing functions while successfully adjusting to change (Steinhauer *et al.*, 1984). It is defined as "the process by which family members influence each other" (Skinner *et al.*, 1995, p. 2). Family differences on important aspects of family functioning such as affect, control and shared activities appear to impact on family functioning. Items on this scale focus on practical issues of control (e.g. "Punishments are fair in our family") as well as the emotional aspects (e.g."I get angry when others in the family don't do what I want").

3.14.7. Values and Norms

Values and *Norms* "define the context within which all other dimensions of the model operate" (Steinhauer *et al*., 1984, p. 85) and are reflected in a family's behaviour. A family's norms consist of what is and is not regarded as acceptable behaviour within that family and are the standards towards which individual members are encouraged to aspire to.

Many of the unique tasks a family needs to accomplish will be influenced by the values and norms of the external community as well as the values and norms unique to the family itself (Steinhauer *et al*., 1984). The family is a subsystem of the society in which they live and discord

and tension result when there is a dissonance between the two value systems (Steinhauer *et al*., 1984).

This scale focuses on three important elements related to values and norms: whether family rules are explicit (e.g. “The rules in our family don’t make sense”); whether family members have sufficient autonomy to develop unique attitudes and behaviour (e.g. “We are free to say what we think in our family”); whether the family norms are consistent with those of the external culture (e.g. “The person is all wrong about the importance of religion”).

The *General Scale* differs from the *Dyadic* and *Self-Reporting Scales* in that it consists of nine subscales. Seven subscales or measures relating to the Process Model and an extra two response style subscales; Social Desirability and Defensiveness.

3.14.8. Social Desirability

A raised score on this scale suggests that the individual is distorting his/her responses and may be attempting to portray themselves and their family in a more favourable light. Non-problem families have a tendency to score higher on this subscale (Skinner, Steinhauer & Santa-Barbara, 1983). An example of these items are “My family and I understand each other completely”. Studies found that the only significant difference between families with a child suffering from cystic fibrosis and a control group was an elevation on the *Defensiveness* and *Social Desirability Scales.* It was felt this was an important response style, which helped these parents cope with the ongoing stress, (Skinner *et al.*, 1995).

3.14.9. Defensiveness

The quality of the family environment has a major effect on the styles of defensive behaviour that individuals develop and eventually make use of in adulthood (Thienemann, Shaw & Steiner, 1998). Individuals who score above or below the norm on this scale suggest that they may be over or under-reporting problems and thus may distort the clinical scales. An example of an item dealing with this possible distortion is “We have never let down another family member in any way”.

3.15. RELIABILITY OF THE FAM SCALE

The FAM-III was developed according to "a construct validation paradigm" (Jackson, 1971; Skinner, 1981,1987, cited in Skinner *et al.*, 1995, p. 43). Initially a large number of items were generated for each construct and the best 180 were administered to a sample of 433 individuals from both clinical and non-clinical families. The results of these analyses resulted in the development of the present 134-item instrument, which has the ability to differentiate information about specific areas of family functioning (Skinner *et al.*, 1995). Reliability refers to "the attribute of consistency in measurement" (Gregory, 1996, p. 84). This concept presupposes that the attribute remains stable over time and possible sources of error such as emotional responses are considered (Huysamen, 1988).

Table (3.1) shows the Internal Consistency Reliability estimates for the various FAM-III subscales and considers possible sources of measurement error, which can occur, for example, if the family is undergoing a stressful period.

Coefficient alpha which is "an index of the degree to which a test measures a single factor" (Gregory, 1996, p. 96), indicated a measure of consistency of individuals responding to items on same subscales. The degree of inter-item correlation for the *Overall ratings* on all scales is impressive. However, there are indications of a decrease in reliability on the briefer subscales as the number of items has an effect on the measure of reliability (Skinner *et al*., 1995).

The researchers felt that the reliability of the *General* and *Dyadic Scales* are satisfactory but attention must focus on increasing the reliability of the self-rating scale with particular attention focusing on the dimension of Control and Involvement (**Table 3.1**).

There is a generally high correlation among the different subscales (**Table 3.1**), which suggests there is "a large general factor underlying the FAM-III scales" (Skinner *et al.*, 1995, p. 45). For example, if an individual rates Communication to be strength, he is likely to also rate strengths on the other constructs. However, there is sufficient variance between the subscales, which justify their separate use, and interpretation (Skinner *et al.*, 1995). Jacobs (1995) found that time frame has no effect on how an individual reports his/her family functioning. Members who report negative or positive relationships do so whatever the period, which suggests that FAM-III scores can be generalized across different time frames (Skinner *et al*., 1995).

Table 3.1: (Skinner, et al., 1995, p. 44) Internal Consistency Reliability Estimates

GENERAL SCALE	ADULTS	CHILDREN
OVERALL RATING	.93	.94
SUBSCALES:		
Task Accomplishment	.67	.60
Role Performance	.73	.64
Communication	.73	.70
Affective Expression	.74	.71
Involvement	.78	.75
Control	.71	.63
Values & Norms	.70	.62
Social Desirability	.87	.87
Defensiveness	.65	.70
DYADIC SCALE		
OVERALL RATING	.95	.94
SUBSCALES		
Task Accomplishment	.74	.73
Role Performance	.82	.71
Communication	.77	.77
Affective Expression	.59	.55
Involvement	.64	.59
Control	.72	.72
Values & Norms	.72	.66
SELF-RATING		
OVERALL RATING	.89	.86
SUBSCALES		
Task Accomplishment	.51	.40
Role Performance	.53	.27
Communication	.67	.58
Affective Expression	.64	.55
Involvement	.44	.44
Control	.39	.39
Values & Norms	.60	.46

3.16. VALIDITY OF THE FAM SCALE

Validity can be defined as "the extent that inferences made from it are appropriate, meaningful and useful" (Gregory, 1996, p. 107). A test is therefore considered to have validity when " the various traits assumed to underlie what is being measured are represented in the test" (Reber, 1985, p. 810).

Skinner *et al*., (1995) assessed many studies of 'problematic' families that had used the FAM-III in the research. Their results included:

- Garfinkel, Garner, Rose, Darby, Brandes, O'Hanlon and Walsh (1983, cited in Skinner *et al.,* 1995) investigated families, which included a child with anorexia nervosa. They presented with elevated general scores relative to the norm, which suggests greater dysfunction.

- The ratings by bulimic patients who were administered the FAM-III were found to be significantly higher on the *Self-rating Scale* and the *General Scale* which indicates a perception of poor family functioning (Woodside, Shekter-Wolfson, Garfinkel, Olmstead, Kaplane & Maddocks, 1995, cited in Skinner *et al.,* 1995)).

- All members of families containing an alcoholic father presented with notably high scores on the *General Scale* suggestive of problematic family functioning (Jacobs, 1991).

- Foster children who completed the FAM-III *General Scale* separately for their foster parents and then for their natural parents consistently gave lower (healthier) ratings to their foster families. The tendency to present the foster families in a positive light was reflected in the higher scores on this scale (Kufeldt, Armstrong, Dorosh, 1994, cited in Skinner *et al.,* 1995)).

Gondoli and Jacob (1993) state that many instruments developed to measure whole family functioning actually measure fewer independent constructs than purported. Their comments regarding the FAM-III include:

- Two subscales related to communication, *Communication* and *Affective Expression* might reflect primary dimensions of family process.
- The substantial intercorrelation reported by Skinner (1987, cited in Gondoli & Jacob, 1993) among the subscales may indicate that the FAM-III measures only a single factor related to affect.
- The intercorrelation may be due to the fact that respondents cannot differentiate between items that are closely related yet distinct. It may also be due to the fact that the underlying model may be unnecessarily complex.
- The FAM-III purports to measure pragmatic aspects of family functioning such as Ta*sk Accomplishment* but instead appears to measure "evaluative judgments of family members" (Gondoli & Jacob, 1993, p. 287).
- It is possible to describe family relations with a few primary dimensions and the model underlying the FAM-III may be overly complex.
- Another possibility is that self-report instruments are just not capable of capturing the multidimensionality of family relations.
- More research is necessary to determine whether theoretical or methodological problems underlie the limited dimensionality of the FAM-III.

3.16.1. Discriminant Validity

Discriminant validity refers to "the ability of an instrument to distinguish groups different in functioning" (Skinner *et al*., 1995). The FAM-III has demonstrated the ability to differentiate between groups. Studies that have demonstrated that the FAM-III has good discriminant validity include:

- Parents of children presenting with school phobia were found to have significantly higher scores on the *Role Performance* and *Affective Expression* dimensions than parents from a matched group with no social phobic child (Bernstein & Garfinkel, 1988, cited in Skinner *et al., 1995*).

- In a study of 69 participants undergoing treatment for relationship problems, the FAM-III differentiated those couples that were distressed by the significantly higher scores on several subscales (Forman, 1988).

- Children of parents with manic-depressive illness presented with significantly higher scores on the *General, Affective Expression* subscale and the *Dyadic, Communication* subscale (Laroche, Sheiner, Lester, Benierakis, Marrache, Engelsmann, & Cheifetz, 1987, cited in Skinner *et al.,* 1995).

3.16.2. Concurrent and Construct Validity

Concurrent and Construct validity determine how well the instrument compares to other instruments with similar purpose.

All instruments designed to assess family functioning have both strengths and weaknesses. However there are many correlations between FAM-III subscales and those of other respected instruments:

- There appears to be a strong relationship between FAM-III subscale scores and the MMPI special family scales (Bloomquist & Harris, 1984).

- There was generally high and significant correlations between the FAM-III subscales and those of *The Family Environment Scale (FES), The Family Adaptability and Cohesion Evaluation Scales (FACES)*, and *The Family Assessment Device (FAD) (Jacob, 1995).*

- Reddon (1989, cited in Skinner *et al.,* 1995), administered a battery of tests to 16 families with preschool children with physical and mental handicaps. There were high correlations between the FAM-III subscales and the other instruments, which included the Parenting Stress Index (PSI) and the Family Inventory of Resources for Management (FIRM). Of significance, is that the PSI includes a 'relationship with spouse' subscale and high scores on this level suggest individuals lack emotional and active support from their partner regarding childcare. This subscale correlated significantly highly with the FAM-III subscale.

- Gondoli & Jacob (1993) disagree and state that correspondence between the FAM, FES, and FACES III was limited to areas of affect, cohesion and control

and was due to the “limited dimensionality of the FAM, the FACES III, and to a lesser extent the FES” (Gondoli & Jacob, 1993, p.287).

Jacob & Windle, (1999) assessed the FAM, FES, and FACES III and their findings regarding the FAM-III included the following:

- Only three general factors (Affect, Activity and Control) best described relationships among the various scales.

- The dimensions of affect and activities appear to be highly correlated but contain enough unique variance to justify their continued separation. Affect focuses on aspects of emotional closeness while activities focuses on behavioural interaction while sharing activities.

- The FAM-III purports to assess whole family functioning but can equally well be applied to child-parent and marital relationships. The generalizability of the primary dimensional structure would be revised and developed so that the focus on the dyadic aspect could reflect the same factor structure.

- Interpersonal relations are characterized by a few basic dimensions, which can be applied to an understanding of whole family functioning, parent-child and marital relationships. These three dimensions are affect, control and communication.

- Future research designs should specify family subsystems as presently, different family members are reporting on the same reality while still having unique perceptions.

3.17. FAM SCALE ANALYSIS

All the respondents completed all three scales of the FAM-III questionnaire in the individual follow-up interview. The researcher read out each item to all individuals when administering the FAM-III and recorded the responses. This way it was possible to

clarify meanings of some ambiguous items and ensure that each participant had full understanding.

All three scales were scored for each participant and those scores that were elevated near or above 60 identified problem areas. Discrepancies between the scores of a particular marital dyad were also noted. Large differences between couples and scores that lie in the 'problematic' range form the basis of the discussion relating to each family's FAM-III results. It was not possible to compute statistical significance for any scores due to the size of the sample.

3.18. CONCLUSION

The FAM-III offers three simple quantitative scales, which are easy to administer and score. The results of the FAM-III are discussed in conjunction with the findings of the in-depth interviews as each instrument compliments the findings of the other and adds value and additional information. It is hoped that the FAM-III can offer support for the findings of the qualitative interviews.

Chapters 4 to 8 cover the case studies and are each presented in a separate chapter. Each chapter is preceded by an introduction to each family and a summary of their story. This is followed by a discussion of all the relevant findings unique to each family.

In Chapter 9, I discuss the general findings and unique perceptions of each family within the family systems framework.

CHAPTER 4

THE PRINSLOOS: EXPRESSIVE MOTHER, PLACATING FATHER

4.1. FAMILY BACKGROUND

Leon and Ansie Prinsloo are in their mid-thirties, and have three children. Pieter is seven years old, Johan is four and Ingrid is seven months. Johan was born with a cleft lip and palate. Leon is a financial manager and Ansie trained and worked as a nursery school teacher but is currently a full time mother. She suffered two episodes of depression about a year after Johan's birth, which necessitated stays in a clinic and which prompted her decision to give up teaching so that she could devote all her time to her family. Leon began studying for a degree in the evenings when Johan was born. He completed his studies but also seems to have suffered from a period of depression when he was finished which he managed to work through himself.

4.2. FAMILY INTERVIEWS

The combined interview with Leon and Ansie took place one evening in their home and was approximately two hours long as I administered the FAM-III to Leon when the discussion was complete. When I arrived they were both very welcoming and my first impression was that this is a loving couple that are committed to their marriage and have strong family values. The two older boys were asleep when I arrived. Ingrid, the baby, was awake and lay happily in her mother's arms throughout our discussion.

Both parents were eager to discuss their experience and although Ansie is the more expressive and emotional of the two, Leon conveyed his feelings in a characteristic pragmatic manner and did not need much prompting. The follow-up interview with Ansie took place the following week and certain issues regarding the first interview were first clarified before the FAM-III was administered.

4.2.1. Interactive Discussion

The Prinsloos acknowledge that the initial news of Johan's cleft lip and palate was a shock as it was not picked up on prenatal sonars and was only discovered at the birth. "It was a terrible shock. A big shock", said Leon and continued to so describe his initial reaction to his son's facial anomaly. With hindsight he maintains that he is grateful that they did not know about the cleft before the birth but Ansie disagrees and maintains that she would have preferred to have been prepared. The cleft was "quite a big gap" and went "right up into the nose so the hole was open." She now feels that it "was a nice cleft" as she has seen many more severe ones since but says, "It doesn't make it easier when it's your child."

They both felt angered at the attitude of the gynaecologist and the paediatrician. Leon felt that the casual attitude of the gynaecologist was "arrogant" as she had not picked up the condition during the pregnancy and just said, "Hy het 'n haas lip." Ansie felt very angry and says, "I was so angry with her that I never went back." She also did not find the paediatrician supportive and instead felt that the only professionals who "took charge" were the nursing sisters who told them exactly how to deal with the problem and directed them to Professor Butow and his team who ran the Facial Cleft Deformity Clinic of the University of Pretoria.

Johan was delivered by epidural caesarean section and as Ansie was awake, her first reaction was that "it was a sick joke." Reality dawned when she saw "Leon crying out of shock and I knew something was wrong." Leon says that both he and Ansie held their son immediately after the birth and did not reject him in any way. "There were no feelings against Johan. It was just the shock and then the sympathy…because I thought he's going to go through so much pain and suffering."

Ansie's parents have always been exceptionally supportive. Her mother is a nursing sister so she relies on her for both emotional and practical support. "I involve my mother and then it makes it difficult in that way". She did not fully comprehend the extent of the stress experienced by her parents until she decided to have a third baby. Her father told her that if there was something wrong with this baby he didn't want to see her until "the baby is right" as he felt he just could not go through a similar ordeal a second time.

After Ingrid's healthy birth, Ansie's mother admitted that the pregnancy had been a very stressful period for them. Neither of her parents rejected Johan and they both have a strong bond with him today.

Leon's parents and sister are also supportive but they do not live in the same city so cannot be available for consistent, practical support. Ansie has a sister and brother who is both involved with their own lives and cannot be relied on to help in any way.

Leon says that once he got over the preliminary shock, Johan's appearance was not a problem for him. "It wasn't an issue." Ansie recalls the first time she had to take him to the paediatrician as "the worst thing that could have happened to me in my whole life". Her initial reaction was to hide him but she suddenly decided that she was not prepared to deal with the problem in that manner. She decided that it was necessary for her child to "see things and get a balance" and forced herself to be open about his appearance. She says that the reactions of adults bothered her much more than those of children. "The children I could handle because you can give them an answer". She resented the mothers who would glance at Johan and then instruct their children not to look.

Both parents are very protective of Johan but Leon feels that Ansie has developed the fiercest protectiveness. "Even today if someone says something about Johan, Ansie will be aggressive. Well not aggressive but assertive." Ansie admits that she can be aggressive if she feels that any of her children are threatened but feels she is more so with Johan due to his facial cleft and recalls the first year of his life as extremely traumatic. "It feels like a tantrum in your life." She spoke of an altercation with nursing staff when Johan was three months old and described her actions as throwing " my toys out of the cot". When the 'tantrum' was over, Leon managed to 'calm her down'.

Ansie appears to constantly react to situations in an intensely emotional manner. When Johan's lip had been surgically corrected, an acquaintance at a social function said, "Don't worry he can grow a moustache". Ansie was so incensed by this unthinking comment that she told the woman that her son was "gorgeous" and he hadn't gone through all the operations so that he could hide his lip with a moustache. She then insisted that her husband took them home. Leon appears to support these outbursts and continually takes on the role of the calming spouse. Throughout the interview, Ansie

did most of the talking and Leon would often respond with, “Mmmm” when she related any incident that was emotionally charged.

The first four months after Johan’s birth were very distressing for all family members. Ansie stated, “I think Leon was in such a surviving mode at that stage.” He had started a three-year degree the week before the birth, which necessitated evening lectures after a full day at work. Sometimes he would not come into the house but would fetch his supper from the postbox and then go on to the University. Ansie felt that she was so exhausted during that period that she could not also cope with her older son’s tears if he saw his father leaving for the University in the evening.

The Prinsloos feel that it is not helpful to tell parents of a physically challenged child, “It’ll come right later on.” They acknowledge that such a comment is often meant well but they feel that parents cannot think ahead and “It’s difficult *now.”* Neither do they feel that it is helpful to be told that “At least he’s not a Down’s syndrome” as everyone’s problem is relative and the parent of a child with a facial anomaly are suffering and do not yet perceive themselves as “lucky”. Ansie feels that comments should be positive and focused away from the mouth. “He’s got such lovely eyes or such a gorgeous smile.” Leon agreed that it is best to acknowledge that it is a difficult time and “be honest.”

When Johan was five months old he had his first operation, which involved correction of his soft palate. He developed an infection, which necessitated a longer hospital stay. Again there was an incident where Ansie felt she was “shoved’ by one of the nurses and she was furious. She told Professor Butow, the maxillo-facial and oral surgeon who performed the operation, that if there were a repeat of such an incident she would “throw a tantrum”.

The second operation at seven months “was like a fat fine operation!” The hard palate and cleft lip were fixed and Ansie stated that he smiled and “looked like he should have when he was born.” She felt that it was like having a baby with a new face. “I would just sit and I was watching him the whole time.” Although Leon says that he told Ansie that Johan looked beautiful with “that wide open smile”, Ansie emphatically said that she did not miss it and felt that she could not stop looking at her son.

The Prinsloos do not display photos of Johan before his corrective surgery. But as Leon correctly stated, they actually do not display early photos of *any* of their children. "It's not as if we've got this picture of Pieter and didn't do the same for Johan." Ansie feels that she is not trying to hide the fact that her son had a facial deformity but she doesn't want to be constantly reminded of it. "This is how he looks now." Leon thinks that Johan also "wants to move on" as he is irritated with his yearly visits to the clinic and having to be subjected to various doctors examining his mouth. He no longer relates to the patients at the clinic and asks his mother why he must go and why the other children look like they do.

Johan has always had problems with ear infections and has had many operations to insert grommets. He appears to be a well-adjusted child who is aware that he had a cleft lip and palate deformity when he was a baby but it is not an issue in his life. His parents show him the photos when he wants to see his album and answer all his questions honestly. When his sister was born he asked his mother why he had had a split lip and she replied, "Because you're very special." He was satisfied with the answer and did not question her again. He seems to be a confident child who does not have low self-esteem and when a child at nursery school asked him "Hoekom is jou bek skeef?" he was not upset and told the child, "Ek sal jou moer!" Ansie was more upset over the incident than he was.

His parents feel that he has a forceful personality and can sometimes be too aggressive and demanding of attention at home. They feel that his older brother has suffered more negative consequences as he lost the limelight when Johan was born and needed so much extra care. They are aware that they must boost Pieter's self-esteem, as he tends to withdraw when his younger brother demands attention. "He backs off a lot." Ansie feels she did her best to make her older son feel secure and "I can't feel guilty." She states that both her children are compassionate towards others as a result of their experience. It was a difficult period for Pieter and Ansie thinks that he did not really understand what the family were going through and was distressed when he saw his mother constantly crying. She now tries not to cry in front of him as she feels that at one stage he was so worried about her he did not want to go to school. She added that she does not think it is a bad thing to be able to release emotions by crying but acknowledges that a child would develop a different perception.

The Prinsloos had always wanted a big family and decided to try for another baby when Johan was nearly three years old. Leon admits that he was very worried that they might have another child with a facial cleft but resisted voicing his concerns to his wife, as she "wanted to have good memories of having a baby." Ansie maintains that she *had* to have another child so that Johan would not think that his birth defect affected their decision. Both parents were very relieved when a healthy daughter was born.

The family survived the first year of Johan's life despite many hardships. However, when things were at last getting better the full effects of the stressful year appeared to take a toll. Ansie felt that Leon 'survived' because he had to support his family and finish his studies and then he "went into a type of depression" which he battled to get out of. She too suffered two episodes of depression, which involved a couple of week's hospitalisation after she returned to work when Johan was 18 months old. She then decided to stay at home and care for her children and not put any more undue pressure on the family.

4.3. FAM RESULTS

I administered the FAM-III to Leon and Ansie individually when I held the separate interviews.

Scores on the following dimensions were compared:
Task accomplishment; Role performance; Communication; Affective expression; Involvement; Control; Values and Norms.

4.3.1. Task Accomplishment

Task Accomplishment implies that family members must perform a range of maintenance and developmental tasks to achieve necessary goals (Gondoli & Jacob, 1993). Within this family, the role of *Task Accomplishment* appears to be satisfactorily accomplished according to the results of the *General* (Figure 4.1) and *Dyadic Scales* (Figure 4.3). However both members of this dyad received high scores on the *Self-Rating Scale* (figure 4.2) with Ansie's score of 62 suggesting that she feels that she does not respond appropriately under stress. According to systems perspective, abnormal or inappropriate behaviour is symptomatic of a dysfunctional family system.

The interview findings confirm the results of the FAM-III as Ansie stresses her need of professional guidance when she has to deal with problems beyond her control. It is evident that minor stresses precipitate a crisis which is confirmed by her many 'tantrums' when things do not always go well for her. Leon's score of 56 suggests that he too may have similar feelings, which he did not verbalize during the interview. His typical behavioural response to stress appears to try and manage problems in a controlled and systematic manner. However, the fact that he went into "a sort of depression after the whole thing" may reflect an individual who has exhausted his coping abilities.

Both Ansie and Leon appear satisfied with the family ability to function effectively and provide security for all members. When times were difficult, they dealt with their emotions and the insecurity of their older child by minimizing and anticipating possible problems. For example, Leon would take his supper from the postbox to prevent emotional upsets in the family. Both Ansie and Leon developed depression in the year following the birth of their son, which confirms this system's lack of coping skills and it's inability to adapt to change and stress

4.3.2. Role Performance

Family roles refer to the patterns of interaction by members to ensure family functioning (Becvar & Becvar, 1996). The FAM-III results indicate that both Ansie and Leon are satisfied with their personal *Role Performance*. They both agree that their partner does not expect too much of them and takes his/her share of responsibilities. (Items 9 & 30 – *Self-Rating Scale*). While this couple seems to have satisfactorily reached agreement as to the roles each one assumes within the family, there is a slight discrepancy of 6 points on their scores on the *Dyadic Scale* (Figure 4.3), which may point to certain feelings of dissatisfaction within their relationship.

There are indications that Leon appears to have feelings of frustration with the *Role Performance* within their relationship. He states that Ansie complains that he expects too much of her (Item 37). Ansie appears to feel less satisfied with the general role differentiation within the family as she assumes the main portion of the domestic responsibilities. She took Johan to the speech therapist to ensure there would be no future problems in that area and deals with school problems and related issues. She

also takes him for his clinic checks and when she could not fulfill all her domestic roles, as she had to be with Johan in hospital, she called on her mother-in-law to step in by saying, “I need you to look after Leon and Pieter for me”. It is interesting that she appears to see the role of ‘looking after’ family members as a female one as she insists that her mother-in-law, and not her husband, temporarily assume the role when she is not available.

The discussion confirmed Ansie’s underlying conflict over her heavier domestic burden but there was no indication that Leon was not content with his ‘breadwinner’ role.

4.3.3. Communication

Communication within a family refers to the exchange of information between family members, which may be clear or masked (Becvar & Becvar, 1996). Both Leon and Ansie seem to be dissatisfied with certain aspects of this process within their family unit and relationship. During the interview, Ansie appeared to be sending covert conflicting messages at times when she spoke of the fact that Leon is not always available to share some of her domestic role. For example, she states that she did not mind that he could not be with her in the hospital when Johan had his operations but contradicts it with the comment, “You sit there for 24 hours a day and you only see him (Leon) at night.”

Ansie’s score of 42 on the *Self-Rating Scale* (Figure 4.2) suggests that she feels she communicates effectively while her score of 60 on the *General Scale* (Figure 4.1) indicates that she is not satisfied with the communication within the family unit. She does not feel that she always gets a straight answer and feels they argue about who said what. (Items 3 and 13. - *General Scale*) However, she states that she knows what is going on in her family and they take the time to listen to each other (Items 23 & 33). Leon admitted that he does not always take the time to listen to his family (Item 33 – *General Scale*).

The results of the FAM-III suggest that Leon is also not totally happy with the communication process within their family unit but his score of 58 on the *Self-Rating Scale* (Figure 4.2) appears to identify the problem as lying within his own communication

abilities. He agreed that he doesn't always say what he would like to as he can't always find the words (Item 24 – *Self-Rating Scale*).

On the *Dyadic Scale* (Figure 4.3), Leon stated that he does not always know what Ansie means when she says something (Item 3) but they both agreed that their partner is available when they want to talk and listens to their point of view (Items 24 & 31).

During the interview, Ansie was the most verbally expressive of the two and she sometimes interrupted her husband and answered for him. This exchange did not appear to irritate him and he generally nodded in agreement to most things she said. There are suggestions that he may not always tell her how he feels about all issues as he admitted that he was very worried when she wanted a third baby but "I didn't want to tell her." Ansie too, acknowledged that she was very worried when she was pregnant with Ingrid but "I would never speak it out." "Healthy communication calls for two or more people to attempt to share the same focus of attention and to derive shared meaning during this effort" (Goldberg & Goldberg, 1985, p. 58). The Prinsloos don't always succeed in achieving this.

4.3.4. Affective Expression

Affective Expression refers to the family's ability to express feelings with appropriate intensity and timing to ensure that all members feel valued and listened to (Becvar & Becvar, 1996). Both Leon and Ansie appear to be satisfied with the expression of feelings within their family and the only discrepancy in this area was that they differed by 14 points on the *Dyadic Scale* (Figure 4.3). Again the higher score was Leon's, which suggests that he is not totally happy with the situation while Ansie does not seem to note a problem in this area. In the interview she admitted to being an emotional person who does not have a problem expressing her emotions, "I'm a crying person".

In contrast, Leon's only comment regarding the stressful first year after Johan's birth was, "It was quite tough." Leon strongly agrees that he can tell when Ansie is upset and feels that she tries to get him to take sides (Items 4 & 39). She strongly agrees that at such times he usually knows why she is upset (Item11). However, they both state that

their partner does not stay upset for days and does not take it out on him/her when he/she has had a bad day. (Items 25 & 32).

Throughout the interview, Ansie never attempted to conceal her emotions. In contrast, her husband presented as an individual who is in control of his feelings and rarely reacts emotionally. The results of the FAM-III suggest that he is dissatisfied with the expression of affect within their relationship. Ansie admits she throws many 'tantrums' and during the discussion, Leon described her as 'aggressive', which he then amended to 'assertive' when describing her protectiveness of her children. It is possible that he may experience the overly intense emotions constantly expressed by his wife as stressful. However, he maintains her emotional expressiveness by reacting in a calming way and therefore conveying the message that he is supporting her affective expressions.

4.3.5. Involvement

Involvement describes the extent of family members' interest and connection with each other (Steinhauer *et al.,* 1984). Leon and Ansie appear to be involved in each other's lives and encouraging of each other. When he decided to study for his degree she did all she could to ensure that he was successful. If she is upset, he in his turn attempts to placate her and reassure her. He felt angry when his brother did not support Ansie when Johan was a baby and she did not have access to a car to get out. The findings of both the interview and the FAM-III results point to a couple who are involved in each other's lives in a healthy manner. There are no indications of dissatisfaction with the involvement they perceive within their family.

4.3.6. Control

Successful *Control* ensures continued functioning of a family system and describes the differing and changing ways in which members influence each other's behaviour (Steinhauer *et al.,* 1984). Again, the Prinsloos appear to have achieved a balance, which incorporates all the healthy aspects of this process. They are consistent in their dealings with each other and constructive, responsible and predictable in their behaviour and interactions. Generally they seem capable of functioning in a competent manner

and have the ability to adapt when the need arises. There is no evidence of covert power struggles within their family interactions.

4.3.7. Values and Norms

Values and *Norms* of a family refer to the ideals of the members to which they aspire (Steinhauer *et al., 1984).* Both members of this dyad appear to share a similar value system and there are no indications that there are major areas of conflict. She supported his decision to study further and he supported her wish to have another child. This family system is also part of the system of their families of origin and their interaction with these subsystems seems to be healthy and balanced. The larger family system continues to have an influence on the behaviour of members after they have grown to adulthood (Fingerman & Bermann, 2000). Their family values and norms are also consistent with the general cultural context within which they live.

4.3.8. Social Desirability

While most of the results of all three scales completed by both Leon and Ansie were between 40 and 60 there were some discrepancies in their responses which points to potential problems in certain areas. Leon's *Social Desirability* score (Figure 4.1) was 44 as opposed to Ansie's higher one of 56 which suggests that she is more likely to distort some of her responses to ensure that her family is reflected in a more positive light.

In the interview she also describes herself and her family in a positive manner although her responses appeared to be honest and from the heart. If she mentioned a negative aspect, she tended to justify her response to lessen the impact. For example, she admits she is "a crying person" but adds that "It's not always a bad thing as a grown up." She describes her father as "bombastic" and amends it to a more positive, "forceful." Findings of other research studies have found that non-problem families have a tendency to score higher on this subscale and it is not necessarily an indication of dysfunction (Skinner *et al*., 1983).

Leon's responses throughout the interview appeared to be carefully thought out and candid. He admitted that his first reaction to his son's facial anomaly was a "terrible shock" and for the first four months "It was very tough." While Ansie too appears to be

truthful in her responses she does tend to portray some issues in a more flattering light. After telling me that the cleft looked bad she proceeded to tell me that it was actually "a nice cleft. I've seen uglier clefts after that." However, she was totally honest in her statement that she did not miss the cleft after the operation and could not stop staring at her child's "new face."

4.3.9. Defensiveness

Again Ansie had a higher score of 46 on the *Defensiveness Scale* (Figure 4.1) as opposed to Leon's 40. Unlike her husband, Ansie stated that she didn't see how any family could get along better or be happier than hers (Items 9 & 15 – *General Scale*). She also felt that her family was a perfect success and they always admit their mistakes (Items 35 & 45 – *General Scale*). She did however agree with Leon that they don't always understand each other and there are certain things that don't entirely please her (Items 29 & 39 – *General Scale*). These discrepancies may indicate that this couple may not always share a common perception of their family. It seems as if they deal with conflict and contradictory viewpoints and expectations by masking what is actually going on between them and thus avoid addressing the real issues and problems.

These FAM-III findings were confirmed throughout the interview where Ansie consistently tended to react in a defensive manner. She spoke of feeling guilty at not noticing her older son's low self-esteem but stated, "I can't feel guilty." Both parents felt the stress of dealing with a child with a cleft lip and palate probably had a negative affect on his older brother. But Ansie stated that even when she was feeding the baby she would try and hold the toddler on her lap so he would not feel rejected. "I tried my best:

"A 10 point differential between how two family members rate the same aspect of family functioning, the more likely the discrepancy is to be clinically relevant" (Skinner *et al*., 1995, p. 25). Some of Leon and Ansie's scores on various scales differ by 10 or more points and others differ by 5 points or more, which is suggestive of a certain level of marital tension or conflict in these areas. By contrasting the *General* and *Self-Rating* scores we can compare how the individuals perceive both the family and his or her functioning.

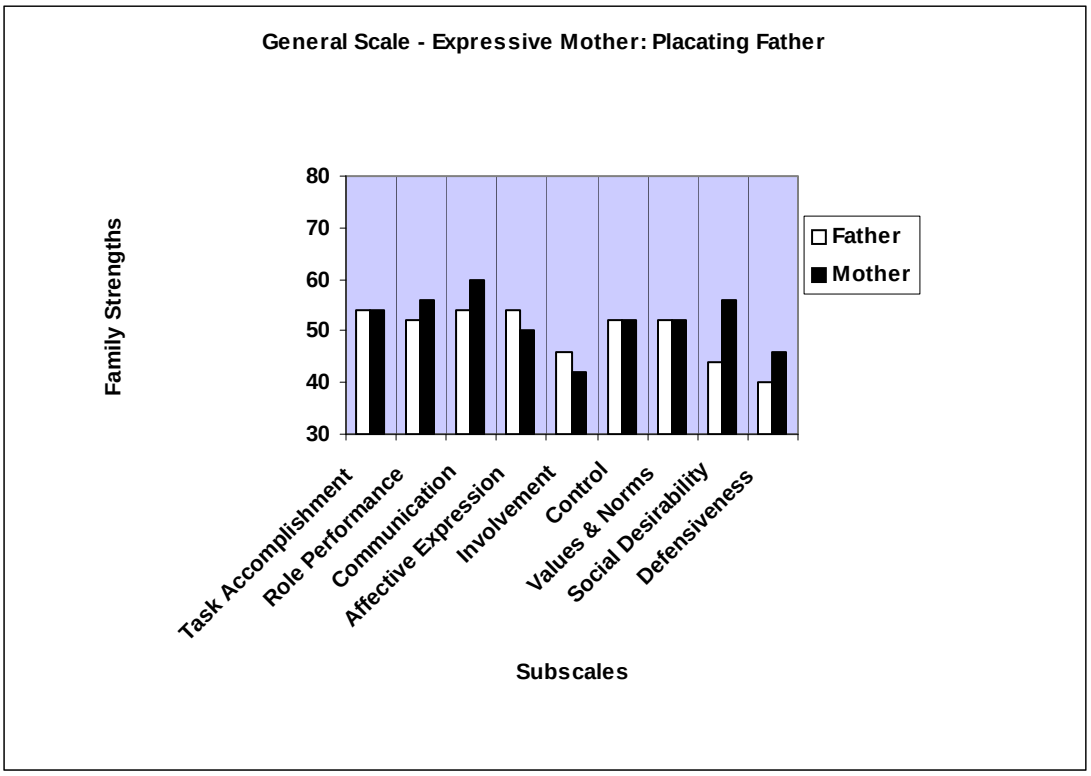

Figure 4.1: FAM-III scores for the different categories of the General Scale (Ansie and Leon)

On the *General scale* they differed by six points on *Communication*, twelve points on *Social Desirability* and six points on *Defensiveness*. They agreed on the rest. Leon's higher score of 60 on *Communication* suggests that he may feel dissatisfied with this process within his family unit. Ansie's high score of 56 on *Social Desirability* indicates that she may wish to portray her family in a more favourable light and this may indicate that all her responses may not be valid. The discrepancy between the scores may point to the fact that this couple may have differing perspectives on the effectiveness of communication in their family.

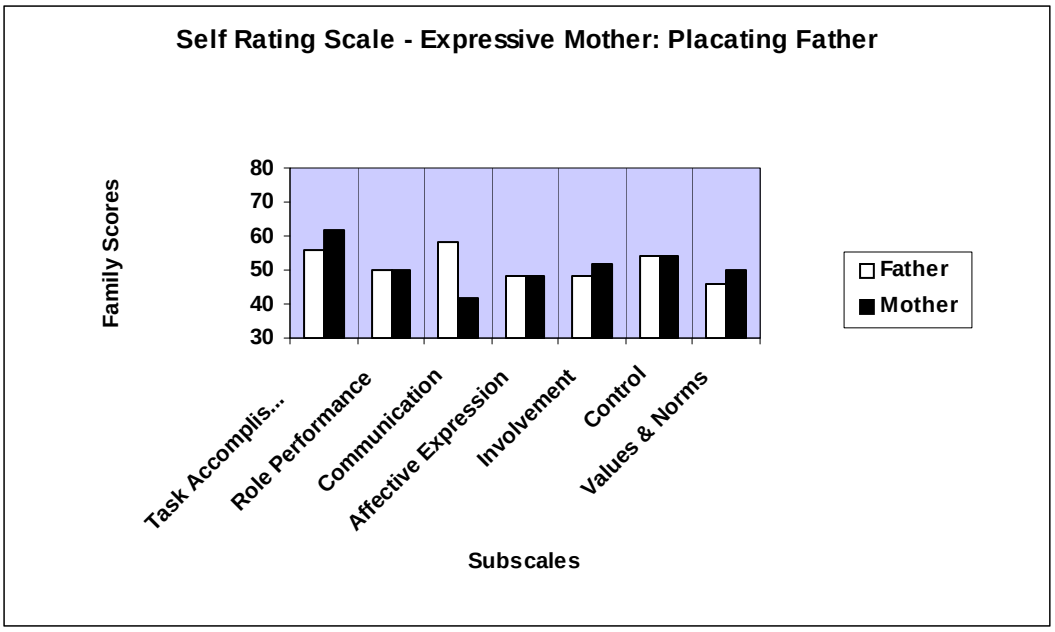

Figure 4.2: FAM-III scores for the different categories of the Self-Rating Scale (Ansie and Leon)

On the *Self-Rating* Scale Ansie's high score of 62 on *Task Accomplishment* suggest that she rates her functioning here as problematic and may feel unable to adapt appropriately to change and minor stresses may precipitate a crisis. She appears to be satisfied with her *Communication* ability, which was 16 points lower than Leon. His score of 58 implies that he feels his functioning in this area is problematic. She indicates that she is not satisfied with her personal *Task Accomplishment* and the process of *Communication* within the family unit generally. This could indicate that she feels unable to adapt appropriately to changes and is aware that minor stresses may precipitate a crisis.

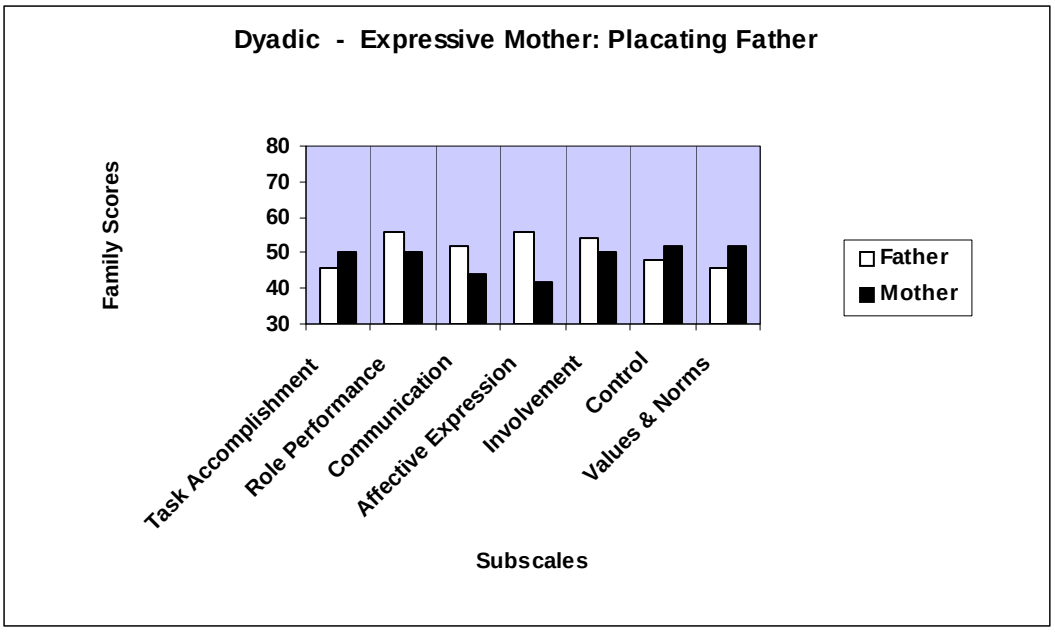

Figure 4.3: FAM-III scores for the different categories of the Dyadic Scale (Ansie and Leon)

On the *Dyadic Scale* they differed by fourteen points on *Affective Expression* and eight points on *Communication*. Leon's higher scores in these areas suggest that he is dissatisfied with these aspects of their relationship. It is possible that her conflicting messages and emotional response to situations is experienced as stressful for him but he does not appear to verbalise these feelings.

4.4. DISCUSSION

Consistent with family systems, the patterns of interaction that take place within the family are the focal point of this study – that is the process and not the content. One tenet of family systems theory is not to make value judgments. We are interested in *how* the family functions to fulfill its own goals rather than *why* they are behaving as they do (Becvar & Becvar, 1996). From family system's perspective we are focused on relationships between individuals within a system and how they interact and influence each other's behaviour. "We see people and events in the contents of mutual interaction and mutual influence" (Becvar & Becvar, 1996, p. 63). From the available information it is clear that there is mutual interaction and influence between the members of the Prinsloo family. For example, the surgery to correct Johan's cleft lip and palate causes

Ansie to become anxious and her response to this anxiety impacts on both her husband and others around her.

The *circularity* of affecting and being affected by Johan's cleft is apparent in the way this family functions. While both parents are very protective of Johan, Leon feels Ansie has developed a "fierce protectiveness" when she feels that outsiders react in a negative way towards her son. She admits to 'throwing tantrums' when she feels threatened and Leon's main response appears to be one of support and calming. This pattern of behaviour typifies this family's interactions.

A well-functioning family system consists of coexisting subsystems, which interact with other subsystems in the external environment (Goldberg & Goldberg, 1985). The concept of *circularity* can also be extended to include both extended family members and various professional people. For example, the gynaecologist who had a negative impact on this system, which contrasts with the positive impact, experienced when interacting with Professor Butow and his team. All extended family members affect and have been affected by the birth of a child with a facial anomaly. Extra support from these various subsystems was needed and the responses impacted both negatively and positively on their long-term relationships. For example, Ansie's parents were consistently supportive but felt the emotional price they paid was so high they felt they could not go through the experience again. A negative response was experienced by Leon towards his brother as he felt he and his wife were not as supportive as they could have been. As this is an open system, both Leon and Ansie were able to make use of and benefit from these available support systems.

The sibling subsystem also has been affected by Johan's condition in that Pieter's response to the lessened attention has been to withdraw. Johan, in contrast to this behaviour, appears to react by "demanding attention" from his parents at the expense of his brother. However both boys show signs of having developed empathy in their interactions with others as a result of their personal experience.

Feedback is a key concept and is a process, which serves as a mechanism to regulate the stability of a system. It is a circular or recursive process, which generates new understandings within the system (Penn, 1982). *Negative feedback* serves to maintain

family functioning, is specific to the system under consideration, and unlike *positive feedback,* it does not permit change or encourage new behaviour. *Morphostasis* refers to the system's tendency towards stability (Becvar & Becvar, 1996). Therefore, when Ansie 'throws her tantrum', the calming response from Leon maintains the status quo and the pattern of behaviour continues.

Positive feedback occurs when Ansie realized that her emotional reactions and weeping behaviour was having a detrimental affect on her older son when he refused to go to school. She therefore made a concerted effort to change and not cry in front of her son, so Pieter's behaviour caused a change in his mother's behaviour and instigated change. *Morphogenesis,* which is the "system-enhancing behaviour that allows for growth" takes place as the result of this feedback (Becvar & Becvar, 1996, p. 66).

Values and *norms* of a family influence how they successfully accomplish all the various tasks. Don Jackson, an early researcher in communications theory stated that a system operates according to three rules which determines the behaviour each family considers acceptable, "covert norms, overt values and metarules" (Becvar & Becvar, 1996, p. 208). According to systems theory, the rules of a system express its values as well as the appropriate roles for behaviour within the system (Becvar & Becvar, 1996). The value system within this family appears strong and clear. Ansie maintains that they have strong Christian values and both aspire to family life. She states that the experience has impacted positively on the development of her children in that they have both a high level of empathy and compassion for other children who may be physically challenged. "At *our* house we know about things like that….My child can speak for those who have Downs syndrome."

The focus of family systems theory is not on individuals but on their relationships "and how each interacts and influences the other." (Becvar & Becvar, 1996, p. 63). The relationship style between this couple, reflected by their characteristic style of interaction appears to be what systems theorists label 'parallel'. In this relationship there is evidence of both *complementary* and *symmetrical* exchanges taking place although the dominant relationship pattern appears to be complementary exchanges. Leon's calming behaviour, which complements her expression of emotions (tantrums) is a complementary exchange. Symmetrical exchanges occur when both Ansie and Leon

expressed shock and anger after the birth of Johan and their protective stance in relation to their son.

A key concept of Bowen's family system's theory is that of "differentiation of self" (Becvar& Becvar, 1996, p. 149). *Differentiation* is the process whereby an individual "becomes a fully integrated 'whole person'" (Lastoria, 1990, p. 50). Individuals, who are differentiated, retain their individuality while still being part of the family and are more self-sufficient and not as dependent on others. Both Leon and Ansie appear to be satisfied with the role differentiation within the family and perceive themselves as satisfactorily carrying out their individual roles.

Individuals need to differentiate from their family of origin to form and maintain intimate relationships with others (Goncalves, 2001). The Prinsloos appear to have achieved a level of differentiation from their families of origin in that the spousal subsystem seems to have clear *boundaries*. However, these boundaries seem to become blurred when Ansie experiences stress. There are indications that Ansie is very dependent on her mother for both practical and emotional support and it does not seem that she is capable of functioning without this emotional support system. She admitted that she constantly phones her mother who is a registered nurse, whenever she has a minor family crisis. "When there's something wrong, I'm like stupid and I pick up the phone to my mother and ask her what to do". Ansie's problematic score on the *Self-Rating Scale* of the FAM-III regarding *Task Accomplishment* supports these findings and implies that she does not have the ability to respond appropriately to change and minor stresses often precipitate a crisis. It is likely that this behaviour has a stressful effect on Leon who appears to take on the role of solving her problems and calming her down in these times of crises.

Healthy relationships require a balance of power (Lauer & Lauer, 1997). There appears to be a consensus as to which role each parent fulfils to ensure that they both assume necessary responsibility for family survival. Leon's work commitments make it difficult for him to be available for clinic visits and Ansie therefore carries the heavier responsibility in this area. However, despite this apparent consensus, there are indications that Ansie feels less satisfied with her role and responsibilities within the family unit. This discontentment has the potential to damage they system as this marital

dyad lack open, effective communication and appear unable to openly discuss problems and feelings.

Effective communication where feelings are shared and which involves the satisfactory flow of information between a couple has been found to be “the most important aspect of well functioning families” (Greef,2000, p. 961). Within this family, *communication* does not appear to be totally open as there are indications of some distorted messages. It is possible that Ansie may feel resentful at times at having to take on the burden of the childcare role although she does not communicate this message openly. For example, she states that Leon has only been to the clinic once and when she speaks of staying with Johan in the hospital she acknowledges that Leon could only visit in the evening and she understood that then adds “You sit there for 24 hours a day and you only see him at night and maybe an hour”.

Incongruent communication results when individuals do not send each other straight messages (Becvar & Becvar, 1996). For example, Ansie maintains that she does not expect Leon to be able to spend long periods at the hospital or attend the clinic but there are suggestions of underlying resentment when she comments, “I think you went with me once.” For a marriage to thrive it is essential that both spouses must “have or learn good communication skills” (Lauer & Lauer, 1997, p. 256).

Affective Expression is a “vital element of the communication process” (Skinner *et. al*., 1995, pg. 1). It has been found that in competent families “both spouses are satisfied with the expression of affect that exists between them.” (Greef, 2000, p. 959). Ansie presents as a highly emotional person who has no problem expressing her feelings either by crying when she is unhappy or in anger when someone offends her. While she seems quite proud of her tendency to ‘throw tantrums’, Leon appears to have to ‘calm her down’ and soothe her when things get out of control. She does not seem to take his needs, feelings and preferences into consideration with these actions and tends to assume that he will support her decisions and behaviour. It is possible that the stress of keeping his own emotions in check has taken its toll of Leon as he was in ‘surviving mode’ for the first year of Johan’s life and he “went into a type of depression after the whole thing.” Although Leon’s high scores on certain scales indicate that he does not

feel totally satisfied with all interactions, their value system does not appear to be in conflict.

Involvement refers to the ways in which the family members support each other, are interested in each other and meet each other's needs. According to Minuchin (1996) boundaries are "emotional barriers that protect and enhance the integrity of individuals, subsystems and families" (cited in Lastoria, 1990, p. 46). If a system has clear but permeable boundaries, family members retain autonomy while still being supported and nurtured and are more able to compromise and adapt to changing circumstances (Becvar & Becvar, 1996).

The Prinsloo family appears to be concerned for each other and is generally nurturing and supportive. They are not disengaged as they are supportive of each other and of their children and are constantly involved in each other's lives without being enmeshed. They seem to have achieved a healthy balance of being interested and involved while still retaining their individuality. However, the integrity of the spousal subsystem is threatened by Ansie's propensity to turn to her mother when the system is undergoing a crisis.

4.5. CONCLUSION

The family unit appears to be close and supportive but there are indications of underlying tension that may be due to Ansie's emotional response to real or imagined crises. Johan's cleft lip and palate impacted on this family system in various ways. The family adapted and coped with the early care and surgeries required but the long-term stress appears to have provoked depressive episodes in both parents. Ansie was hospitalized during her 'depression' and she has adapted to the situation by choosing to be a full time mother for this period in her children's lives.

Leisure time is focused on the children and to a lesser extent, friends and extended family members. While they receive practical and emotional support from their families of origin, the stressful period following Johan's birth did have some negative consequences with these relationships.

CHAPTER 5

THE PARKERS: A SUPPORTIVE FAMILY

5.1. FAMILY BACKGROUND

Jenny and Andrew are in their early thirties and have two children. Peter is five years old and Melissa is nineteen months. Peter was born with a cleft lip and palate. The Parkers were friends at school and dated for about nine years before they got engaged. According to Andrew the "base of our relationship is friendship" and he feels their relationship has grown stronger with the difficulties they have had to face. He is a forensic accountant who runs his own company, which he began with his partner a few years back and now employs over thirty people. Jenny is an estate agent.

5.2. THE INTERVIEWS

I had four separate interviews with the Parkers, each of which was approximately an hour long. My initial interview was with Jenny in my home as Andrew was busy with work commitments. I had a follow-up interview with both parents in their home and then final separate interviews with both Jenny and Andrew in which I administered the Family Assessment Measure-III (FAM-III). Again Jenny came to my home and I met Andrew at his office.

Both parents were welcoming when I arrived at their home and were keen to share their experiences. Jenny is the more expressive and demonstrative of this dyad and was very emotional and tearful at times in our initial interview. She admitted that she still is affected by the memories of her experiences in the first year of her son's life.

Andrew was relaxed and comfortable when discussing his feelings and experiences and presents as an individual who sets high standards for himself and is very committed to both his career and family. Peter and his younger sister were awake and watching T.V when I arrived. They are friendly, sociable children who happily chatted to me, showed me their artwork and Peter's 'special lip' and seem to enjoy a warm relationship with their parents. During the interview, Jenny and Andrew sat on opposite couches but their interaction and body language indicated a warmth and closeness.

5.3. INTERACTIVE DISCUSSION

The Parkers appear to be a loving, supportive couple who share a strong bond and similar values. Andrew feels they compliment each other and share roles where possible. "We dovetail quite a bit. When I was down and out she was the one that was strong and vice versa." However practical reasons dictate that Jenny carries most of the domestic responsibilities at this stage as Andrew is the main breadwinner and has a demanding job, which entails frequent travel. In a separate interview Jenny voiced a similar feeling when she was discussing the early traumatic days of dealing with a premature baby who also had a facial anomaly, "When he (Andrew) was good, I was bad so we carried each other through."

After she got over the initial shock, Jenny appeared to be the more accepting of Peter's appearance and happily took him shopping with her when she had to go out. In contrast, her husband felt the need to withdraw from strangers' reactions and felt he would rather stay in "the comfort zone that I moved in" and remain with trusted family members and friends. He was grateful that he only had to deal with the appearance issue for a few months and said, "I hid behind that little gap that I knew I didn't have to face this for the rest of my life." He made a video of Peter to send to a friend in the United States and found he was shocked when he looked at it, as his reaction was, "Geez! That's what people see. Not a pretty sight."

Andrew admits that his son's appearance was a big problem for him. "It did bug me to the point that I wasn't comfortable with taking him out to the shops". He has high expectations of himself and has always been a high achiever so felt he had let everyone down in some way when he produced a less than perfect son. He acknowledges that these were his own feelings and not a sense that his family actually *was* disappointed. Immediately after the birth he felt conflicting feelings, as he was both elated that he was now a father and disappointed that his son was not perfect. Jenny too felt that she had let everybody down as they are "expecting this perfect child and you can't even do that right."

According to Andrew, his biggest fear is the unknown. He feels frustrated and helpless when faced with something over which he has no control and has to depend on others to fix. He only started to relax once he understood the process. "That this was going to

happen and that was going to happen…. then I was comfortable with it." He admits that he is "a bit of a control freak" and is not even comfortable if he has to be the passenger in a car – preferring to be the driver. He does not like illness in any of his family members and says he loses patience and gets upset when they're sick. "That feeling of helplessness I don't enjoy."

The unknown was the most predominant fear in the first few days. Both Jenny and Andrew knew very little about cleft lip and palate anomalies and therefore did not know the extent of the problem. Every time they witnessed a new medical procedure they worried about the results. "You just thought, ' What next? What else is going to go wrong?'" The fact that Peter was premature added to their adjustment problems as he was always connected to machinery, which they experienced as intimidating. Bonding was hindered as they could not physically hold their child in their arms.

If there is a problem Andrew wants to know all the facts immediately so that he can deal with them. He needed to know if the cleft lip and palate would affect Peter's hearing or speech and wanted these issues sorted out immediately. After an initial false alarm, they learned that their son had perfect hearing. They also went to a speech therapist to rule out the possibility of future speech problems. Andrew feels that his concern over Peter's appearance was connected to the fear of the unknown and the possibility of future complications.

Jenny's pregnancy was not problem free as she vomited constantly. The doctor was concerned about her lack of weight gain and discovered that her placenta was no longer functioning at 35 weeks gestation. An immediate epidural caesarian section was scheduled and both parents were therefore prepared for a premature baby with all the problems that entails. However they had no idea that their child had an orofacial cleft, as it was not picked up in prenatal diagnostic tests. While the initial discovery of the deformity was a traumatic shock for Jenny, she maintains that she is glad that she did not know beforehand as "it would have been an issue wondering how bad and so on it would be."

Jenny says that the news of the cleft lip and palate caused her to go into shock after the birth and she "started shaking like a leaf". In the following days she was too nervous to go and see Peter in the incubator and was happy as long as Andrew was with him.

However after three days she felt she could now accept her son and “once it clicked in that I was going to be okay, I was fine.” Andrew feels that the initial shock was greater for Jenny than it was for him but he felt powerless and disliked the fact that he had to depend on the doctor’s reassurances that “it could be fixed”.

Peter and Jenny remained in the hospital for five weeks, as he needed extra care as a consequence of his prematurity. The main concern for the first ten weeks of his life was to ensure that he gained sufficient weight before his first operation. Jenny was exhausted throughout this period, as she initially had to feed Peter every hour and a half.

It took Jenny a fair amount of time to adjust to both her son’s appearance and to how she perceived the reaction of her friends - twelve of who were pregnant at the same time. She experienced feelings of both anger and hurt when she heard that all twelve went to their doctors after Peter was born to check that they too did not have a child with a cleft palate deformity. She admits that she withdrew for a certain period as she felt they were talking about her when she left the room and “I couldn’t handle that.” But she acknowledges that they were all very caring and supportive but “in my mind everyone was talking about us.”

The Parker’s admit that they felt sensitive and defensive regarding the responses of their friends towards Peter’s atypical facial appearance. They were aware that most people were not totally honest in their initial reactions and experienced most responses as false and designed to spare their feelings. They resented people saying, “He’s so cute!” while deliberately not mentioning the fact that he had a facial cleft and felt others could not possible understand what they were going through. However, they now acknowledge that their friends meant well and were trying to protect their feelings. Jenny says, “I actually think that no matter what they did it wouldn’t have been right.” Andrew says that when they visited friends who had a son with spina-bifida he found that they too tried to be reassuring to their friends about *their* son’s prognosis.

Jenny’s mother was constantly supportive throughout her ordeal and she remains so today. Her father found it more difficult to accept the problem although he loves and cares for his grandson. He will still make comments such as, “I think he’s a bit nasally today.” Jenny attributes his attitude to his associated feelings of guilt as he once made

disparaging remarks about an acquaintance who had a cleft lip and palate deformity. He therefore now feels responsible for his grandchild's affliction. Jenny says her mother-in-law is supportive but not a "hands on type of mother". Her father-in-law, who died last year, had a special close bond with Peter. Andrew feels that both families have always been supportive and involved but never controlling or interfering in their lives.

Jenny is very protective towards her son and throughout all our interviews repeated that he is a very special child who has a depth of feeling and empathy for others. She feels that the orofacial cleft has contributed to this empathy. "I think in a way it's been a good thing. Definitely a more caring child." This fierce protectiveness developed during the first few weeks after he was born. When he was in the incubator she could not always hold him so sat next to him and held his foot as she felt she *had* to give him some sense of security. This protectiveness intensified during the three-week hospital stay after his first operation. She stayed with him night and day and carried him with her for the first 48 hours. " I *never* put him down. He slept with me. And today when he wants to sleep I just hold his foot

Jenny constantly referred to Peter's 'little lip' rather than his appearance generally and says she did get used to it and accepted it. Peter slept on his stomach in the first few months and she felt hurt that people felt she was placing him that way in order to hide his cleft. However she admits that she is glad that the first operation fixed his lip as, "although he still had a hole he looked decent – and that made a difference" and he now looked similar to all her friends' babies. In the combined interview Andrew used the same description when he spoke of Peter's post-surgery appearance when he stated, "at least it looked decent."

It was a shock for Jenny when Andrew cried when he saw Peter for the first time after the operation and told her that now he's got a son. She was totally unaware of the extent of his feelings about Peter's appearance. However, she feels in the first few months before the operation they were both too busy surviving to deal with deeper issues. Andrew admits that when he saw his son when the plasters came off he felt that Peter was born again and "it was almost like bonding with him from the beginning again."

Neither Andrew nor Jenny felt they had any family history of cleft lip and palate. Jenny then mentioned that her sister lost one baby when she was five months pregnant who was diagnosed with anacephally, spina bifida and "the palate open". However she did not appear to make any connection between this condition and her own son's birth defect. Her sister-in-law also suffered two miscarriages between the births of two healthy children and Jenny herself had a miscarriage before Melissa was conceived. She had a healthy, uneventful pregnancy with Melissa and although she was assured that her daughter did not too have a cleft, she only relaxed when she saw her immediately after the birth. The Parkers had always decided that they would only have two children and the decision not to have a third child has nothing to do with the fact that Peter was born with a cleft lip and palate.

Andrew does not share his wife's overpowering need to protect Peter. He strives to treat Peter as he would any child who was born with no affliction. He loves his son and feels he is special. "I want to treat him as a special person but I don't want him to see me treating him as a person with a special lip – but rather as my son." He is adamant that Peter neither seeks nor receives special attention because of the facial anomaly. "I don't want the 'Shame! Poor child!' reaction. I resent that 100%". Peter is an outgoing child who is fairly disciplined and there appears to be a healthy balance in his relationship with both parents. Work commitments are such that Andrew cannot always spend as much time with both his children as he would like but the time he has is quality time and very precious. He feels the experience has made his bond with both Peter and Jenny stronger.

Andrew feels that the whole experience has made him change in many ways and he now has empathy for others who have to deal with similar or worse afflictions. He relates to the suffering of other parents and can now approach a child who is disabled and talk to him/her. He remembers that he was the type of adult who avoided holding babies and toddlers and didn't really connect with them. Yet when Peter was born, "the change was as if I flipped a coin." Now he can connect with children and "understand where they're coming from."

Both Jenny and Andrew feel they have grown from their experience. They are grateful that the Peter's condition was relatively minor compared to what other parents have to cope with. They have dealt with their problem and feel they have a confident little boy

who will face life's challenges head on. As Jenny said, "Instead of blaming we were very protective of each other. It was wonderful. We were in it together."

5.4. FAM-III RESULTS

I administered the FAM-III to Jenny and Andrew individually when I held the separate interviews.

Scores on the following dimensions were compared:
Task accomplishment; Role performance; Communication; Affective expression; Involvement; Control; Values and Norms.

5.4.1. Task Accomplishment

According to the results of the FAM-III scales, the role of *Task Accomplishment* appears to be satisfactorily achieved within the Parker's family system. The Process Model of Family Functioning maintains that families share common goals and they must perform certain tasks, which change over the life cycle to meet these goals (Gondoli & Jacob, 1993). Andrew and Jenny compromise to ensure that the family system is organized in such a way that all the basic, developmental and crisis tasks are taken care of. For example, Andrew has a demanding job and therefore Jenny assumes responsibility for taking the children for medical appraisals and liaises with the school regarding their academic progress.

The healthy scores on the *Self-Rating Scale* (Figure 5.2) suggest that they are satisfied that they generally meet all the basic tasks and respond appropriately under stress. The interview findings confirm the results of the FAM-III in this area. It is unlikely that minor stresses precipitate a crisis. For example, when they feared that there was a possibility that Peter might be deaf they took him immediately to a specialist and dealt with the problem.

At this stage of their family life cycle, Jenny and Andrew are parents of young children and therefore must adapt their goals and roles accordingly. This ensures that financial, physical and emotional needs are met and all family members experience a high level of security; share a feeling of cohesion and function effectively as positive members of

society. They accomplish this by acknowledging their problems and implementing the best solutions to cope with and solve these issues. For example, Andrew felt uncomfortable in going to the shops with Peter before his cleft was corrected so Jenny took on that task.

They both are satisfied with how they and their spouse accomplish specific tasks to maintain family functioning. Each agrees that his/her partner generally see problems the same way, considers his/her solution to a problem and helps him/her when there is a problem (Items 1, 8 & 15 *Dyadic Scale*).

The discrepancy between their scores on the *General Scale* (Figure 5.1) suggests that there may be differing perceptions as to how successfully tasks are accomplished and goals are met within the family unit. Andrew's score of 48 as contrasted with Jenny's 58 points to the possibility that she may feel more dissatisfied with overall task accomplishment within the family. Jenny stated that when things aren't going well it takes too long to work them out (Item 31 – Gen*eral Scale*). But both she and Andrew agreed that they deal with their problems even if they are serious and they never let things pile up until they are more than they can handle (Items 41 & 21 – *General Scale*).

5.4.2. Role Performance

Differentiation and performance of various roles is necessary for successful *Task Accomplishment.* Successful role integration is achieved when "all essential roles have been allocated, agreed to and enacted" (Steinhauer *et al.,* 1984, p. 79). Andrew and Jenny successfully manage role differentiation and performance within their family unit. Andrew finds it difficult to cope with any form of illness, so Jenny deals with that aspect of family functioning and takes the children to the doctor and oversees their care when they are not well. As she says, "He doesn't handle that well."

However healthy relationships require a balance of power (Lauer & Lauer, 1997). Andrew does not avoid all the childcare tasks and took his shift in caring for and feeding Peter in the first few months of his life so that Jenny could sleep. Where possible he helps her with the family responsibilities but they both acknowledge that at this stage it is

Jenny who must assume the major portion of the child caring roles while he focuses on the 'providing' role.

The FAM-III results confirm the interview findings that they are satisfied with their individual role performance and the differentiation of roles within their family. They agree that family duties are equally shared (Item 2 - *General Scale).* Jenny did state that she feels that she is expected to do more than her share at times (Item 12 – *General Scale*). However, in the interview she stressed this is not due to Andrew refusing to help but the practical reality of what they each have to cope with at this stage of the family life cycle.

The slight discrepancy in their scores on the *Dyadic Scale* (Figure 5.3) may indicate that Andrew is more satisfied at the role differentiation within the family. However they are both in agreement in all items on this subscale and both felt that their spouse accepts what is expected of him/ her and does not complain that too much is expected of him/her (Items 2 & 16 *Dyadic Scale).* The 6-point discrepancy on this scale may therefore be attributed to the fact that the Jenny answered 'agree' to most of the items and Andrew answered 'strongly agree'.

5.4.3. Communication

Communication is a complex process, which has a high potential for misunderstandings (Lauer & Lauer, 1997). The process of C*ommunication* is an important factor to ensure successful *Role Performance* and ultimately *Task Accomplishment.* Well functioning families have been found to have a better communication process than families that do not function so well (Scabini *et al.,* 1999). Both Jenny and Andrew appear to communicate effectively and have a deep level of mutual understanding. They agree that there is consensus about who should do what in the family and they take the time to listen to each other (Items 22 & 33 - *General Scale*) (Figure 5.1). They feel their family knows what they mean when they say something and they are available when others want to talk to them (Items 3 & 31- *Self Rating Scale*) (Figure 5.2).

It does not appear that their communication is in any way distorted and they are open in their dealings with each other. They send and receive congruent messages in their

verbal and nonverbal communication behaviour and often referred to each other with eye contact, nods of the head and smiles during the discussion.

Andrew says that in the early stages he knows that Jenny *thought* that he was holding her responsible for Peter's facial anomaly but he maintains "It never crossed my mind" and "It definitely didn't drive us apart". Their scores on all three subscales of the FAM-III confirmed these findings. They both agreed that their partner is available when they want to talk to him/ her and listens to his/her point of view even if he/she disagrees (Items24 & 31 – *Dyadic Scale*) (Figure 5.3).

5.4.4. Affective Expression

The level of *Affective Expression* within a family is reflective of family members perceptions of emotional closeness (Jacob & Windle, 1999). Although stress often causes a problem with the expression of feelings, this does not appear to have happened within the Parker's marriage. As Andrew said, "It sort of tightens the bond".

During the very stressful time of their lives immediately after Peter's birth, they felt they were just 'surviving'. However, they still supported each other and were sensitive to each other's feelings. Jenny was not even aware that Andrew felt so strongly about Peter's appearance and admits that she was shocked. However, she feels that he did not tell her, as "he knew that I was busy surviving".

The Parkers appear to be satisfied with the expression of feelings within their family and relationship which is supported by their scores on the three FAM-III scales which were all well within the normal range. They were in agreement on most items on the *General* and *Dyadic* subscales. Jenny agreed with Andrew that family members tell each other about things that bother them (Item 14 - *General Scale*). However, Jenny felt that when someone is upset they don't find out until much later and they take too long to get over things when they are upset (Items 34 & 44 *General Scale*).

There was a 10-point discrepancy between their scores on the *Self-Rating Scale* (Figure 5.2) and again Andrew's lower 42 may suggest that he is more satisfied with his personal level of affective expression. Jenny presents as a more emotional person and

she admits that she does not get over things quickly when she is upset (Item 18 - *Self-Rating Scale*). This seems to confirm the findings of the interview when she admitted that she withdrew from her friends for a period as she felt they were discussing her child, "I felt everyone was talking. They were very caring…but in my mind they were talking about us ". Both Jenny and Andrew are in agreement as to the level of affect expressed within their relationship. They state they can tell when their partner is they don't stay angry for long periods (Items 4 & 25 *Dyadic Scale*).

The discrepancy between their scores on the *Self-Rating Scale* may be due to Jenny's more expressive nature. While Jenny and Andrew both felt that they do not take things out on the family when they are upset (Item 25 – *Self-Rating Scale*), Jenny agreed that she may get upset too easily at times (Item 39).

5.4.5. Involvement

Like *Affective expression, Involvement* is another factor, which determines the success of *Task Accomplishment. Involvement* refers to the ways in which the family members support each other, are interested in each other and meet each other's needs Skinner *et al.,* 1995). The results of the FAM-III *Dyadic Scale* (Figure 5.3) denote satisfaction with the mutual level of involvement they share. They agree that they are close and they know their partner cares when they are upset (Items 5 & 12). They also agree that all family members feel loved and trust each other (Items 16 & 36 - *General Sc*ale*).*

An example of this couples involvement with each other is during the early days of coping with problems associated with feeding a child with a cleft lip and palate. Both members of this dyad acknowledge the support they received from each other through difficult stages and feel they "carried each other through". Jenny states that Andrew "was fantastic" while Andrew states that he never felt rejected by his wife because so much of her attention was necessarily focused on their son, "We were a team".

5.4.6. Control

Control refers to the diversity of strategies utilized by family members to influence each other's behaviour in order to sustain family functioning or permit adaptation (Steinhauer *et al.,* 1984). Jenny and Andrew appear to be satisfied with this area of family

functioning within the family unit. They were in agreement on all items of the *Dyadic Scale* (Figure 5.3) and the discrepancy of eight points between their scores again appears to be due to the fact that one partner responded as 'strongly agree' or 'strongly disagree' when their spouse just responded 'agree' or 'disagree'.

They state their partner is reasonable when they make a mistake and forgives them when they are wrong (Items 6 & 13 - *Dyadic Scale*). Again, this supportive couple appears to have achieved a balance, which incorporates all the healthy aspects of this factor such as consistency in their dealings with each other, constructive, responsible and predictable in their behaviour and interactions with each other. As Andrew said, their response when they learned they had a child with a problem was, "Well this is how we're going to deal with it". They are capable of functioning in a healthy manner and have the ability to adapt when the need arises. There is no evidence of destructive behaviour in their interactions.

However, Andrew's scores on the *General* (Figure 5.1) and *Self-Rating Scales* (Figure 5.2) are bordering on the problematic, which may signify possible areas of conflict. He stated that he doesn't always get a straight answer when he asks why there are certain rules (Item 7 – *General Scale*) and admits that he makes a big deal of things if someone makes a mistake (Item 6 – *Self- Rating Scale*). In the interview, Andrew readily admitted that he likes to be in control and the biggest frustration over Peter's condition was that he had to 'hand over' that control to doctors. "The biggest fear for me is the unknown."

5.4.7. Values and Norms

A family's value system develops over time and incorporates influence from families of origin and the culture and society with which they interact (Steinhauer *et al.,* 1984).
Individuals need to differentiate from their family of origin to form and maintain intimate relationships with others (Goncalves, 2001). This couple appears to have differentiated sufficiently form their families of origin and interact with these subsystems in a healthy manner. Both Jenny and Andrew share a similar value system and are in agreement as to how they interact within their family unit. Their responses on all three subscales were very similar.

They state that it is not difficult to tell what the rules are in the family and these rules make sense (Items 18 & 38 *General scale*) (Figure 5.1). They believe they share the same views about right and wrong (Item 7 - *Dyadic Scale)* (Figure 5.3). They also agree that they both decide what is acceptable family behaviour for their family (Items & 42 *Self-Rating Scale*) (Figure 5.2). These norms are also consistent with the general cultural context within which they live.

5.4.8. Social Desirability

Andrew's score of 56 on this subscale (Figure 5.1) may imply that he attempts to portray himself and his family in a more positive light. He acknowledges that it was initially very difficult for him to accept his child's appearance and he felt he had let everyone down. "It did bug me". Both Jenny and Andrew described Peter's cleft lip as "looking decent" once it was surgically repaired. Jenny admits that it made her feel better and she could now feel connected with her friends again. They both agreed that it was realistic to say that other families could be happier than theirs but theirs is as well adjusted as any family could be (Items 19 & 5 - *General S*cale). Jenny differed from Andrew who stated that no other family could get along better than theirs and their family could not be happier than it is (Items 9 & 15 - *General Scale*).

5.4.9. Defensiveness

Again Andrew's score on the *Defensiveness* subscale (Figure 5.1) is slightly higher than the norm and appears to confirm the results of the *Social Desirability* subscale. Andrew admits that he feels defensive at times and responds by insisting that Peter should be treated the same as any other child. He acknowledges that he found it difficult to go to the shops with Peter and he "preferred to stay at home with him".

The Parkers were in agreement with most of the items on this subscale and appeared to be very truthful and frank in their responses. They admitted that they do get upset with each other and sometimes they can be unfair to each other (Items 40 & 20 *General Scale*). These findings are confirmed in the interviews where both partners were honest in their feelings regarding Peter's cleft. "Everybody is expecting this perfect child…and you can't even do that right".

"A 10 point differential between how two family members rate the same aspect of family functioning the more likely the discrepancy is to be clinically relevant" (Skinner *et al*. 1995, p.25). Jenny and Andrew's scores on the various scales were very much in sync and the discrepancies that did exist can be explained to a large extent by one partner responding 'strongly agree' or 'strongly disagree' when the other just stated 'agree' or 'disagree'. The overall results do not indicate any marital tension or conflict within this family. By contrasting the *General* and *Self-Rating* scores we can compare how the individuals perceive both the family and his or her functioning.

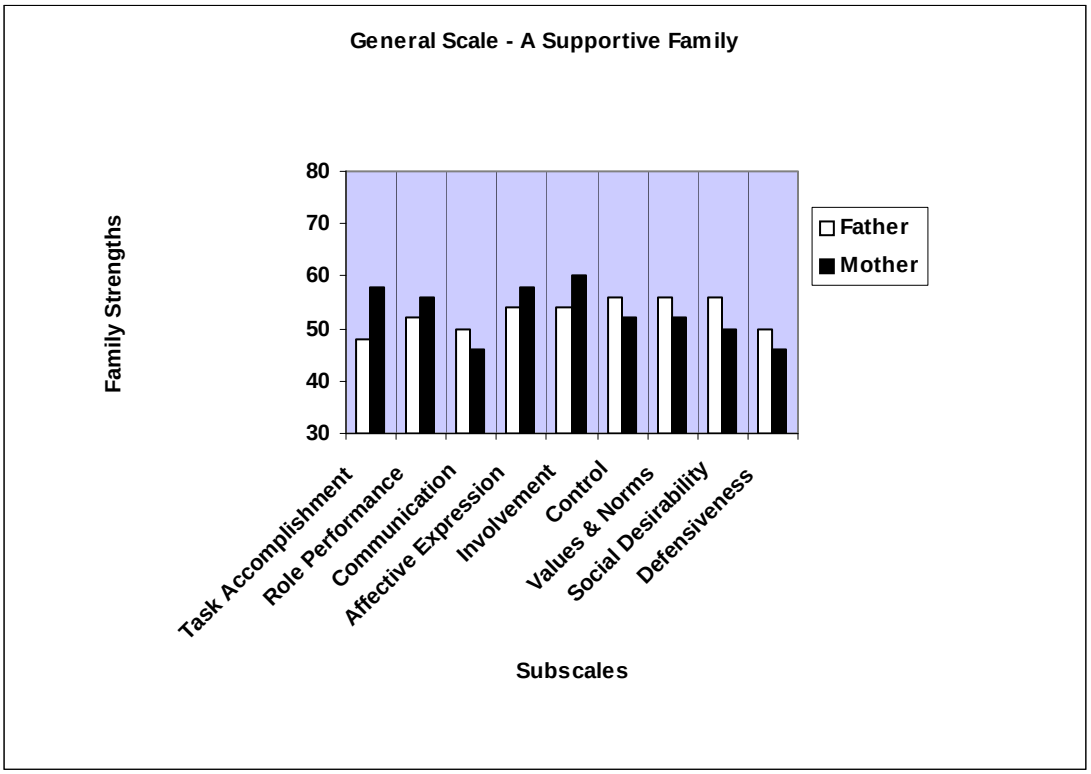

Figure 5.1: FAM-III scores for the different categories of the General Scale (Jenny and Andrew)

On the *General Scale* this couple differed by 10 points on *Task Accomplishment.* They agreed on the rest. Jenny's higher score of 58 suggests that she may feel dissatisfied with this process within his family unit as she stated that when things aren't going well it takes too long to work them out (Item 31). Andrew's higher score of 56 on *Social Desirability* indicates that he may wish to portray his family in a more favourable light. However it is not an excessively high score and in the interview he admits that he has high expectations of himself and he felt he had 'let his family down' in some way. "There were big expectations for Peter".

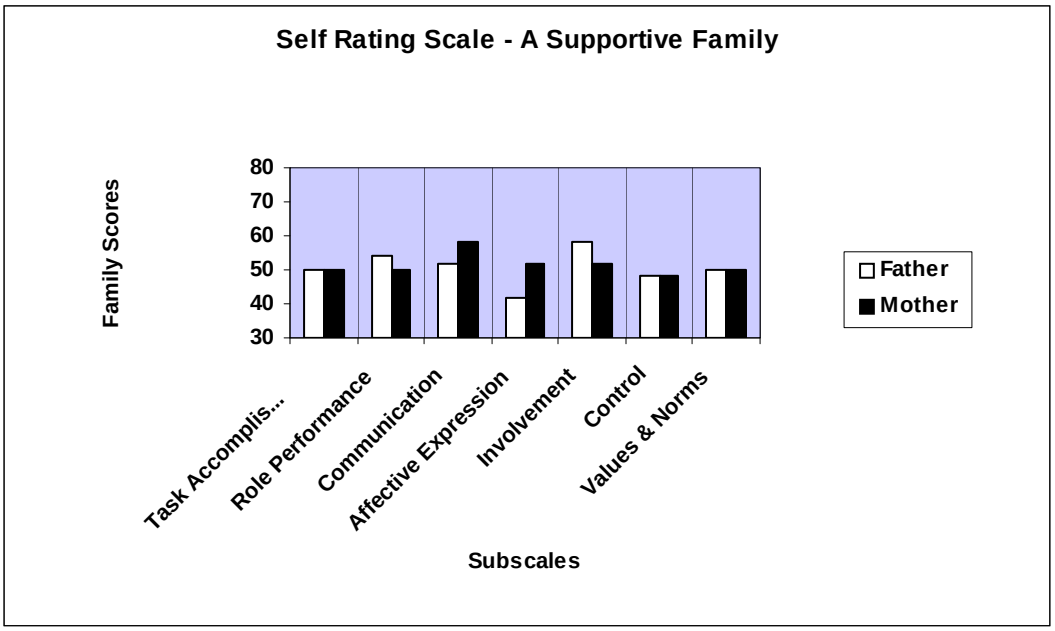

Figure 5.2: FAM-III scores for the different categories of the Self-Rating Scale (Jenny and Andrew)

On the *Self-Rating* scale Jenny and Andrew had healthy scores on most aspects but differed by 10 points on *Affective Expression*. However Jenny's score of 52 on *Affective Expression* is well within the 'healthy' range and may be a reflection of her emotional, expressive personality

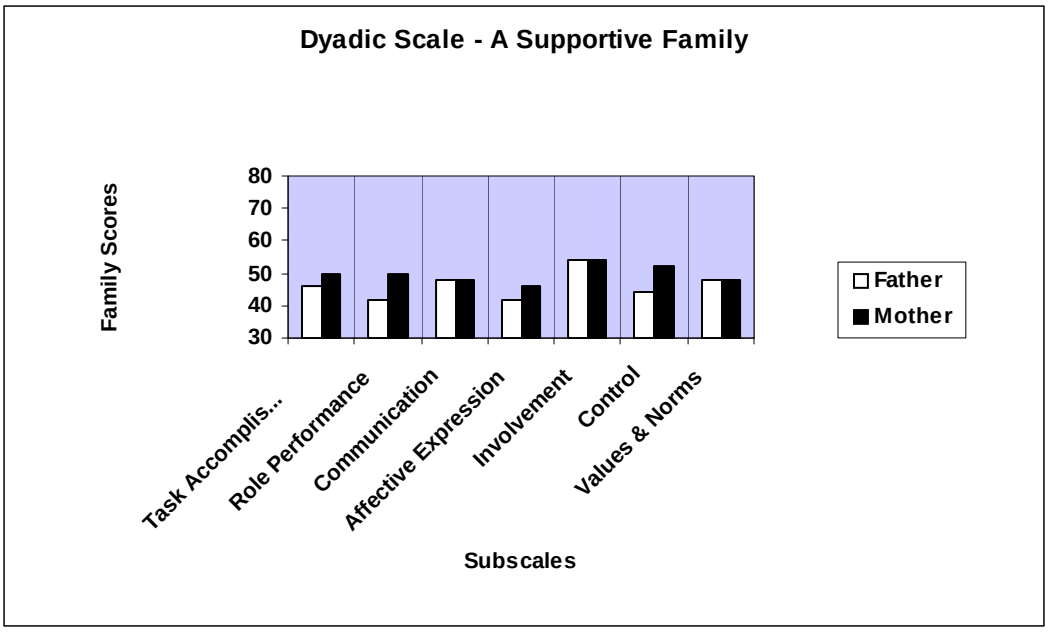

Figure 5.3: FAM-III scores for the different categories of the Dyadic Scale (Jenny and Andrew)

On the *Dyadic Scale* they differed by eight points on *Role Performance*. Jenny's higher score of 50 is well within the 'healthy' range and appears to suggest that she may feel less satisfied than Andrew with her role differentiation. However, during the interview they both acknowledge that Jenny takes the greater responsibility for childcare at this stage of their life cycle and there are no indications of real conflict.

5.5. DISCUSSION

Consistent with Family systems theory, the family is viewed as "an autonomous organism with its own rules and roles, its own structures and processes" (Bloch, 1984, p. 387). The emphasis is on *what* is happening rather than *why* it is happening and we focus on the interaction *between* family members (Corsini, 1984). As all parts of a system are interconnected, any change in one component results in change in all other components. Family members therefore adjust their behaviour in response to the behaviour of others to maintain the overall relationship structure (Bloch, 1984).

The behaviour of each component of a system is determined both by its own previous behaviour and the behaviour of the other components (Penn, 1982). For example,

Andrew felt that his family had high expectations of him as he has always achieved throughout his life. He admits this is *his* perception and not necessarily how his family feel. However, this sensitivity had an influence on how he experienced the news of his son's facial anomaly as he felt he had somehow 'let everyone down'. Andrew is an individual who has high personal standards and it is possible that in his development he has achieved a high level of personal responsibility, which ensures "responsible and productive social behaviour" (Steinhauer *et al.*, 1984, p. 83).

Jenny and Andrew meet Kaslow's (1982) characteristics of a healthy family as reflecting "a systems orientation, with a sense of mutuality, a clear and definite structure, openness to growth and change, and shared roles and responsibilities" (cited in Becvar & Becvar, 1996, p. 125). They are both committed to their marriage and family and accept the responsibilities that being the parents of a child born with a cleft lip and palate entails. For example, once Jenny had recovered from the shock of the situation she adapted to the new demands and worked day and night to ensure that Peter would gain the necessary weight for his forthcoming surgery. Andrew, while still continuing to work during the day, assisted both emotionally and practically in this process so that they both could achieve their immediate goal.

"C*ircularity* is the reciprocal pattern of interaction in which an event can be both the effect of an earlier event and the cause of a later event" (Goldenberg & Goldenberg, 1991, cited in Jonsson Jones, 2001, p.128). When Jenny gave birth to her daughter, Melissa, she did not relax until the paediatrician showed her the healthy child after the birth.

Circularity is also evident in the interaction with extended family members. Jenny derives a lot of support from her mother who has forged an extra close bond with Peter because of his condition and the time she has spent with him. The *circularity* of affecting and being affected by Peter's anomaly was evident in his relationship with Andrew's father who had an operation for throat cancer. While other children reacted with fear to his changed voice, Peter "would talk to him and was really not scared" and they developed a close bond.

Feedback is a process whereby a system changes and adjusts itself (Corsini, 1984). *Positive Feedback* occurs when both parents accept the possible problems that can arise due to a cleft deformity and take steps to deal with them. For example they take Peter for speech therapy, inform the teacher of the condition and have his hearing checked. *Positive feedback* also occurs when both Andrew and Peter develop increased empathy for others in a similar situation. *Negative Feedback* is illustrated by Andrew's reluctance to leave the 'comfort zone' of his home in the early months before Peter's lip was surgically corrected.

As a hierarchical organization, a family system consists of component subsystems and is also a subsystem of suprasystems (Bloch, 1984). The larger family system continues to have an influence on the behaviour of members after they have grown to adulthood (Fingerman & Bermann, 2000). Jenny and Andrew experience support and encouragement from both their families. Andrew referred to it as "a comfort zone that I moved in" and says of extended family members, "When we needed them they supported us. I never felt let down".

According to Minuchin (1996), *boundaries* are "emotional barriers that protect and enhance the integrity of individuals, subsystems and families" (cited in Lastoria, 1990, p. 46). If a system has clear boundaries, family members retain autonomy while still being supported and nurtured and are more able to compromise and adapt to changing circumstances (Becvar & Becvar, 1996).

This particular dyad appears to have healthy, clear boundaries. They seem to have achieved a healthy balance of being interested and involved in each other's lives while still retaining their individuality. They are also part of a suprasystem and relationships with extended family and friends appear to be strong and supportive. Jenny feels that her mother has a special bond with Peter that has lasted till today and Andrew feels supported by his own extended family without feeling overwhelmed. As he says, "They were supportive but they also knew how to keep their distance".

Changes in life circumstances, such as the birth of a child with a cleft lip and palate, acts as a *disequilibrator* which forces the family system to adjust to a new set of conditions (Bloch, 1984). The extent to which the family system is able to change and demonstrate

flexibility is its *adaptability* (Olson, Russell & Sprenkle, 1983). This particular family system has the healthy ability to remain stable when undergoing change and to change and adapt in a consistently stable way when it is necessary. Although both Jenny and Andrew were initially shocked when they learned of their son's birth defect, they developed adequate coping skills to deal with their situation.

According to systems theory, an appropriate balance between *morphogenesis* and *morphostasis* must be maintained for a system to remain healthy. *Morphostasis* refers to " the pattern of resistance to change" while *Morphogenesis* describes " the potential to develop and grow as a system" (Olson *et al*., 1983, p. 70). So as the Parkers moved to the new stage of parenting they dealt with the problems that arose, differentiated their roles and incorporated the changes into their family life. In this way they managed to maintain their level of family functioning and not only did they 'survive', but grew.

Families that function in a healthy manner are characterised by *differentiation* between generations, individuals and roles. Effective communication and problem solving skills are necessary to ensure successful integration between these roles and subsystems (Alexander, 1985). The Parkers have achieved a healthy level of differentiation. They are involved and supported by their extended family members but not to the point that they are *enmeshed*. Although Jenny relies on her mother for support, she did not allow her to come to the hospital immediately after Peter's birth as she felt she must not become dependent and must be strong for her son. "I haven't got time to feel sorry for myself, I've got to look after my son."

Positive *Communication* skills such as listening and supportive comments and problem solving skills encourages family members to share their needs and feelings to each other (Olson *et al.,* 1983). Within this family, communication is open and effective within a warm, caring environment and support and nurturing is evident while still encouraging autonomy and independence.

Although Andrew and Jenny generally appear to be open in all their communication with each other, Andrew admitted that he could not tell his wife how much the atypical facial appearance affected him until it was surgically corrected. In response to one of the FAM-III items, Andrew agreed that he might not always say what he would like to

because he can't find the words (Item 24 – *Self-Rating scale*). Jenny was initially unaware of the depth of his feelings and said," It was the first time he ever told me that. It was hard". However, there was no indication that either partner feels that they are not free to say what they think in the family (Item 48 – *General Scale).* As Jenny stated, "But I think he knew that I was busy surviving. We were all just surviving at that stage".

Research has found that spouses in non-distressed marriages attributed positive behaviour to their partners (Forman, 1988). The Parkers have constantly supported each other and neither blames the other for their son's condition. As Jenny said, "Instead of blaming we were very protective of each other. It was wonderful. We were in it together". The relationship style between the parents appears to be what systems theorists label '*parallel*'. Such relationships are flexible, allows for greater variation of behaviour and problems of power struggle is rarely an issue. (Becvar & Becvar, 1996). Andrew feels that the bond he and Jenny share has grown stronger since their experience and together they found ways to deal with the various problems

Values and *norms* of a family influence how they successfully accomplish all the various tasks. According to systems theory, the rules of a system express its values as well as the appropriate roles for behaviour within the system (Becvar & Becvar, 1996). The value system within this family appears strong and clear. Both Jenny and Andrew feel their marriage is based on a solid friendship base and they share similar views on education, religion and parenting. Both members of this dyad have respect for their own and each other's families of origin and their home provides a secure environment for their children.

The emotional bonding between family members is defined as *family cohesion* (Olson *et al.,* 1983). In this family the warm supportive relationship experienced by the parents appear to have an influence on the subsystem of their children who present as secure, content, well-balanced individuals. There were no indications of underlying conflict or resentment during any of the interviews or administration of the FAM-III.

5.6. CONCLUSION

This 'Supportive' family system appears to have a strong sense of cohesion, have adapted well to their crisis and have both grown and developed in the process. This particular marital subsystem appears to have had a strong base before the transition to parenthood and both individuals adapted and restructured their roles and behaviour to meet the increased demands of the stressful period. Both Jenny and Andrew share similar values and work together to ensure their responsibilities are met and their goals are achieved.

According to Quatman (1997), well functioning families do not have an absence of conflict but are able to deal with differences in a positive way by means of both positive and negative feedback loops which encourage change while still maintaining the stability of the system. Competent families are characterised by open communication processes, strong family coping mechanisms and high family and marital satisfaction (Greef, 2000). All these characteristics appear to be present in this family unit.

On the surface, the positive impact of a child with a cleft palate deformity appear to dominate within this family system and the negative effects are not overtly apparent. Andrew, Jenny and Peter have developed a heightened empathy and awareness of similar conditions and support others who are going through stressful situations themselves. They appreciate being parents of a healthy child and do not take their marriage or healthy children for granted. However, as in all stressful situations, there are also negative effects of such an experience. Although five years have elapsed since Peter's birth, Jenny is still very emotional when talking of her experience. Andrew wants to get on with his life but is still very defensive when speaking of treating Peter differently.

CHAPTER 6

THE STANDERS: AN OVERWHELMED FAMILY

6.1. FAMILY BACKGROUND

Laura and Kobus are in their late twenties and have one baby daughter, Chantal, who was two months old at the time of the interview. Chantal was born with a cleft-lip and palate, which was only discovered at birth and not detected during the pregnancy. Kobus was born with Retinitis Pigmentosa, which is an inherited disorder, which causes degeneration of the retina. He was partially sighted until five years ago when the condition deteriorated into total blindness. He manages a call desk in his work and deals with management information with the aid of a computer speech program 'Jaws', which enables him to be totally independent in his work. Laura worked as an Administrative Controller until her daughter was born. She battled to fall pregnant so plans to stay at home to look after Chantal for at least two years.

6.2. THE INTERVIEWS

I had two separate interviews with the Standers but initially I interviewed them together in their home in the evening. Kobus, whom I knew to be blind, met me at the door. However his ability to walk unaided by a stick gives one the impression that he has partial sight. He says he has "light perception" so possibly this factor facilitates movement. He also looks closely in your face when he talks which again gives one the impression that he has partial sight.

They were both very warm, friendly and hospitable people and keen to share their experiences. They appear to be a loving, supportive couple who care for their daughter and each other. Chantal is a contented baby who was present at all the interviews, never was fretful and often gurgled happily. Laura is the more outgoing and assertive of the two but Kobus exhibits a quiet strength, which she appears to appreciate and depend on. The general impression was of an extremely compatible couple.

When our interview was completed Laura attended to Chantal while I administered the FAM-III to Kobus. I returned the following week to their home during the day and administered the FAM-III to Laura.

6.3. INTERACTIVE DISCUSSION

Kobus who was partially blind when he met his wife, appears to enjoy a warm, supportive relationship with Laura. Although the purpose of our discussion was the birth of a daughter with cleft lip and palate, Kobus' blindness is naturally a big issue in their lives and therefore reference to this disability continually occurred.

Laura is very protective towards her husband but resents the fact that many people see his disability and not the whole person. "I don't see him as a blind person. Never will and never did." She maintains that he is totally independent and self-sufficient and she even lets him drive her car while she directs him. She feels anger when other people undermine his independence or treat him differently, "Like when you go and visit people, they normally ask me, 'How many sugars does he take?'"

The shock for Laura was that the facial cleft was so unexpected as the pre-natal tests had not indicated a possible problem. She was prepared for the slight possibility that Chantal could inherit her husband's eye condition and, "I knew the consequences that I'd follow". She had not been prepared for the possibility of any other anomaly. She also felt that the manner in which the doctor informed her of the cleft added to her trauma. After the caesarian section he came to her bed and said, "I'm sorry." Laura thought he was telling her that the baby was stillborn and she felt she could have coped better with the news if he had only told her immediately that her child had a cleft lip and palate, which could be corrected. She says that she has read in the literature that people hate the person who first tells them the news that their child has a birth defect. "You hate them for the rest of your life. And I felt like that ..."

However, she feels that she accepted and loved Chantal from the beginning and never experienced feelings of rejection towards her. She felt that there never was a question of whether she would accept her daughter or reject her. "She's *there!* It's like a gift from God." She experiences feelings of anger at other people's reactions at times. One

woman at her local supermarket told her that she would pray for Chantal and she was annoyed and replied, “Don’t pray for my child. There’s nothing wrong with her.”

Kobus feels that Laura is a very strong person who copes with problems and does not let obstacles get in her way. “She’s stronger than me.” He admits that he took longer to adjust to his daughter’s condition. It was a shock when he heard the news as he was overseas at the time and felt that he was so far away when his wife needed his support. Also he did not know what a cleft lip and palate was and as he could not see the extent of the cleft this added to his worry. It was only after Christmas when Laura and Chantal came home that he could partially allay his fears as, “It was really the first time I could touch Chantal and feel what it was like.” Until that time he constantly needed reassurance from Laura that everything was going to be fine.

A colleague had a healthy baby around this time and Kobus felt resentful that this father would be boasting about his child at work and he would not be able to do the same. “How can I take my baby like this to work?” Immediately Laura protectively justified his reaction by explaining that he had gone through life with a disability and “he knows how it feels when people stare at you.” Kobus feels that the turning point for him was when they met a friend of Laura’s who had a three-year-old child who is severely cerebral palsied. He said he could not imagine what it must be like to have such a disabled child who can never be ‘fixed’ so he realized the problems they will have with Chantal are minor in comparison.

Laura battled to fall pregnant and went through an emotional period when she would cry if she saw a pregnant woman. She therefore feels grateful that it *was* possible to have a child, as many people are unable to conceive. “ I never looked up to Him and said ‘Why me?’” At first her gynaecologist told her she had a cyst, so she did not realize she was pregnant for five months. A caesarian section had been planned at 38 weeks gestation, which coincided with Kobus’ overseas trip. However Laura insisted that he go as she felt it was too good an experience to miss. “It was my decision that he should go.” There were problems with the operation and an attempt at an epidural was unsuccessful. However during the anaesthetic, “…my heart…my lungs failed. And that was more of a shock to me the next day.”

While Laura continues to feel anger at well-meaning comments of friends and acquaintances, she acknowledges that they lack necessary information so their comments are due to ignorance. She feels that her experience of dealing with people's reactions to her husband's blindness has taught her to deal with similar comments regarding Chantal's anomaly. Her parents-in-law live close to the flat and have always been accepting and supportive. Laura feels this attitude is partially due to the fact that they have had the experience of coping with a child with a physical disability. They are always available to help and were a tower of strength for Kobus when Laura was in the hospital and he needed someone to drive him to see her.

Laura's mother is also supportive but found it hard to accept the initial news of the cleft lip and palate and kept crying and asking why it had to happen. Eventually Laura told her, "Stop crying because it's not going to solve the problem". Her mother later told her that Laura's matter of fact attitude helped her to accept it as she saw then that "It was no big thing."

Laura feels that her visits to the Facial Cleft Deformity Clinic of the University of Pretoria have helped her to get everything into perspective. It has been heartening for her to talk to other mothers who are going through or have gone through what she is experiencing. Seeing older children with a repaired cleft lip and palate is encouraging as she sees how wonderful they now look and how invisible most of the scars are. Kobus did not like it when Laura would look at the photos of badly deformed children at the clinic as he felt it made her quite negative afterwards. Laura disagrees and says it makes her grateful that Chantal does not have such severe problems. She feels a support group at the clinic where everyone could discuss their experiences would be beneficial.

Neither Laura nor Kobus have a family history of cleft lip and palate. Laura's sister had a baby who was born with a medical condition "where his forehead is like a cone." However it does not seem to be a serious problem and appears to be due to the fact that the fontanelle was "born closed" and a simple operation can rectify it. They were not concerned as to the cause of this problem and did not make any connection with their daughter's orofacial cleft which they feel is caused by high levels of air pollution in their area.

6.4. FAM-III RESULTS

I administered the FAM-III to this couple on separate occasions. Laura was busy with Chantal in a separate room when I administered the test to Kobus and I returned a few days later to administer it to Laura in the morning when Kobus was at work.

Scores on the following dimensions were compared:
Task accomplishment; Role performance; Communication; Affective expression; Involvement; Control; Values and Norms.

6.4.1. Task Accomplishment

Successful *Task Accomplishment* results in the attainment of various fundamental developmental and crisis tasks (Skinner *et al.,* 1995). Within the Stander family, the role of *Task Accomplishment* appears to be satisfactorily achieved. Laura and Kobus compromise to ensure all the basic, developmental and crisis tasks are taken care of. This ensures that all family members experience a high level of security, share a feeling of cohesion and function effectively as positive members of society. They accomplish this by acknowledging their problems and implementing the best solutions to cope with and solve these issues.

Kobus is the sole income earner at this stage of their lives and Laura carries the main responsibility for childcare and other domestic issues. They ask an extended family member for support when they feel the problem is not manageable alone. For example, Kobus' mother looked after Chantal for a night when Laura had received medication, which made her too drowsy to care for her daughter. Scores on the *Self-Rating* (Figure 6.2) and *Dyadic* Scales (Figure 6.3) were in agreement and there was a discrepancy of six points on the *General Scale* (Figure 6.1). This is possibly due to the fact that Kobus' disability prevents him carrying out certain tasks such as the physical care of Chantal and Laura must therefore cope with those aspects of their life. However there is no indication that this causes resentment between this couple.

They agree that they do not spend too much time arguing about problems and both try different ways of problem solving (Items 1 and 11 – *General Scale*). However Laura

feels that they do let things pile up until they are more than they can handle (Item 21). They both agree that their spouse can be counted on to help them in a crisis and views family problems in a similar way (Items 36 & 1 – *Dyadic Scale*).

6.4.2. Role Performance

Successful *Role Performance* involves each family member being allocated specific activities, agreeing to carry out these activities and performing these actions to the satisfaction of all (Skinner *et al.,* 1984). The Standers successfully manage role differentiation and performance and again there were no discrepancies on any scales in this area. They feel that their partner takes an appropriate share of responsibility and they agree that they both have the same views about who should do what in the family (Items 9 and 37 – *Dyadic Scale).* However Kobus felt that Laura might think that he expects too much from her (Item16). Neither Kobus nor Laura think that too much is expected of them (Item 1 – *Self-Rating Scale),* but Kobus acknowledges that he does sometimes argue about who does what in the family (Item 37 – *Self-Rating Scale).*

Kobus is the financial provider at this stage of their lives and they have reached what appears to be a satisfactory compromise regarding their domestic roles. Laura feels that it is her responsibility to ensure she fulfills all domestic duties. "I mean it's like telling him to cook. I don't do it. This is my responsibility." Due to her husband's disability, Laura necessarily has to take on extra roles such as driving. However, he strives to maintain his independence and is reluctant to ask others for unnecessary help.

There are contradictions in certain aspects of Laura's behaviour, which intimates that she finds it difficult to either, totally deal with his disability or to come to an acceptance of the reality of his condition. For example, she strives to treat him as a 'normal' person by allowing him to drive a car and yet she does not encourage him to deal with any aspects of the physical care of their daughter. When the physical aspect of child care was discussed in the interview, Kobus admitted that "It's difficult for me because…ja…ummm…ja. It's difficult". He was referring to his blindness but he appeared to be embarrassed at his inability to deal with the practical aspects such as the cleaning of the plate. However, Laura immediately interrupted to say that she would not

ask him to do it as she felt it was often difficult for her to insert (the plate) and therefore it was her responsibility.

6.4.3. Communication

The process of *Communication* is an important factor to ensure successful *Role Performance* and ultimately *Task Accomplishment.* A satisfactory communication process increases clarity of meaning and mutual understanding (Bernstein & Borchardt, 1996). During the interview, Laura was the most verbally dominant and assertive and often interrupted her husband and answered for him or elaborated on a reason for his behaviour. This exchange did not appear to irritate him and he often nodded in agreement to most things she said.

There are discrepancies between their FAM-III scores in this area, which may be indicative of possible problems. Both Laura and Kobus scored 52 on the *Self-Rating Scale* (Figure 6.2), which suggests that they both feel they communicate effectively. However Laura scored 40 on the *General Scale* (Figure 6.1) and Kobus scored 54 which points to possible discrepancies in how they each perceive communication within their family. Kobus' higher score seems to indicate that he is less satisfied with this aspect of their relationship as he also scored 52 on the *Dyadic Scale* (Figure 6.3) as opposed to Laura's score of 44. On the *General Scale,* Kobus felt that they do argue about who said what (Item 13). They agreed on all the other items on this scale and the discrepancy may be attributed to the fact that Laura often responded as 'strongly agree' or 'strongly disagree' as opposed to Kobus' 'agree' or 'disagree'. They also agreed on all items on the *Dyadic Scale* differing only in that Laura again responded 'strongly disagree' to item 17 and 'strongly agree' to item 24.

Laura appears to send conflicting messages in her communication at times. For example, she insisted that Kobus should go overseas even though the trip would clash with the birth of their child. Kobus said that when she phoned him after Chantal was born, "She can't remember it but she told me at that moment I must decide then and there if I'm going to come back". The fact that Laura insists she cannot remember saying that, suggests that it was a verbalization of her underlying true feelings.

Early in the interview I asked Laura how she felt once she got over the initial shock of hearing of Chantal's facial cleft. She immediately responded by saying, "I didn't ever feel that!" And later, "For me it was nothing actually". Instead of admitting to her own feelings of shock she referred to Kobus' response to the news, " ….he was like very shocked". She did acknowledge that she hated the doctor who gave her the news of the cleft but maintains it was not due to the facial anomaly itself but to the fact that she thought he was telling her that her baby was stillborn.

Kobus admits that at first he found it difficult to speak of Chantal's birth deformity. "At the beginning…. really….I didn't want to speak about it". Before he had a chance to fully express his feelings, Laura gave her interpretation of his response, "He didn't want to talk about it. So I said to him, "Let's talk about it". And he was…he was…he'd rather go and do something else. I think he was shy of her. He was hiding her".

Laura is extremely protective of both her husband and daughter and she is very verbal in expressing her feelings. It may be that Kobus would sometimes appreciate it if he could verbalise his own emotions without her interpretation of them. Although Laura is angry with other people who direct questions to her instead of directly to her husband, it is a tendency she also has picked up and she consistently spoke of his blindness as if he was not in the room. Inconsistent communication patterns can lead to pathological transactions. Laura appears to convey contradictory messages to her husband, which may result in feelings of confusion, frustration and despair.

6.4.4. Affective Expression

Affective Expression refers to the intensity, timing, appropriateness and inhibition of the communication process between family members and aids in *Task Accomplishment* and *Role Performance* (Bernstein & Borchardt, 1996). However distorted or blocked expression of feelings can impede these processes.

This area of the FAM-III presented with a large discrepancy on the *Dyadic Scale.* Although still within the norm, Kobus scored a higher 56, as contrasted with his wife's 42 (Figure 6.3), which suggests that he is dissatisfied with the expression of affect within their relationship and may feel inhibited to satisfactorily express appropriate emotion.

However a clinical assessment would be necessary to determine if these divergent scores are mainly due to the contrasting aspects of their personalities or possible areas of conflict within their relationship.

On the *General Scale* (Figure 6.1), Kobus scored 50 as opposed to Laura's 44 but they were in agreement on the *Self-Rating Scale* (Figure 6.3), which suggests that they both are satisfied with their personal expression of affect. Generally, both partners were in agreement on all items of the *Dyadic Scale* but again Laura tended to respond, 'strongly agree' or 'strongly disagree' to most of the items in contrast to Kobus' 'agree' or 'disagree'. This again may be a reflection of her more emotive, expressive personality as contrasted with his quieter, calmer nature.

Kobus states that they take too long to get over things when they are upset (*General Scale* – Item 44) and feels that Laura takes it out on him when she has had a bad day. (Item 32 - *Dyadic Scale*). However, they both strongly agreed that they could tell when their partner is upset and their partner cares shows he/she cares (Items 4 & 18– *Dyadic Scale).* Couples who appear to be satisfied within their relationship have been found to make "relationship-enhancing attributions about their spouses" (Forman, 1988, p. 980).

Laura presents as an assertive individual who has no problems expressing her feelings and who holds strong views on various issues. Throughout the interview she often interrupted her husband and finished his sentence for him or spoke for him as if he wasn't present. Possibly his lesser ability to express himself may result in him allowing Laura to verbalize his feelings as she sees them. However, Kobus' high score on this level on the *Dyadic Scale* suggests that he is dissatisfied with the expression of affect within their relationship and her behaviour may impact negatively on his ability to express appropriate emotion.

6.4.5. Involvement

Involvement refers to the manner in which family members support each other and affective involvement contributes to the success of *Task Accomplishment* (Skinner *et al.,* 1995). Within a trusting relationship individuals share information in a supportive

environment while still maintaining their own personal boundary and autonomy (Lauer & Lauer, 1997)

The Standers appear to perceive their own behaviour as nurturing and supportive and Laura's scores on all subscales suggest that she is satisfied with the involvement on all aspects of her relationships within the family unit. There are indications that Kobus is not wholly satisfied and it is likely that his perception of family involvement differs somewhat from that of his wife. His high score of 60 on the *General Scale* (Figure 6.1), differs 18 points from hers and there is a discrepancy of six points on the *Self-Rating Scale* (Figure 6.2). It is possible that Kobus may have feelings of either alienation or over-involvement within his family unit. Both partners however, agreed that everyone feels loved and other family members do not try to run each other's lives (Items 16 & 26 – *General* Scale).

These marital dyad was in agreement on all items on the *Dyadic Scale* which appears to contrast with the findings of the *Affective Expression* subscale. The discrepancies between their scores can possibly again be attributed to their differing personality styles. Again Laura tends to respond to most items as 'strongly agree' or ' strongly disagree' whereas Kobus states that he 'agrees' or 'disagrees'. Due to the differing personality characteristics of this couple it would appear that no definite conclusions could be made from these responses without first carrying out a clinical assessment.

Throughout the interviews there are no indications that either Stander feel that they are not both totally involved and supportive of each other's lives. Laura insisted that Kobus go overseas while he would not allow the doctors to wait until his return to do the caesarian section as "….I didn't want her to take the risk". He also was angry with her for looking at the photo's of badly deformed children at the cleft palate clinic as he felt it upset her. "Actually she was quite negative when she looked at these photos".

6.4.6. Control

Moos (1974) described *Control* as "the extent to which the family is organized in a hierarchical manner, the rigidity of family rules and procedures and the extent to which family members order each other around" (cited in Bloom, 1985, p. 237)

The results of the FAM-III reflect that this couple are satisfied with the level of *Control* present in their relationship and family unit and are able to adjust and compromise to changing circumstances. Their unique style of interaction appears to be generally consistent, responsible and constructive. They agree that they are amenable if someone else makes a mistake and they know what to expect from each other (Items 6 & 20 – *Self-Rating Scale*). Each partner feels that his/ her spouse is reasonable when he/she makes a mistake and is predictable and consistent (Items 6 & 20 – *Dyadic Scale).*

Although well within the average range, there is a discrepancy of 10 points on the *General Scale* (Figure 6.1), which suggests there may be differing perceptions in this area. They agreed that they have a chance to explain when there is a problem and rules within their home have a good reason (Items 27 & 7 – *General Scale).* It is again possible that the discrepancy is due to the fact that Laura again tends to respond 'strongly' to more items than does Kobus who is less emotive and more cautious in his responses.

The interview findings confirmed the FAM-III results and generally this couple seems capable of functioning in a healthy manner and has the ability to adapt when the need arises. There is no evidence of covert power struggles within their family interactions although Laura presents as the most dominant partner. When I asked her if Chantal's birth was premature as Kobus was not present at the birth, she immediately responded, "It was my decision that he should go. I told him that he could go. I said to him he must go." Somehow this statement highlights her responses throughout the interview where she constantly talks of her husband as if he is a 'little boy' whom she must defend against the attitudes of the world. Throughout the interview she spoke *of* Kobus and *about* Kobus, but rarely directly *to* him. However, at no time did he appear to feel irritated or uncomfortable with this behaviour.

6.4.7. Values and Norms

Values of a family comprise the ideals to which they aspire to and *Norms* are "the specific behaviours by which adherence to the rules, and therefore to the family ideals, are judged" (Steinhauer *et. al.,* 1984, p. 84).

Both Laura and Kobus appear to share a similar value system. This family system is also part of the larger system of their families of origin and their interaction with these subsystems seems to be healthy and balanced. Couples who share similar values to their families of origin have been found to have more satisfying relationships (Wilcoxon & Hovestadt, 1985, cited in Lauer & Lauer, 1997).

The scores on the *Dyadic Scale* (Figure 6.3) indicate that the Standers are in agreement as to how they interact within their family unit. They agree that they have the same views about what is right and wrong and they both feel that religion and education are important (Items 7, 21 & 28).

However there is a 10-point discrepancy between their scores on the *General* (Figure 6.1), which indicates that there are certain components of the family's value system that are dissonant. This implies that there may be some conflict of values between the couple, which may not be overtly expressed and appears to support the findings of the *Communication* subscale. Both members of this dyad agreed on most items but again Laura tended to respond 'strongly agree' or 'strongly disagree' in contrast to Kobus' 'agree' or 'disagree' which could explain the discrepancy in the results and may be due to Laura's more strongly expressed opinions.

The findings of the interview confirm their basic shared value system. Laura makes many references to God in her discussion and the belief that there is a higher power controlling one's life, which one must accept. "She's given to you. It's like a gift from God". Kobus does not refer to God in his acceptance of his daughter's condition but he talks of his 'turning point' towards acceptance by discussing a child with a much more severe handicap. "I can't imagine…" However, he verifies his faith and trust in Laura by stating, "I believe what Laura tells me".

6.4.8. Social Desirability

The Standers both scored a high 58 on the *Social Desirability* sub-scale, which suggests that they are likely to distort some of their responses to ensure that the family is reflected in a more positive light. These results may explain the conflicting findings on the *Dyadic Scales* regarding the areas of *Affective Expression* and *Involvement.* It is possible that

they are aware that others regard blindness as a 'disability' and they appear to be focused on presenting a 'normal' family image. However, studies have found that a higher score on this subscale is common among non-problem families and it is not necessarily an indication of dysfunction (Skinner *et al.,* 1983).

They both state that no family can get along better than theirs, they understand each other completely and neither admits that anything in their family unit displeases them (Items 9, 29 & 39 – *General Scale*). They do however admit that the family is not a perfect success (Item 49).

In the interview Laura constantly referred to Kobus' blindness and her anger at other people's reactions, which suggests that it is a very sensitive issue with her. "He said to me he *knows* how it feels to have a disability and people staring at you. He knows how it feels". Kobus stresses how well he can catch a bus and get around on his own like a 'normal' person and admits, "It's very difficult for me to ask somebody, 'Please can you take me there.' I'll rather walk on my own".

6.4.9. Defensiveness

This overwhelmed couple had high scores on the *Defensiveness Scale,* which appears to confirm the findings of the *Social Desirability Scale*. Laura's higher 58 as opposed to Kobus' 50 is confirmed by the interview discussion. Although earlier on in the interview she admitted she cried to her mother and blamed the meeting of a child with a facial cleft during her pregnancy on her daughter's deformity, she later stated, "For me it was nothing actually." She also states that she never tries to hide her child from outsiders as, "I'm not shy of her you know" but admits she doesn't like it when people stare.".

I asked Kobus to explain his work to me and he went to great pains to present himself as an independent worker who functions adequately in the workplace and has no need of any assistance. Regarding his family unit he stated, "I think we're going on like a normal family. There's nothing…" and Laura responded, "I don't see him as a blind person. Never will and never did."

The results of the FAM-III confirm the interview findings. Unlike her husband, Laura stated that they are never unfair to each other and they never hurt each other's feelings (Items 20 & 30 – *General Scale)*. They both agreed that they do get angry and upset with each other (Items 25 and 40).

"A 10 point differential between how two family members rate the same aspect of family functioning the more likely the discrepancy is to be clinically relevant" (Skinner et al. 1995, p.25). Some of the Stander's scores on various scales differ by more that 10 points and others differ by 5 points or more, which is an indication of possible marital tension. By contrasting the *General* and *Self-Rating* scores we can compare how the individuals perceive both the family and his or her own functioning.

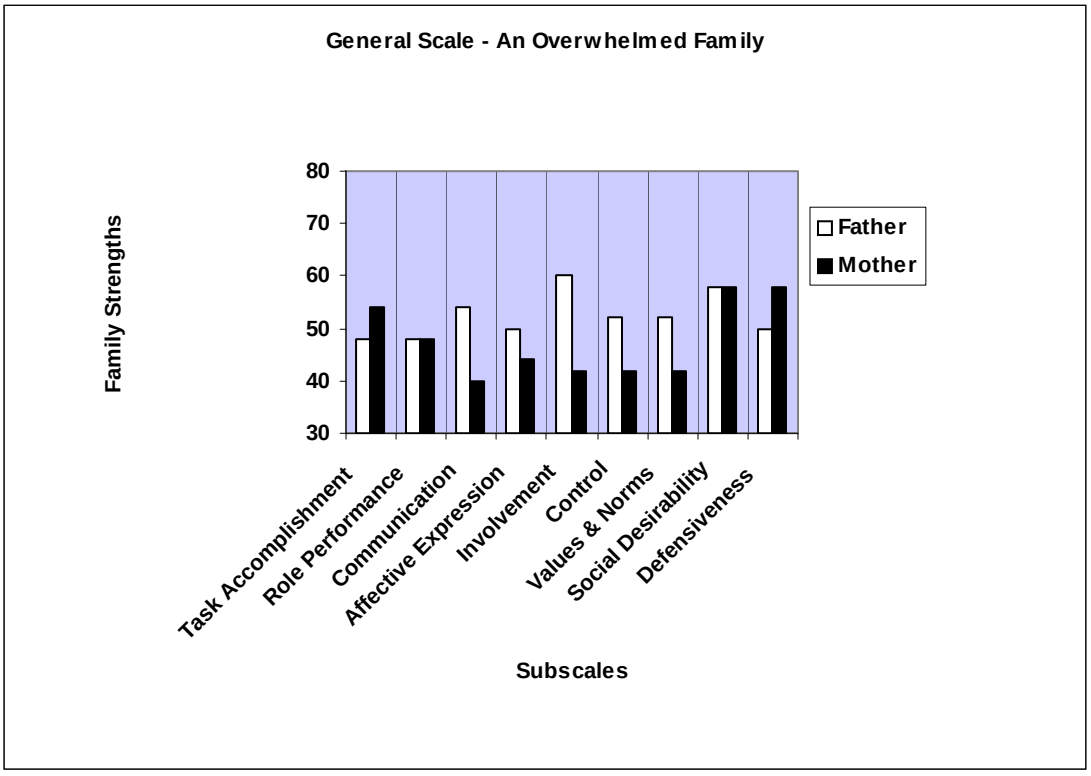

Figure 6.1: FAM-III scores for the different categories of the General Scale (Laura and Kobus)

Laura appears to be satisfied with how she perceives family functioning on the *General Scale* although her high *Social Desirablility* and *Defensiveness* scores suggests that all these responses may not be valid. On the *General Scale* they differed by 18 points on

Involvement; 14 points on *Communication;* 10 points on *Control* and *Values* and *Norms* and six points on *Affective Expression.* Kobus' higher scores suggests that he feels they may not be satisfactorily communicating and successfully expressing their feelings. The 10-point discrepancy on *Contro*l implies that there is a possibility of some covert power struggles although there was no indication of this in the interview findings. The discrepancy between these scores may indicate that Laura and Kobus have differing views as to how successfully they actually communicate and meet each other's emotional needs.

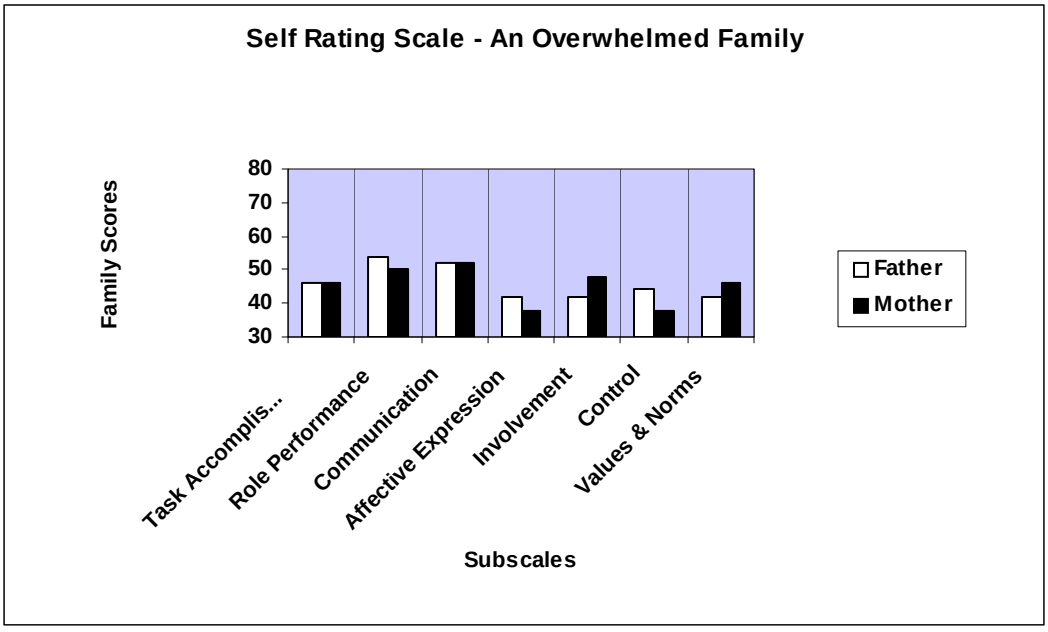

Figure 6.2: FAM-III scores for the different categories of the Self-Rating Scale (Laura and Kobus)

On the *Self-Rating Scale* Laura and Kobus differed by six points on *Role Performance* and Kobus' higher score, while still within the norm, may suggest that he is not totally satisfied with his personal ability to deal with problems and is likely due to his disability. There was also a six-point discrepancy on their scores for the *Involvement* subscale, which suggests that this couple may have differing perceptions in this area. Both members of this dyad appear satisfied with their own behavour in most areas and do not admit to any personal problematic areas. The scores for both Laura and Kobus on this

sub-scale were all clustered around and below the average range. However, their elevated scores on the *Social Desirablity* and *Defensiveness* subscales may indicate that responses have been distorted to reflect their family unit in a more positive light.

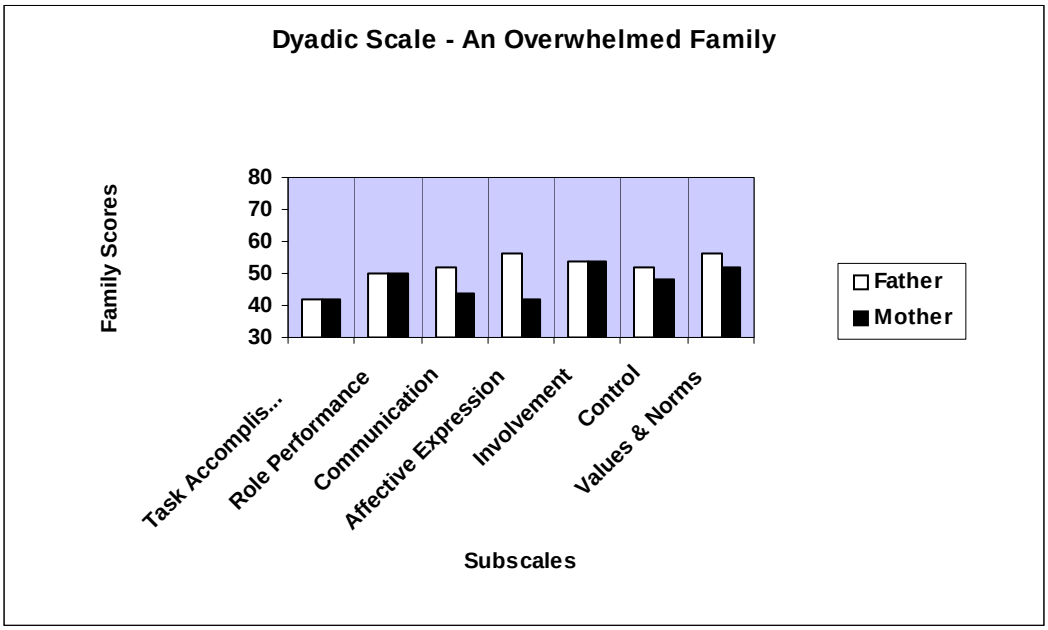

Figure 6.3: FAM-III scores for the different categories of the Dyadic Scale (Laura and Kobus)

On the *Dyadic Scale* they were in total agreement on *Task Accomplishment, Role Performance* and *Involvement* that suggests that they adapt appropriately to changes and generate possible solutions to deal with any crises. Interestingly, their scores for *Values* and *Norms* are also in sync which points to the discrepancy in this area on the *General Scale* possibly being due to external factors. This couple differ by eight points on *Communication* and Kobus' higher score indicates that he is not totally satisfied with the process within their relationship. This appears to confirm the earlier findings of the *General* and *Self-Rating Scales* which suggests he is satisfied with his own communication process but not totally with the process he experiences within the family unit. The biggest problem area for Kobus appears to be *Affective Expression* as he differs from his wife by 14 points on this aspect. This score confirms the findings of the *General Scale* and the results of the *Communication* subscales and supports the findings that there are inadequate communication processes within this spousal subsystem.

6.5. DISCUSSION

Consistent with family systems, the concept of a family is that this group cannot be regarded as a collection of individuals but as "an autonomous organism with its own rules and roles, its own structures and processes" (Bloch, 1984, p. 187). The focus of this study is therefore on relationships between individuals within this particular system and how they interact and influence each other's behaviour. This family unit has developed certain roles and patterns of behaviour to cope with the existing physical disability within their family and these patterns of behaviour appear to have remained basically unchanged with the birth of their child. Laura has adopted a caring, very protective role in her attitude to her husband and this role is now extended to include her daughter.

Morphostasis, which is the system's tendency to maintain a state of dynamic equilibrium, is evident in these interactions (Becvar & Becvar, 1996). Change in any one component of a system results in change in all other components as they are intrinsically connected (Bloch, 1984). Therefore, if Laura should encourage Kobus to take a more active child caring role it would necessitate a change in his and her behaviour. Either he would resist the change and refuse to accommodate her wishes or he would comply and possibly find that he could cope with the situation.

Feedback is a process, which serves as a mechanism to regulate the stability of a system. *Negative feedback* functions to maintain the equilibrium of a system and does not encourage new behaviour. This occurs when Laura does not encourage Kobus to take an active, practical role in the care of Chantal as "It's like telling him to cook". By continuing her 'caring' role and by his acceptance of his and her separate roles the pattern of behaviour, which is typical of this system, continues and the status quo is maintained.

Positive feedback, which permits change within this system, occurs when Laura's mother accepts the situation and realises that she can support her daughter through this period, as the cleft is "not a big thing". Another example of *positive feedback* is when Kobus accepts his daughter's facial anomaly after meeting Laura's friend who has a child with severe cerebral palsy. *Morphogenesis,* which is the "potential to develop and

grow," (Olson *et al.,* 1983, p. 71) takes place as the result of feedback. However, there is no evidence of positive feedback in the habitual patterns of interaction between this marital dyad who appear to continually resist change and the opportunity to develop and grow.

Both Kobus and Laura accept without question that he will have no part in the physical care of Chantal which Laura justifies by stating "I battle sometimes to get the plate…" Kobus was unable to visualise the extent of the cleft until he could 'feel' the opening, which he was reluctant to do while Chantal was being cared for by the nursing staff. As complications necessitated that both his wife and daughter remained in hospital for two weeks, he was unable to set his mind at rest for this whole period. Although both members of this dyad go to great lengths to emphasise the normality of their existence they do not acknowledge that Kobus' blindness and his reluctance to publicly 'feel' the cleft ensured that he remained uncertain for a far longer period than was necessary.

The ability of a system to change "it's power structure, role relationships and relationship rules in response to situational and developmental stress" (Olson *et al.,* 1983, p. 70) is its *adaptability*. This particular system appears to be resisting change at this stage and generally the power structure, role relationships and relationship rules within the spousal system have remained fundamentally the same as before their baby's birth.

Parents of physically challenged children who are helped to develop a positive and confident perception and attitude to the condition have been found to cope better with the stressful aspects of their situation (Pelchat *et al.,* 1999b). Laura is consistently positive and optimistic in her attitude towards Chantal's cleft lip and palate and this suggests that it is likely that she and her husband will gradually adapt to the new demands of the situation. The birth of a 'normal' child introduces change into the existing family system and the birth of a child with a physical deformity introduces extra stressors to which the parents must adjust. Not only must they adapt to the physical appearance but must also cope with the reaction of others (Van Staden & Gerhardt, 1994a).

Research findings indicate that parents of a child with a physical anomaly "often experience feelings of social isolation and marginalisation" (Carlson, Ricci &Shade-

Zeldow, 1990, cited in Pelchat *et al*., 1999b, p. 466). It is likely that disabled adults too experience aspects of this social isolation and may explain why this couple emphasise their 'normality' and as a result have such high scores on the *Social Desirability Scale*.

The *circularity* of affecting and being affected by both Kobus' blindness and Chantal's orofacial cleft is apparent in the way this family functions. Although Laura states that she " doesn't see him as a blind person," she contradicts this statement throughout the discussion by constantly referring to his disability and relating it to people's attitude to her daughter's facial anomaly. Kobus acknowledges that it took him longer to adjust to condition and admits that he "took it very badly at first". Although he never verbalizes his feelings about his blindness he does not contradict Laura when she states, "He *knows* how it is to have a disability and people staring at you". Families who adjust positively to the birth of a disabled child have been found to enjoy a high level of involvement and support from extended family members (Trute & Hauch, 1988).

All extended family members affect and have been affected by the birth of a child with a facial deformity and the concept of *circularity* can be extended to include them. The support from these subsystems appears to have been willingly given which serves to facilitate the adaptation and adjustment within this family unit. The extended family network is essential to enable the nuclear family to deal with stressors within their lives (Bloch, 1984). Kobus' parents appear to be accepting of their grand daughter's condition and are always available to offer both practical and emotional support. Laura appears to have a positive relationship with her in-laws and is also very close to her own mother and sisters. She has a reciprocal relationship with them in that she both receives and offers emotional and practical support. Social support has been found to lower levels of stress and enable individuals to better cope with situations (Feldman, 1999).

The Stander family is an *open system* in that selectively permeable boundaries exist where there is a certain level of exchange of information (Bloch, 1984). This couple interacts with their extended family members to support each other and exchange information on dealing with a child with a cleft lip and palate. They also interact with health professionals who inform and educate them on how to cope with this particular medical problem. At this stage of their adjustment they do not appear willing to gain information as to the possible causes of the anomaly. They choose not to question the

possibility of a genetic predisposition present within the family and ignore the fact that Laura's sister also gave birth to a child with a physical abnormality.

Values and *norms* of a family are reflected directly or indirectly in all aspects of family functioning and describe the interaction between the family system and the larger social system in which it interacts (Steinhauer *et al.,* 1984). The value system within this family appears strong but there are certain discrepancies, which indicate there are conflicting differences. Laura is the more expressive of this marital dyad and is very vocal in her beliefs and opinions. She refers to God several times during the discussion and states that Chantal is "a gift from God". Kobus is more cautious and tends to think carefully before he responds to questions. He neither agrees nor contradicts her when she makes these statements. Although his manner is more understated and less emotional than that of his wife, Kobus speaks of his parents with love and respect. After discussing all the practical help they gave the family when Laura was in hospital he says, "I think my parents were very supportive and they helped me a lot". He carries this value system into his present family unit and also speaks of Laura with love and respect, "Laura is a very strong person".

The focus of family systems theory is on relationships between individuals and their unique patterns of interaction (Becvar & Becvar, 1996). The characteristic pattern of interaction between this couple, indicates a relationship style which systems theorists label '*complementary*'. Such relationships are characterised by "high frequency of opposite kinds of behaviour" (Becvar & Becvar, 1996, p. 73). For example, Laura is assertive and expressive while Kobus is quieter and more withdrawn and tends to let her take over and even finish his sentences for him. The extrovert, emotional behaviour of Laura appears to be maintained by her husband's relative passivity.

Although both members of this marital dyad accept appropriate responsibility there is little evidence of role flexibility. Laura is content with the domestic role as she battled to fall pregnant and wishes to enjoy her time at home with her daughter. However, she does not appear to be able to allow Kobus to take on any of her self-assigned roles and although there is no sign of open power struggles, she is definitely the one in charge. Her role as a mother appears to have developed from her role of 'mothering' her husband whom she 'tells' to go overseas and 'allows' to drive the car. For change to

truly occur in this particular family system it will be necessary for behavioural change to take place within both these individuals (Bogdan, 1984).

Family cohesion is one of the basic dimensions of family functioning (Coyne, 1987). The Standers are both very supportive of each other, attribute positive characteristics to each other and appear to be emotionally bonded and have a high level of family cohesion. Kobus admires his wife's strength and coping abilities and she is very protective of her spouse and gets very annoyed when people stare at him "I don't like it at all because there's nothing wrong with him". *Involvement* refers to the ways in which the family members support each other, are interested in each other and meet each other's needs. Although both Kobus and Laura appear to have clear, permeable boundaries, the discrepancies on the various scales indicate potential problems. They both appear satisfied with their personal level of family involvement but Kobus' higher scores on the *General* and *Dyadic Scales* suggest that he may have certain feelings of insecurity or may experience a lack of autonomy within his family unit. However, there are no indications that this marital couple are disengaged or overly enmeshed as they support each other while still encouraging personal interests. Laura encourages Kobus to take an interest in sport and they also share an interest in tandem cycling.

For successful *role performance* each family member must be allocated specific activities, which they willingly assume and carry out (Skinner *et al.,* 1995). In this family unit, both members of this dyad have assumed responsibility for specific roles and carry out these roles with apparent willingness. Healthy families often have more flexible structures and roles, which enhance their system and allows for optimum functioning (Maccoby & Martin, 1983, cited in Quatman, 1997).

A study to determine the characteristics most valued by lay people for healthy family functioning found that effective communication was deemed most important. The respondents stressed that such communication did not imply that there was no room for conflict but the process allowed for *positive* and *negative feedback* loops which enhanced conflict resolution (Quatman, 1997).

Negative communication skills restrict the ability of family members to share their feelings, needs and preferences (Olson *et al.,* 1983). Within this family, *communication*

does not appear to be totally open and effective as there are indications of some distorted messages. Laura states that she does not see Kobus as a disabled person but her constant references to how other people react to his disability tends to contradict the total truth of this communication. Generally Laura is very vocal in expressing her opinion and Kobus tends to neither agree nor contradict her. However, during the discussion his body language never indicated irritation so it is possible he is generally content to be the quieter partner in this relationship. The discrepancy between their scores on *Communication* and *Affective Expression* suggest that a more open communication process may encourage Laura to develop an awareness of feelings that her husband may have difficulty expressing.

Research indicates that well functioning couples tend to focus on positive behaviours and traits of their spouse and ignore or minimize negative aspects (Forman, 1988). Laura was very verbal throughout the interview but she appeared very caring in her attitude towards Kobus. Much of her verbosity centred on her anger at others reactions to her husband's blindness. "Like when you go and visit people they normally ask me, 'How many sugars does he drink?'". Kobus presented as a calm individual who considers issues carefully before he expresses his feelings. When he made a statement during the interview, Laura would often elaborate on his response as if his answer did not adequately express the feelings experienced or as if he was not even present. "He knows how it feels when people stare at you". However, throughout the interview he was full of praise for his wife's strength and coping abilities and did not communicate any dissatisfaction. "Some people need pills to calm them down but Laura is a very strong person. She's stronger than me".

At the time of the interview Chantal had not yet undergone her first operation so it is to early for this couple to evaluate any long-term positive or negative effects this experience has had on family members. However, Laura feels the experience has already made her more empathetic to others in a similar situation and she feels that she was better able to support her sister when her newborn child had to undergo an operation. When Kobus met Laura's friend who had a cerebral palsied child he felt he could put his own situation into perspective while still feeling great empathy for parents who have so much more to deal with.

6.6. CONCLUSION

Kobus' blindness dominated the discussion and actually became the focus of this interview with the cleft lip and palate becoming a secondary issue for discussion. The reality of his condition has had an impact on the interactions and relationships within this family unit and affects all aspects of their lives. Laura has a protective attitude towards her husband and while she strives to see him as 'normal' the attitude of other people serves as a constant reminder of the reality of their situation. The overriding theme in this small family unit is of Laura as a protective mother figure with a dependent husband and daughter.

'Family pain' is a concept used to describe the "state of disequilibrium the family is thrown into when confronted by sudden disease, disability or death" (Van Staden & Gerhardt, 1994a, p. 15). It is possible that this couple has had a long experience of this 'family pain' as a result of the reactions of others due to Kobus' handicap and they now must deal with it in a different form due to their daughter's atypical facial appearance.

Having lived with the gradual deterioration of his sight, Kobus is naturally more accepting of his disability but he too strives too appear as independent and self-sufficient. He speaks of his work with pride and it is obviously important for him to be able to fulfill the role of a financial provider.

Leisure time at this stage is focused on each other; close family members and Kobus' sport. All couples at this stage of the family life cycle have to give up for a time many activities they previously enjoyed due to the practical demands of a new baby. The Standers enjoyed tandem cycling together before the birth and hope to take up the shared activity at a later stage. Laura stated that she always only wished to have one child and her decision has not been affected by the fact that Chantal was born with an orofacial cleft. Kobus did not comment or indicate that he had a differing opinion.

There is evidence of a flawed communication process within this couple's relationship, which prevents them from dealing openly and honestly with their problems. The incongruent messages they both send and receive inhibits adaptation and their ability to adjust to the current crisis within their family unit. A system is likely to malfunction if the

processing of information is faulty and clear communication channels must be developed to ensure effective family functioning (Goldberg & Golberg, 1985). While this marital dyad continue to avoid patterns of open communication, they will remain stuck and will not develop effective problem solving and conflict resolution skills.

The fact that both the Standers had high scores on the *Social Desirability* and *Defensiveness* subscales suggest that they have a strong need to present themselves as a 'normal' couple with a healthy newborn daughter. These scores are likely to have affected the responses on the other scales and only a clinical assessment can determine the validity of their responses and the possible conclusions that can be made. It is likely that this family unit would benefit from therapy where they could be confronted with the discrepancies in their responses on certain scales and be aware of how their perceptions of their unique family functioning differ. Such confrontation within a safe environment could encourage the development of new insight and a more interactive view of their relationship. Studies have found that when therapy has successfully reduced defensiveness the family system tends to respond in a more open manner and begin to acknowledge problem areas (Skinner *et al.,* 1995).

CHAPTER 7

THE WILTSHIRES: AN ANGRY FAMILY

7.1. FAMILY BACKGROUND

Rowan and Lesley are in their late twenties and have been married for three years. Their son, David is three months old and was born with a cleft lip and palate deformity. All ante natal sonars and tests did not indicate that there was a possibility that their son had a facial deformity so they were both very shocked when he was born as it had not been anticipated and they were unprepared.

The Wiltshires have experienced a high level of stress in the year preceding their son's birth. Rowan was retrenched from his work and they moved to her parent's farm for a period. He received a retrenchment package so they were not financially in need, which lessened the stress of that time to a certain extent.

Rowan appears the more outgoing and sociable of two and says that he is "trying to be a very tranquil person" and he is generally "optimistic" in his approach to life's problems. He considers Lesley to be a perfectionist who puts an immense amount of pressure on herself to achieve in every area of her life. According to Rowan she has never had to cope with adversity before and depends heavily on him for support. He feels he has to be the 'strong one' in the relationship and admits to feelings of frustration as she has the habit of venting her frustration on him without really considering his feelings.

7.2. THE INTERVIEWS

I had three separate interviews with the Wiltshires. I had an initial interview in their home in the evening, which lasted approximately two hours. I first interviewed both Lesley and Rowan together and then administered the Family Assessment Measure-III (FAM-III) to Rowan while Lesley tended to their son. I had a follow up interview with Rowan the following week in a coffee house near his work. This session lasted for 30 minutes and I clarified certain issues that had arisen in the initial interview. I had a follow-up interview two weeks later with Lesley – again in a coffee house. This session

lasted almost an hour as I also clarified certain issues from the original interview and administered the FAM-III.

Both parents were welcoming and hospitable when I arrived at their home. Lesley appears to be the more reserved of the two and gives the impression of needing distance. She projects the impression that she is not totally comfortable with discussing her feelings - especially those emotions she feels regarding her son's cleft lip and palate. They are both Afrikaans speaking but Rowan, who presents as friendly and warm, is more competent in English. Although she understood everything that was said, Lesley sometimes battled to express herself. I gave her the option to speak in Afrikaans but she continued to speak English. Rowan tended to dominate the interview and interrupted frequently.

Of all the case study interviews carried out I found this one to be the most difficult in that I found I had to prompt both Lesley and Rowan for answers when discussing their experience and feelings. Lesley in particular tended to often answer with "yes" or "no" and did not always elaborate. I felt this was due to both her natural reticence and her discomfort with expressing herself in English. Rowan was much more relaxed and talkative when Lesley was not in the room and the impression I had was that he had a lot to say which he could not say in front of her. There were indications of tension and many bottled-up emotions.

When I administered the FAM-III to Lesley in the separate interview, she admitted that she is a perfectionist and acknowledged that Rowan is her strongest support system. She also admitted that she has the tendency to vent her feelings on her husband while he never retaliates in a similar manner.

7.3. INTERACTIVE DISCUSSION

The news of the unplanned pregnancy was a huge shock for Lesley who had been told by her gynaecologist that she would not be able to fall pregnant without medical help, as "I don't have any progesterone in my body." According to Rowan it took a while for them to adjust to the idea "but afterwards we made peace with it and we prepared ourselves for everything and looked forward to the baby." The pregnancy was uneventful and they

did not expect any problems or complications. At 38 weeks gestation, believing she was full term, the gynaecologist induced her. Lesley admits to feelings of guilt that she may have caused her son's birth defect by unknowingly taking some medication. She feels that a pregnancy should be planned and you are responsible for your baby as "he's nine months inside you."

Both parents feel that the gynaecologist was extremely supportive and empathic throughout their ordeal. David was his final delivery as he was retiring after working in the field for 34 years. He was devastated that he had not picked up the orofacial cleft and "his eyes filled with tears" when he realized that David had a defect. Neither Lesley nor Rowan feels anger at this doctor and Rowan is grateful that they did not know about the cleft lip and palate before the birth. He feels that once he started reading up about the anomaly and discovered other problems that are sometimes associated with the condition he would have "been freaked out" if he had known about these possibilities before the birth of his son. He feels that the stress of not knowing the extent of the cleft would have also been harmful to the baby, as he would have picked up on their increased stress. Although Lesley admits that she would have worried about possible worse conditions, she feels she would prefer to have known about the cleft before the birth so that she could have been prepared.

Neither Lesley nor Rowan knew much about orofacial anomalies before their son was born. Rowan recalls a child who was at school with him who had a cleft lip that had not been repaired. His impression therefore was that a cleft was not repaired and "I didn't know if they can stitch it up." They researched the condition through *widesmiles.com* and read many books to learn as much as they could. The newly gained knowledge both set their minds at rest in some instances and created new worries in others when they learned of conditions that are sometimes associated with facial cleft deformities. They feel grateful that their son was not as bad as many cases they saw but also took him to three or four paediatricians to ensure he would have no other deformities or problems. "We were paranoid to be sure."

Rowan admits that his first sight of his son "was quite a shock" but says that now "we don't even see it." Apart from always having his hands covering his mouth when Lesley had a sonar during her pregnancy, David also was born "facing down" so the first

indication she had that there was anything wrong was when she heard the doctor say, “We have a little problem.” Lesley says she saw him but refused to hold him. Rowan agrees she was “a bit rejecting” until her older sister who is a midwife and who was present for the birth insisted that Lesley hold her son, look at him and put him to her breast. She feels grateful that her sister forced the issue and was reassured when she said, “It’s not so bad. They can fix it.” She admits that she did not really believe her at that stage and it took her about two weeks before she felt she could begin accepting her child.

Although the appearance was an initial shock for Lesley, she feels that her rejection of her child was not just because of the face but the “whole thing”. She feels that it was a huge shock and she felt that they had had “such great expectations” which were now “shattered”. Rowan feels that the birth of David was the only “light shining on the horizon” in what had been a very difficult year for them both. The reality of another problem to cope with was very difficult for them “but we’re over it now”.

Rowan found it difficult to deal with the initial reaction of family members who were waiting outside the ward for news of the birth. He experienced their reaction as “shocking” as they reacted with both distress and denial and he found he had to console them and “be the strong one” when he himself felt like crying. He felt that he received more support from his own mother when she came from Cape Town to visit them a few weeks later. He describes his mother as a relaxed, tranquil person who is very much like him, “So we don’t tend to show our emotions that obviously”. She has bonded with David but like everyone else she too had to adjust to the practical aspects of the situation initially. It frustrates Rowan that many members of the family are not “100% over it “ as the facial cleft is still constantly brought up during various conversations.

Lesley did not want anyone to know and neither did she want to see anyone. When friends phoned, Rowan explained the situation and asked them to be patient. Most of them were understanding and supportive. After a few weeks Lesley gradually saw all her friends but says no one actually talked about the cleft lip and palate and tended to avoid even mentioning it. She feels it is “unreal…frustrating” but felt comforted by the support of her best friend who brought her cousin to visit who had had a child who had also had a facial cleft deformity two years previously. She says it helps to talk and would

love to attend a support group for mothers with children with clefts just to be able to interact with others who understand her situation.

The nursing sisters at the Facial Cleft Deformity Clinic of the University of Pretoria have been very helpful and encouraging and Rowan feels they could not have survived without their support. Lesley appears to be very dependent on the support of her older sister who lives abroad but was present at the birth and stayed in the couple's home for a few weeks to help them adjust to their new situation. Rowan agreed that she was very supportive and "amazing." They both agree that they were initially reluctant to go out with David. However, when he was four days old Lesley's sister forced them to go out with her and David and she acted so naturally with the baby that they felt more comfortable about with interacting with other people who might stare at their child. As Rowan said, "You tend to be ashamed but she showed us not to be."

It was extremely difficult to get Lesley to respond in detail to most of my questions and when she did Rowan would often interrupt her and answer the question himself. Generally she agreed with what he said and would nod her head in response but rarely added in-depth comments. She did become quite vocal when she was describing how she felt when David was about one month old and she would see other 'normal' babies in their prams. She admitted that she felt so angry that she wanted to take every pram and "…throw all the babies out on their heads and faces!" Rowan acknowledged similar feelings but said that it was a response that stemmed not from jealousy but from a sense of loss. "Why does that baby look so nice and why…?"

Lesley went off to the bedroom and we began the series of questions for the FAM-III. It was almost as if Rowan was waiting for the opportunity to speak openly and honestly without his wife being there. He lowered his voice and spoke in depth in response to many of the questions. I had an underlying feeling that Rowan was subtly manipulating the interview and 'getting me on his side'. He appeared to be supportive of his wife throughout our combined interview but there were many incidents when he took the opportunity to boost his image at her expense. For example, he was quick to point out that Lesley initially rejected David while he "bonded straight away."

Although he stated in the combined interview that Lesley's sister was "amazing" and very supportive he told me in the separate interview that they had clashed and she eventually apologized to him for her behaviour.

Rowan has one sister who does not appear to be very responsible and he is close to his mother who he feels has a similar temperament as himself. He admires his mother who brought himself and his sister up alone when their alcoholic father left the family when Rowan was 14. His mother has since remarried and he feels close to his stepfather. He has no contact with his father.

He feels that his childhood was such that he had to take responsibility from an early age and always be the 'strong one.' This is his natural role in relationships and one that he has naturally fallen into since his marriage. While he is overtly supportive of Lesley, there are indications that he is tired of having to be the 'strong one' yet again and there is underlying feelings that he resents the role although it appears to be important to his projected image to keep playing it.

He considers Lesley to be a perfectionist who puts an immense amount of pressure on herself to achieve in every area of her life. She has had a relatively easy life with no traumatic incidences and he does not think she has learned how to cope with adversity. As a result she depends on him for support and has the habit of venting her frustration on him without really considering his feelings. Rowan feels that he learned to cope with adversity and responsibility from an early age and the worst that Lesley has ever had to cope with is a "bad hair day".

7.4. FAM-III RESULTS

In the individual administration of the FAM-III, Lesley and Rowan were shown a list of statements and asked to rate their level of agreement.

Scores on the following dimensions were compared:
Task accomplishment; Role performance; Communication; Affective expression; Involvement; Control; Values and Norms.

7.4.1. Task Accomplishment

Biological, psychological and social goals of a family system are met through successful *Task Accomplishment* (Steinhauer *et al.,* 1984). Within the Wiltshire family, the role of *Task accomplishment* appears to be problematic. The situation is such that both Lesley and Rowan are attempting to ensure that the family system is organized and all the basic, developmental and crisis tasks are taken care of. Rowan is working away from home during the day so Lesley carries the main responsibility for the care of their son. As she is still holding down the same job as she had before his birth she attempts to continue to work when he sleeps and Rowan assumes the care in the evening to allow her to work uninterrupted. While they continue to function they have had many setbacks and appear to be 'surviving' at this stage. Neither individual appears to be compromising to cope with the demands of their new situation. Lesley is a self-professed perfectionist who sets herself high standards and goals and she does not appear capable of diminishing her load to ease her stress during this period. Although they do not have financial problems, neither one appears to feel that it may be an option for her to focus on their child until all the medical problems are dealt with. They do receive limited support from extended family members so basically they attempt to cope with their situation alone.

There were fairly large discrepancies on their scores on the *General* and *Dyadic Scales* (Figures 7.1 and 7.3) in this area, which suggests possible conflict and differing perceptions as to how successful they meet basic, development tasks. Rowan scored 64 on the *General Scale* and 62 on the *Dyadic Scale*, which is above the norm and suggests that he sees problem solving as problematic and may feel that the family is not responding in an appropriate manner to the current stresses and changes. Lesley's score of 58 on the *General Scale* indicates that she too may perceive the family unit as failing to successfully achieve certain basic tasks.

There is also a discrepancy of 16 points on the Dyad*ic Scale*, which is suggestive of conflict in this relationship. Both Lesley and Rowan agree that they spend too much time arguing about what their problems are but felt they do try different ways of solving problems and do not let things pile up until they are unmanageable (Items 1, 11 and 21 –

General Scale). Unlike his wife, Rowan also feels that it takes too long to work out problems when things aren't going well (Item 31 – *General Scale*).

They both agreed that their partner helps them with a problem and can be counted to help in a crisis (Items 15 & 36 – *Dyadic Scale*). Rowan felt that Lesley doesn't see problems the same way as he does, can never accept his answer to a problem and does not find a new solution to a problem (Items 1, 8 & 22 – *Dyadic Scale*). Both individuals appear satisfied with their personal task accomplishment according to the scores on the *Self-Rating Scale* (Figure 7.2). They both agree that they do keep on trying to work things out, do not let others solve their problems and they can be depended on in a crisis (Items 22, 29 & 36 – *Self- Rating Scale*). Rowan admitted he finds it difficult to accept someone else's answer to a problem (Item 15) while Lesley says she is comfortable with accepting help and feels she sees problems the same way as her husband (Item 1).

The findings of the interview reflect their attempts to find solutions to their son's medical condition and are researching relevant information to enable them to make informed decisions. "I took him to three or four paediatricians just to make sure". Rowan maintains that much of the difficulty for Lesley to adjust to David's disability is that her personality is such that she "…needs to plan ahead and that wasn't in her plan".

7.4.2. Role Performance

Each family member's role describes patterns of behaviour, which is both expected and permitted (Goldberg & Goldberg, 1985). Elevations in this area suggest that family members have difficulty in adapting to new and changing roles (Steinhauer *et al.,* 1984). Rowan has elevations on all three subscales, which indicates he has high feelings of dissatisfaction regarding *Role Performance* within the family unit. While still well within the normal range, Lesley and Rowan had a 10-point discrepancy on the *General Scale* in this area (Figure 7.1), which suggests they may not have similar perceptions as to the management of role differentiation within their family unit. They both feel that duties are fairly shared and they agree about who should do what in the family. (Items 2 & 22 – *General Scale*). Lesley does not feel that she is expected to do more than her share while Rowan feels he is expected to carry the heavier burden (Item 12). Lesley takes care of David during the day and tries to catch up with her work in the evenings when

Rowan is at home. " So at 6.00 p.m he takes over". Overall they both feel they do their share of duties within the family and do not expect too much from other family members (Items 9 & 16), but Rowan feels that too much is expected of him (Item 2).

The interview findings confirm the fact that Rowan appears resentful of his role of "the strong one". It appears to be a role he has assumed since childhood when his alcoholic father left the family and he felt he had to be a supportive son for his mother. There are indications that he is battling to adjust to his new parenting role as he says he felt exhausted at having to support other family members when he himself felt the need of support, "I must be the strong one. I wanted to cry".

The discrepancy of eight points on the *Dyadic Scale* (Figure 7.3) indicates that Rowan is less satisfied with *Role Performance* within their relationship and may feel that Lesley is not fulfilling his expectations in this area. He feels that she expects too much of him (Item 30). However, both members of this marital dyad acknowledges that their partner takes his/her share of family responsibilities and they both are in agreement about who should do what in the family (Items 9 & 37). In the separate interview, Rowan stated that he knows David's lip will be fixed and he therefore does not worry about the long-term effects. However he feels that Leonie's reaction does cause him anxiety, "It gets to me if other people stress – like now".

Rowan's score of 64 on the *Self-Rating Scale* (Figure 7.2) falls into the problematic range and suggests that he may be experiencing difficulty with adapting to his new role. Lesley's lower 54 indicates that she is more satisfied with this area. In her separate interview, Lesley admitted that she is a perfectionist and often stresses unnecessarily over issues but she perceives Rowan as the dependable support in her life.

7.4.3. Communication

Communication and the exchange of information define the nature of relationships within a system and is the means by which they are held together (Becvar & Becvar, 1999).

During the combined interview, both Lesley and Rowan were not particularly forthcoming with information and had to be prompted to talk in depth of their experience. Rowan is

the most expressive and interrupted Lesley at times. However it is possible that this may also have been due to her lesser comfort with speaking English. When Lesley left the room to care for her son, he immediately became much more verbal and confided feelings, which he seemed to be reluctant to express in front of his wife. Many of his comments were thinly veiled criticism of Lesley and he vented his frustration at many aspects of their marital situation.

In the second separate interview when I administered the FAM-III to Lesley she was slightly more expressive. She is aware of her characteristic personality traits and easily admits to her own faults without any prompting. She was totally positive in her comments regarding Rowan and never criticized him in any way. Generally, Lesley reflects a natural tendency to avoid discussing in-depth feelings. When Rowan said that he had to be optimistic about the future she merely stated when prompted, "I have my worries".

There are discrepancies between the Wiltshires scores on all three scales relating to *Communication,* with the 10-point discrepancy on the *Dyadic Scale* (Figure 7.3) suggesting the highest problem area. Rowan's score of 60 on this level indicates that he is particularly dissatisfied with the pattern of communication within their relationship. Both members of this dyad state that they know what is going on in their family and they take time to listen to each other (Items 23 & 33 – General Scale). However Lesley maintains she does not always get a straight answer and Rowan says they argue about who said what in the family (Items 3 & 13 – General Scale).

The discrepancy of eight points on the *Dyadic Scale* (Figure 7.3) They both state that they know what their partner means when he/she says something, their partner is available when they want to talk and they believe what their partner tells them (Items 3, 24 & 38). However, Rowan feels Lesley often takes what he says the wrong way and does not listen to his point of view (Items 10 & 31).

Lesley's awareness that she does not always get straight answers appears to be confirmed in the interview findings. Rowan tends not to be open in his communication with her and there are signs of incongruent messages. For example, when she stated that her sister was extremely supportive he agreed that she was "Amazing". However,

during our separate interview he confided that his sister-in-law was controlling and domineering and he had had a confrontation with her. He neither criticized nor praised his wife during our combined interview but spoke in depth about certain frustrating aspects of her personality when she was not present. He stated that the situation is difficult as she is a perfectionist who has never before had to deal with stressful issues. "Maybe the worst is not getting her hair right". It was not apparent that this couple ever really discusses these fundamental differences and frustrations within their relationship.

Rowan's higher score of 58 on the *Self-Rating Scale* seems to indicate that he is less satisfied with his own communication process and he may feel an inability to seek clarification in case of conflicting messages. He maintains that he doesn't always understand what Lesley is saying and admits that he does not always say what he would like as he cannot find the words (Items 9 & 24). Both partners feel that their family knows what they mean when they say something; they are available when other want to talk and they listen to the opinions of others even if they disagree (Items 3, 31 & 38).

Lesley does not appear to send conflicting message in her communication process. However, the problems within their relationship appears to be due to the fact that she 'offloads' all her stress onto her husband and he feels that he must deal with it.

7.4.4. Affective Expression

Affective Expression refers to the communication of feelings between family members and insufficient and inappropriate affect can impact on task accomplishment and role performance (Bernstein & Borchardt, 1996). Both Lesley and Rowan appear satisfied with their personal expression of affect and the expression of affect within their relationship. They both agreed that they could tell when their partner is upset; their partner communicates his/her feelings and does not get him/her to take sides (Items 4, 18 & 39 – *Dyadic Scale*) (Figure 7.3). They also stated they do not keep feelings to themselves, do not stay upset for long periods and do not get upset to quickly when they are with each other (Items 4, 18 & 39 – *Self-Rating Scale*) (Figure 7.2).

The discrepancy of six points on the *General Scale* (Figure 7.1) may indicate slight dissatisfaction with the overall expression of affect within their family unit. They agreed

that they tell each other about things that bother them but Rowan felt that they take too long to get over things when they are upset (Items 14 & 44). The findings of the interview suggest that Rowan is dissatisfied with the expression of affect within their relationship. He feels that he must be continually "strong" and be available to support his wife when she has emotional outbursts.

There were no indications that Lesley is aware of his frustration at this situation. He stated that he bonded with David immediately after the birth but his wife initially rejected her son and said she never wanted to see him. However he acknowledges that she eventually accepted the situation and "she did all the normal things a mother would probably do and….I bonded straight away". This statement confirms his tendency to send incongruent messages as even when he was making a positive statement about Lesley, he negated it's effect by contrasting her behaviour with his own and succeeded in portraying himself in a more positive light.

7.4.5. Involvement

Involvement refers to both the quality and extent of family members involvement with each other. Elevations on this subscale are indicative of difficulties within the emotional aspects of family relationships (Bernstein & Borchardt, 1996). Rowan's ratings of 52 on both the *Self-Rating* and *Dyadic Scales* (Figure 7.2 & 7.3), indicates he perceives his own behaviour and that within the marital relationship as nurturing and supportive. However, his score of 60 on the *General Scale* (Figure 7.1) suggests that he may have feelings of either alienation or over-involvement within his family unit. In the interview he stated that he is like his mother and "we don't tend to show our emotions that obviously", which seems to indicate that he is feeling overwhelmed with his wife's emotional offloading. Leslie does not appear to be aware of any problem and seems content with the level of involvement within the family unit generally and also within her relationship with her husband. The discrepancy of six points on the *General Scale* (Figure 7.1) indicates that Lesley is more satisfied with the level of involvement within the family unit. In the interview she appears to be naturally reticent and did not seem to feel comfortable with discussing deep feelings although she states that Rowan is her strong support but never indicates how she supports him in return.

The results of the *Self-Rating Scale* (Figure 7.2) suggest that he is satisfied with his own behaviour in this area but feels emotional needs are not being fully met by Lesley. This appears to be confirmed by his statement in the interview that he must always be "the strong one". He states that he stays out of other family member's business and really cares about his family (Items 12 & 26 – *Self-Rating Scale*) and feels that he is close to Lesley and she cares when he is upset (Items 5 & 12 – *Dyadic Scale*). He agrees he feels loved but admits that he feels he does not always get a chance to be an individual (Items 16 & 5 – *General Scale*).

Lesley's score of 42 on the *Self-Rating S*cale (Figure 7.2) confirms these findings and the discrepancy of 10 points between her and Rowan's scores on this sub-scale implies that they may have differing perceptions of this area. While still within the normal range, her score of 58 on the *Dyadic scale* (Figure 7.3) reflects possible conflicts within their relationship. She states she is close to Rowan and knows that he cares when she is upset but feels he worries too much about her (Items 5, 12 & 40 – *Dyadic scale*). However she feels loved and trusted and feels she does get a chance to be an individual (Items 16, 46 & 5 – *General Scale*). She strongly agreed that she cares about her family and knows that she can count on Rowan (Items 26 & 33 – *Self-Rating Scale*).

7.4.6. Control

Control refers to the strategies or techniques used by family members to exert influence on each others behaviour to ensure that the system continues functioning and all basic tasks are successfully accomplished (Steinhauer, 1984). The results of the FAM-III reflect that this couple is satisfied with the level of *Control* present in their relationship but the discrepancy of 10 points on the *General Scale* (Figure 7.1) suggests that they have differing perceptions. Rowan's higher score indicates that he feels certain aspects may be problematic and it is possible that he feels that his family unit is inadequately adapting to changing demands. They both feel they do what is expected of them and get a chance to explain if they do something wrong (Items 47 & 27 – *General Scale*). However Rowan disagreed with Lesley and stated he did not always know what to expect when he did something wrong (Item 17).

Lesley's score of 60 on the *Self-Rating Scale (*Figure 7.2*)* differs by 16 points from Rowan's and indicates that she finds this aspect of family functioning problematic. She possibly feels unable to adapt to changing demands and may interact in a destructive and rigid manner, which may result in overt or covert power struggles within the family unit. Their scores on the *Dyadic Scale* suggests they both experience overt or covert power struggles and may have difficulties adjusting to changing life demands. Lesley admits that she does make a big deal of it when he does something wrong and she gets angry when others in the family don't do what she wants (Items 6 & 13 -*Dyadic Scale*) (Figure 7.3). Rowan feels his family know what to expect from him and he is responsible and does not need to be reminded what to do (Items 6, 27 & 34 – *Self-Rating Scale*). However they both acknowledge that their partner forgives them when they are wrong and gives them a chance to explain (Items27 & 13 – *Dyadic Scale*). But Rowan feels that he doesn't always know how Leslie will react when he makes a mistake and she feels that she needs to remind him to do his share (Items 20 & 41).

The interview findings confirmed the FAM-III results and generally this couple seems to be resisting adaptation to the new demands of their present situation. There is evidence of covert power struggles within their family interactions in that Rowan consistently attempts to portray his wife in a less favourable light and she presents as the more dependent partner. Their responses appear to be consistent with their general pattern of interaction within other relationships. Lesley is very dependent on her sister for support while Rowan seems to naturally assume the role of carer and nurturer.

7.4.7. Values and Norms

This subscale assesses the level of agreement between family members regarding *Values* and *Norms* and the concordance with the values of the family and the environment within which it lives (Steinhauer, 1984).

Both Lesley and Rowan appear to have certain areas of dissonance within their value system although the results of all three subscales showed fewer discrepancies than other areas. There are six-point differences on the results of the *Self-Rating* (Figure 7.2) and *Dyadic Scales* (Figure 7.3) reflect certain basic differences that may be connected with their differing interactions with their families of origin. Rowan has achieved a level

of differentiation from his family members and appears to enjoy a healthy relationship with his mother. In contrast, Lesley appears to be very dependent on her sister and there is evidence of enmeshment as she permits her sister to intrude into her marital subsystem. A healthy spousal subsystem must develop boundaries, which protect it from demands of other systems, or conflict and imbalance will result (Minuchin, 1996). When a couple form a new family unit it is essential that the families of origin adjust to the new system to allow a new structure to develop and grow. At this stage there is no indication that this family structure is able to adapt to the new circumstances.

They both agree on the importance of education and feel they have the same views on what is right and wrong but Rowan stated that he does argue with Lesley about the importance of religion (Items 14, 21 & 7 – *Self-Rating Scale*). However they were in total agreement on all items on the *Dyadic Scale* with the only difference being that Rowan responded 'strongly agree' to Lesley's 'agree' on the importance of education (Item 28). They both state they do not argue about the freedom to make their own decisions but Rowan felt that he is not always free to say what he thinks (Items 28 & 48 – *General Scale*) (Figure 7.1).

These findings were confirmed in the interview in that Rowan did not feel free to openly speak his mind of his feelings regarding his wife, sister-in-law and their present situation when Lesley was present. However, he does appear to support her in her desire to continue working and to maintain her career.

Both individuals appear to be very close to their parents and seem to enjoy a healthy relationship with other extended family members. Lesley admits that her mother did not initially react well to the news of David's cleft and Rowan agreed by saying that their reaction was "Shocking!" Lesley did not take offence at his comment. The discrepancies appear to be due more to personality characteristics and differing responses to stressful situations than a disparity in their basic, shared value system.

7.4.8. Social Desirability

Rowan scored well below the norm on this subscale, but Lesley's higher 52 suggests that she may have distorted some responses to ensure that the family is reflected in a

more positive light. In the discussion she acknowledged that she avoided all her friends in the first few weeks after David's birth, as "I didn't want anyone to know".

Although Rowan received a low score there were indications throughout the interview that he wished to portray himself in a more favourable light - often to the detriment of his wife. For example, he stated that unlike Lesley, he bonded immediately with his son, "I bonded in the hospital. I was more with him than she was."

They both state that they are as well adjusted as any family can be but admit that some things about their family don't entirely please them and their family is not a perfect success (Items 5, 39 & 49 – *General Scale*) (Figure 7.1). Lesley also maintains that no family can get along better or be happier than theirs (Items 9 & 19).

7.4.9. Defensiveness

Lesley scored highly on the *Defensiveness sub-scale* (Figure 7.1), which appears to confirm the findings of the S*ocial Desirability subscale* and indicate that she may feel the need to portray the family in a favourable manner. Rowan's score was also elevated and there were indications during the interview that he too makes use of defensive behaviour at times. For example, in reference to David's cleft lip he said, "If we look at it now we don't even see it". Both members of this dyad admitted that they are more easily annoyed on some days and they do get upset with each other at times (Items 10 & 40 – *General Scale*). However Lesley disagreed with Rowan and stated they are never unfair to each other and do not hurt each other's feelings (Items 20 & 30).

While most of the results of all three scales completed by Lesley and Rowan were between 40 and 60 there were many discrepancies in their responses which points to possible problems in various areas. Rowan's *Social Desirability* score was 44 while Lesley had a *Social Desirability* score of 52 and a *Defensiveness* score of 58, which suggests her responses, may not always be valid and she may attempt to portray her family in a more positive light. In the combined interview, Lesley admitted that her shock at David's birth was in part due to the fact that "You expect this perfect boy and ummm…." Unlike Rowan she stated that no family could get along better or be happier than hers and they understand each other completely (Items 9, 19 & 29 – *Genera*l

Scale) (Figure 7.1). She also felt that they are never unfair to each other and always admit mistakes without trying to hide anything (Items 20 and 45). However, she did admit that they do get angry at each other, they could be happier than they are and the family is not a perfect success (Items 15, 19 & 49). These discrepancies may indicate that this couple may not always share a common perception of their family

"A 10 point differential between how two family members rate the same aspect of family functioning the more likely the discrepancy is to be clinically relevant" (Skinner *et al*. 1995, p.25). Many of Lesley and Rowan's scores on various scales differed by 10 points or more and others differ by five points or more, which is an indication of conflict and underlying tension. By contrasting the *General*, *Self-Rating* and *Dyadic* scores we can compare how the individuals perceive both the family and his/ her own functioning.

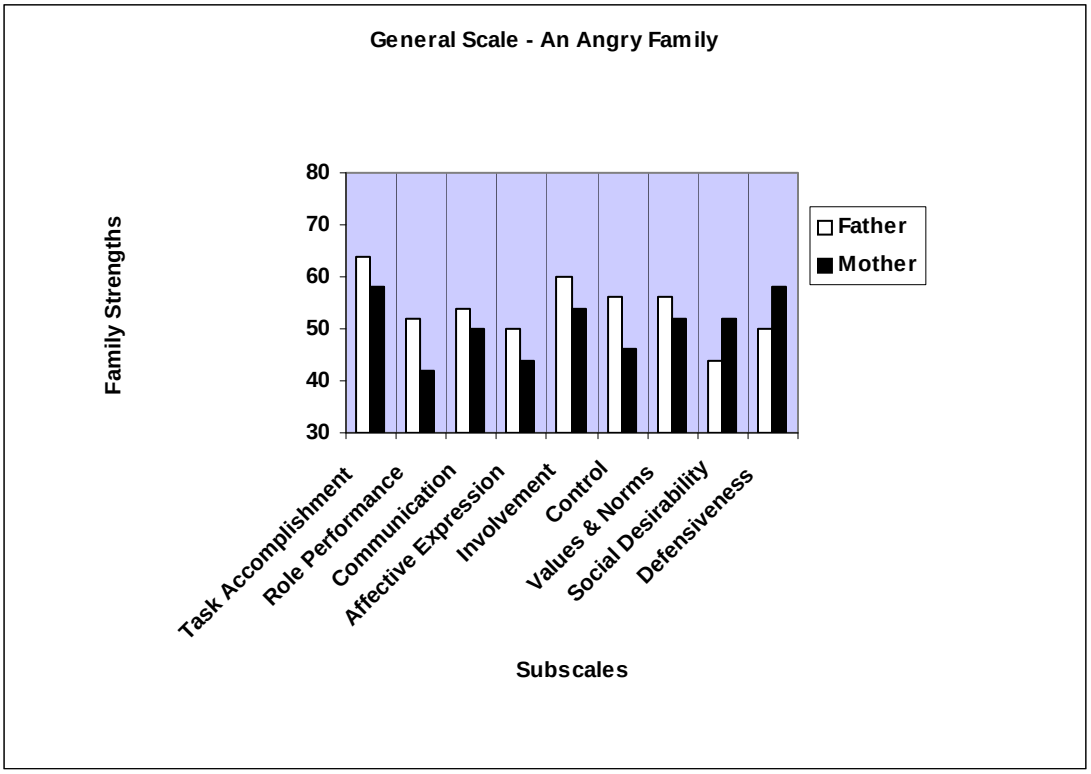

Figure 7.1: FAM-III scores for the different categories of the General scale (Rowan and Lesley)

On the *General Scale* they differed by 10 points on *Role Performance* and *Control;* eight points on *Social Desirability* and *Defensiveness*; six points on *Task Accomplishment,*

Affective Expression and *Involvement*. They only agreed on *Communication* and *Values* and *Norms*. The many discrepancies between their scores on so many areas may suggest that Lesley and Rowan may have differing perceptions as to their family functioning.

Rowan's higher score of 52 on *Role Performance* suggests that he feels dissatisfaction with the differentiation of roles within the family. His high score of 64 on *Task Accomplishment* indicates he may feel that the family unit is not successfully accomplishing basic tasks or adapting to changes in their family life cycle. However, Lesley's score of 58 on this subscale is also bordering on the problematic and suggests she too feels the family is not successfully achieving in this area. Lesley's high scores on both the *Defensiveness* and *Social Desirability* subscales suggests that she may have distorted some of her responses to attempt to portray her family in a more positive light.

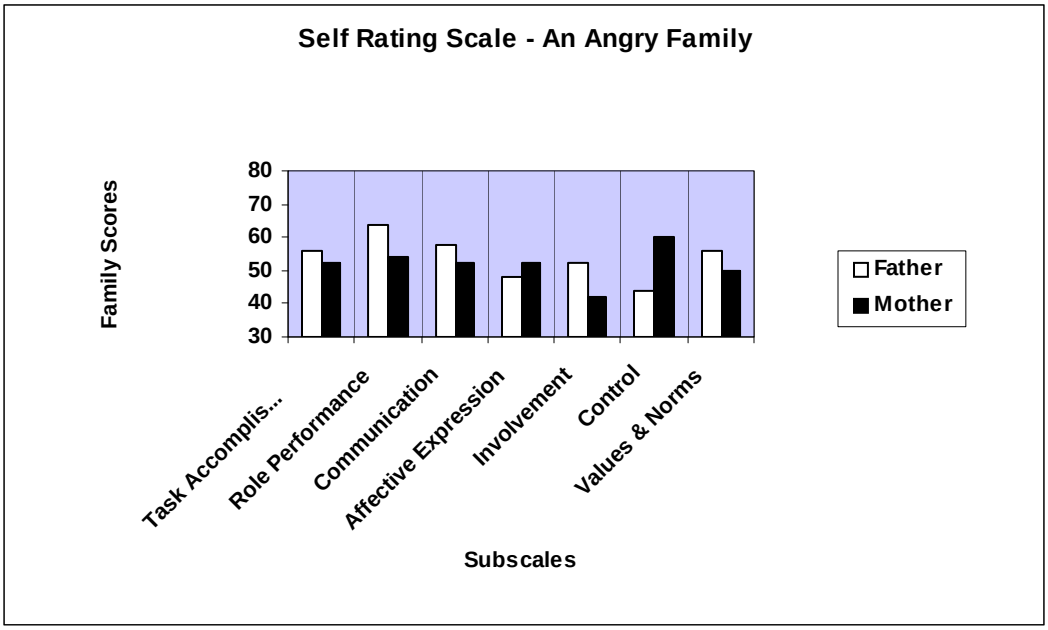

Figure 7.2: FAM-III scores for the different categories of the Self-rating scale (Rowan and Lesley)

On the *Self-Rating Scale,* the Wiltshires differed by 16 points on *Control;* 10 points on *Role Performance* and I*nvolvemen*t; six points on *Communication* and *Values* and *Norms*. Again, these large discrepancies suggest possible areas of marital or personal

conflict. Rowan's high score of 64 on *Role Performance* is highly indicative that he is dissatisfied with this area of functioning and may feel that he is not willing or able to adapt to the new role required in his family system. Lesley's high score of 60 on *Control* is problematic and may indicate that she is unable to adapt to the changing demands of her family system. However, her scores on the other subscales imply that she is satisfied with her general functioning on all other areas.

Rowan's higher score on the *Values* and *Norms* suggests that he may felt that there are certain components of their values system, which are dissonant. His scores indicate that the only areas of functioning he is satisfied with are *Affective Expression, Involvement* and *Control*.

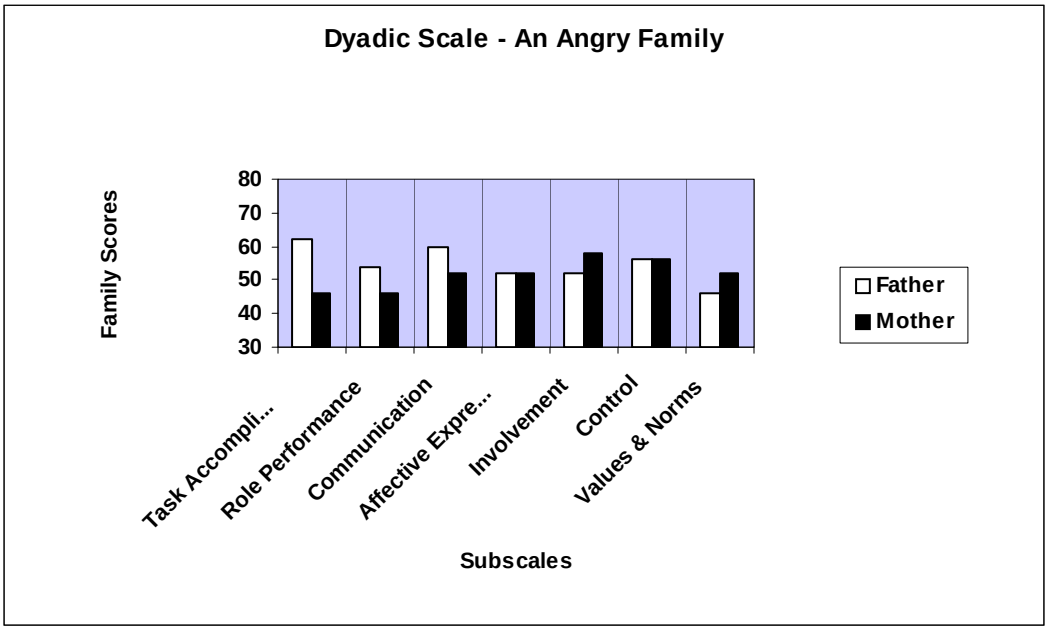

Figure 7.3: FAM-III scores for the different categories of the Dyadic scale (Rowan and Lesley)

On the *Dyadic Scale* they differed by 16 points on *Task Accomplishment* and eight points on *Role Performance* and *Communication* and six points on *Values* and *Norms.* They agreed on the rest. This suggests that certain aspects of their relationship are problematic and there is dissatisfaction with successful task accomplishment, role differentiation and communication. The discrepancy between the values and norms seems to confirm the findings of the other scales, which suggests some underlying

dissonance within their value system. Rowan's score of 62 as opposed to Lesley's 46 on *Task Accomplishment* suggests that it is Rowan who is dissatisfied with the problem solving within the family and the accomplishment of basic family tasks. His higher score of 54 on *Role Performance* appears to confirm the findings of the other scales and suggests that he may feel there is insufficient role integration within their relationship. *Communication* is another area that is problematic for him and indicates that he feels their communication process is not congruent and there is a lack of mutual understanding within this relationship. He appears satisfied with the level of *Affective Expression* and *Involvement* within the relationship.

The elevated result on the dimension of *Control* suggests both members of this marital dyad may feel there is a failure of this system to adjust to necessary changes and control attempts may be destructive. Lesley in contrast appears satisfied with most areas within their relationship but perceives the areas of *Involvement* and *Control* as problematic. This may suggest that she has a higher need for involvement from her relationship and she too may experience the difficulty of the system to adapt to changing needs.

Generally the results on all three subscales indicate that Rowan is experiencing the highest dissatisfaction on most areas within the family unit and marital relationship. However, Lesley's elevated scores on the *Defensiveness* and *Social Desirability* scales suggest her responses may not be valid. A clinical assessment would be necessary to determine the accuracy of these results.

7.5. DISCUSSION

Synergy implies that the Wiltshire family cannot be fully explained by breaking it down into its component parts. Synergy is the combined and concurrent action of components that function in a cooperative manner to achieve a common goal. Together they produce a greater total effect than the sum of the individual effects (Goldberg & Goldberg, 1985). Interactions between family members, which are supportive, and cooperative produces synergy. Rowan and Lesley managed to support each other and functioned successfully as a unit before the birth of their son. However, the added

stress of the addition to the family appears to have resulted in a crisis, as this couple no longer can cope with the pressures of their new and demanding roles.

Relationship refers to the patterns of interaction between two individuals and also the rules governing how they interact (Becvar & Becvar, 1999). Relationship styles and communication patterns may be complementary, symmetrical or parallel. This family style appears to be responsible and consistent but there is evidence of elements of destructive patterns of behaviour. A *complementary* relationship style is evidenced by the repetitive patterns of interaction between Lesley and Rowan. When she gets stressed she tends to 'take it out' on her husband and he responds by being calm, soothing and supportive. *Mutuality* is evident in the patterns of interaction within this relationship. For example, Rowan automatically takes on the supportive role while Lesley expects and elicits this support without realizing that he too has similar needs.

Although Rowan and Lesley share roles and responsibilities there appears to be a resistance to adaptation and change at this stage of their family life cycle. Lesley is unable to compromise her standards to the new situation and the resulting stress, which this increased load brings, appears to be affecting their relationship. She is a perfectionist who maintains high standards for herself and others. This aspect of her behaviour has an effect on her interaction with her husband and other family members. Rowan has assumed a caring, supportive role in his interactions with others throughout his life and has continued this role into his marriage. A dysfunctional pattern of interaction has developed due to their inability to adapt to changing circumstances.

C*ircularity* is evident in the reciprocal interaction between both members of this marital dyad and each persons behaviour is both caused by and the cause of the others behaviour In the reciprocal pattern of interaction, which is evident within this spousal subsystem, the emotional outbursts of Lesley appear to be resulting in increased resentment and withdrawal from Rowan who does not feel he is receiving sufficient emotional support. Most family members develop a unique pattern of relating and communicating so that no matter how an issue begins it tends to end in a similar way (Goldenberg & Goldenberg, 1985). So every time Lesley 'off loads' about an incident the end result is always the same. Rowan will respond with supportive comments and will assure her that he will 'deal with the situation'. Reciprocal causality implies that we

do not study individuals but their relationship and interactive behaviour and the influence each has on the other (Becvar & Becvar, 1996). Therefore, in this family system, Lesley cannot be dependent on Rowan without his cooperation and consent, which encourages this dependence. His overt supportive comments serve to maintain her emotional outbursts and their unique pattern of family functioning. These negative feedback loops then perform a homeostatic function and the status quo is maintained.

Circularity is also evident in the interaction with extended family members and friends. After David's birth Lesley chose to withdraw from interacting with her friends for a while and Rowan therefore explained the situation to them and asked them to be patient. The friends responded by respecting their wishes but the Wiltshires experienced a level of rejection in that no one seemed to discuss David's facial deformity. "All the others tend to look away. To avoid it ". Lesley derives a lot of support from her older sister who is a nursing sister and provided both practical and emotional help. The circularity of affecting and being affected by David's cleft lip and palate is also evident in the relationship between Rowan and his sister-in-law. Although he acknowledges that she provided much positive support he felt rejected in that the focus of this support was on his wife and no one seemed to be aware that he too was in need.

Family adaptability refers to the ability of the family system to change its rules, roles and structure in response to developmental or situational stress (Olson *et al.,* 1983). The Wiltshire family system does not appear willing or able to change at this stage of their functioning to accommodate the developmental crisis, which has resulted from the birth of a child with a facial anomaly.

A family's changing life cycle ensures that a family system must adapt and restructure to ensure that it continues to function in an effective manner. Developmental stress may result if the system resists change and adheres determinedly to its previous structure and manner of interacting and functioning. All families have inherent weaknesses, which may give way when the coping capacity is stretched too far. However, a family system that experiences problems due to a recent transition is easier to help than one which has blocked adaptation behaviour over a long period (Minuchin, 1996). Lesley and Rowan are in an early stage of their personal crisis, which is hopeful for long-term change.

They both agreed to see a psychologist to discuss their current problems and there appeared to be a positive outcome from the sessions.

Feedback loops are servomechanisms that return both positive and negative information back into a system to maintain homeostasis and to trigger necessary change (Goldberg & Goldberg, 1985). *Positive Feedback* occurred when Lesley's sister forced the couple to go out with David and not try and hide his appearance from others. This experience taught them that others are more accepting than they had expected. As Rowan said, "You tend to be ashamed but she showed us not to be". *Negative Feedback* is demonstrated by the fact that the Lesley is still trying to continue with her life and job as it was before the birth of her son. Instead of allowing herself a brief period of adjustment she tries to continue her lifestyle unchanged. By allowing her sister to take responsibility for her life she is also maintaining the old status quo and resisting change in her behavioural patterns.

All families are " a separate subsystem of a larger suprasystem" (Becvar & Becvar, 1999, p. 71). Lesley's sister was the main source of support in the initial few weeks after David's birth. Other family members appear to be having difficulty in coming to accept the situation although Lesley's mother is now more involved in the practical aspects of caring for her grandson. As Rowan said, "She loves to take over and when she comes we can relax". They are generally involved with and supported by their extended family members but they both seem to have difficulties with asking 'outsiders' for help. Rowan feels that most family members have not yet really accepted the situation at this stage as reference to the cleft lip and palate constantly comes up in various conversations. "And that to me is not really over it."

An individual who is *differentiated* becomes "more of a self in his family and other relationship systems" (Kerr & Bowen, 1988, p. 107). Lesley does not appear to have achieved a sufficient level of emotional detachment from her family of origin, as she is extremely dependent on emotional and practical support from her sister and mother. Her sister, who is a midwife, was present at the birth and appeared to take a dominant role in the proceedings, which was viewed as acceptable by Lesley who said, "Yes she was there. That was the best thing".

The birth of a child is a major change in the family unit and the spouse subsystem needs to reestablish roles and functions to meet the new demands. *Boundaries* with extended family and friends need to be renegotiated to accommodate this new parental subsystem. A boundary problem occurs when inappropriate patterns of behaviour are maintained and a new subsystem has difficulty in negotiating new and appropriate rules (Minuchin, 1996). As no one was aware that David was going to be born with a facial deformity, the presence of Lesley's sister at the birth appears to confirm her intrusion into the marital subsystem. As she took over the role of 'husband' at this time, Lesley and Rowan temporarily lost their in-group sense of "us/we". The *boundaries* within this family unit are therefore too loose as they permitted this infringement and those between Lesley and her sister are blurred and indistinct with suggestions of *enmeshment*.

Involvement refers to the ways in which the family members spend time together, are supportive and develop a sense of cohesion (Quatman, 1997). Boundaries both regulate and protect a system as they help keep the elements within intact and cohesive while also permitting interaction with the outside environment. The system loses its identity if the boundaries are too permeable and becomes isolated if the boundaries are too rigid (Goldberg & Goldberg, 1985).

In contrast, the boundaries between Lesley and other subsystems, such as her circle of friends, appear to be rigid and inflexible. She is reluctant to exchange information with 'outsiders' and cut herself off from any contact with her friends for the first two weeks after the birth of her son. As a result, she did not acquire alternative coping skills to help her deal with her crisis. The support from friends was experienced as disappointing but this is likely due to the fact that Lesley distanced herself from their support at the beginning. She says that she finds it a big help to discuss the situation with other mothers at the clinic and both Rowan and Lesley also experienced the staff as immensely helpful and supportive.

Cohesion is defined by Olson *et al., (*1983, p. 80) as "the emotional bonding members have with one another". The overall emotional bonding within this family unit appears too high to the point of enmeshment as Rowan states that although he feels loved he does not feel he gets a chance to be an individual. Resentment develops as Lesley expects support and involvement from Rowan but does not appear aware that he too

has a need for support in return. It is as if her crises take precedence and he must rely on his mother for the necessary nurturance he needs.

This particular family unit presents as stable at this stage but there are strong indications of underlying conflict and resentment and a resistance to change. The difficulty with adapting to their changed circumstances appears to be compounded by the fact that Lesley did not plan to fall pregnant and she was only beginning to adapt to the thought of motherhood when she experienced the added stressor of a child with a cleft lip and palate. As Rowan said, "It wasn't what she'd looked forward to so it set her back another few months".

The Wiltshires have attained a certain level of differentiation in that they are in agreement as to what roles and responsibilities each should fulfill. Research indicates that women who are committed to their work roles experience increased work- family conflict (Barnett & Baruch, 1985, cited in Marshall & Barnett, 1993). Lesley appears to be totally committed to her work and is reluctant to compromise this role to accommodate this crisis period in their lives. As her son is demanding of her time during the day, she expects Rowan to 'take over' in the evening so that she can meet her work requirements. Khan (1964) defined work-family conflict as "a form of interrole conflict in which the role pressures from the work and family domains are mutually incompatible" (cited in Higgins & Duxbury, 1992, p. 391). Both Rowan and Lesley appear to be experiencing this conflict as they attempt to deal with the unexpected pressures of their son's condition.

The process of *Communication* is an important factor to ensure successful *Role Performance* and ultimately *Task Accomplishment.* Negative communication skills prevent family members from sharing their feelings and changing needs (Olson *et al.*, 1983). There are indications that Rowan's communication messages are often distorted and he does not seem able to be totally open and truthful in his interactions with his wife. For example, he agrees that his sister-in-law was very supportive, "She was amazing!" but admitted in the separate interview that she was controlling and dominating and they had clashed during her visit. As he avoids congruent messages, healthy and open communication processes cannot evolve and this couple will remain stuck as they will be unable to develop effective coping abilities and conflict resolution skills. Well functioning

marital dyads have been found to adopt a style of interaction that involves focusing on positive characteristics of their spouse and ignoring negative aspects (Forman, 1988). The presence of stress often causes a problem with the expression of feelings and although both Lesley and Rowan's scores are well within the norm on this area, there were discrepancies between their scores, which may point to potential problems.

Control within a family system has varied forms and this particular family epitomizes the form of "saving the family" (Becvar & Becvar, 1996, p. 359). For example, Lesley tends to 'off-load' her feelings of stress on Rowan and presumes that he will 'take care of it'. Systems theory is not concerned with *why* a problem exists but *what* maintains this problem. In this family it appears that Rowan willing assumption of the supportive role encourages and maintains Leonie's dependence and it is therefore his role to 'save the family'. Frustration develops when individuals within a family system are involved in a futile power struggle to be cared for (Becvar & Becvar, 1996). Now with a change in their family life cycle, Rowan appears to feel tired of the constant role of 'supporter' and 'carer', which he willingly assumed up until this transitional period. He now feels the need to also be cared for and this need does not appear to be met by Lesley.

The values of a family system constitute their ideals to which they aspire and include moral, religious and social aspects. Norms that are unique to a family are all that is or is not considered acceptable to that family unit (Steinhauer, 1984). The shared value system within this family unit appears to be sound although there are suggestions of disagreement in some areas such as religion. The main area of disagreement appears to be related to communication in that Rowan does not feel he can talk openly and freely in front of his wife.

7.6. CONCLUSION

This 'Angry' family unit appear to have many areas of underlying conflict which have surfaced as they face a stressful family crisis which is overloading their coping abilities. The birth of a baby is usually experienced as stressful to most young parents even when the child is planned and happily anticipated. However, an unexpected pregnancy produces an increased level of stress, which is further intensified when the child is born with a birth defect.

To survive and grow from this crisis it will be necessary for both Lesley and Rowan to restructure their family system to adapt to the new demands of this transitional period of their life cycle. To evolve as a stronger family unit it may be necessary for this marital dyad to renegotiate their relationship with extended family members and define clear boundaries. The nature of relationships is defined by the existing communication patterns and effective communication is a characteristic of healthy family functioning (Goldberg & Goldberg, 1985). It is vitally important that this couple learn to recognize destructive communication patterns and develop effective communication skills to enhance their relationship.

Lesley's elevated social desirability and defensiveness scores are likely to have affected her responses on all subscales to a certain extent so a complete clinical assessment would be necessary to determine the accuracy of the responses. However, the interview findings did appear to support the findings of the FAM-III.

This study offered a glimpse of a family who functioned adequately as a couple but who are struggling to accommodate a third family member into their unit.

CHAPTER 8

THE LAWSONS: A DIVIDED FAMILY

8.1. FAMILY BACKGROUND

Karen and Dennis are in their early thirties and have two children. Ryan is seven and Kelly is four years old. Kelly was born with a cleft lip and palate. Dennis is a property developer and Karen runs her own successful business.

8.2. THE INTERVIEWS

I had four separate interviews with the Lawsons, each of which was approximately an hour long. It took many weeks to interview both Karen and Dennis as Karen appeared initially avoidant and there were many excuses as to why we could not meet. She appears to be very much in control and presents as a reserved person who does not show her emotions easily. However, she became very emotional and tearful as she talked of her experiences and eventually we had to terminate the first interview, as she was too overwhelmed to continue the discussion.

I had a combined interview with the Lawsons together in their home, which was much more relaxed although Karen still became tearful and emotional at times. In the final separate interviews I administered the Family Assessment Measure-III (FAM-III). I met Dennis in his office and Karen in her home.

Both children were in bed when I held the second interview and I have only seen photos of them. When I arrived at their home they were both initially rather guarded but relaxed as the interview went along and spoke frankly about their feelings. The response of a family to an outsider is a reflection as to how they generally "negotiate boundaries with the outside world and of what the family wants to project as an image" (Minuchin, 1996, p. 207).

Unlike other couples I had interviewed, Karen and Dennis sat directly opposite each other on couches, which were separated by a coffee table. I was positioned in the center on a single chair, which necessitated me swinging my head between the two to

include both in the discussion. They had moved house two weeks previously and were still in the throes of unpacking. They appear to be a loving couple who care about their children.

There were indications of tension from Karen at times, especially when the discussion centered on her parents-in-law. I also felt that there were moments of underlying resentment towards Dennis when she spoke of having to deal with certain aspects of the operations on her own. She presents as an individual who is striving to be in control of her emotions and appears reserved on first meeting. When she was discussing Jenny Parker's reaction to Peter's cleft lip and palate (Chapter 5), she stated, "I don't think it had less of an impact on me but I think I'm not as emotional as Jenny…I deal with it differently. I don't show it easily."

8.3. INTERACTIVE DISCUSSION

Dennis appears the more outgoing and matter-of-fact of the two and does not appear to be as emotionally affected by the experience as Karen. He states that "not much fazes me in life" and although he felt the initial shock of the facial cleft deformity was bad, he felt there were many more things that could be worse so he could deal with it. When Karen phoned him after her sonar to tell him that the baby had a cleft lip and palate his response was, "Oh, is it only a cleft palate – then that's not too bad." She was devastated by the news but felt that his calm response comforted and reassured her.

Kelly's cleft lip and palate was picked up when Karen had a so nar when she was 32 weeks pregnant. She says she knew there was something wrong as she could hear the gynaecologist telling the radiologist to "Come and sort this out" and she also could see the cleft on the screen as "It was a very big cleft… you could probably put your whole finger in it when she was born." While she was "devastated" at the news she maintains that she is glad she knew beforehand as she could then prepare herself for what to expect.

Both parents feel that the gynaecologist lacked empathy throughout their ordeal and this added to their stress. Karen again seems to be the most affected and traumatized by his manner. When he told her that Kelly had a birth defect he offered her an abortion,

which was just not an option for her. She was further traumatized by the fact that he had promised her that she could have an epidural caesarian section so that she would be awake and able to see the extent of the cleft lip and palate. However, when the time came there were problems with the epidural and the gynaecologist appeared to be only concerned with not keeping the anaethetist waiting. He rushed Karen to the theatre and said, “Sorry, I’ll have to put you under.” Even though she was very distressed she felt no one gave her any support as they all just told her not to cry.

Karen worried that the cleft lip and palate would be severe and, “Am I going to be repulsed?” She also was extremely worried about various issues such as how her baby would cry. “Was she going to sound normal?” How the baby would sound appeared to be a big issue for Karen. She again spoke of it in our second interview and says the first thing she asked Dennis was if Kelly cried normally. Another concern at that time was how Dennis would cope with the situation while she was under anaesthetic. He admitted that although he was prepared he did get a shock. Karen responded with surprise to this statement and said that was the first time she was aware that he had been shocked. “It never occurred to me that you got a big fright!”

Dennis felt that the worst aspect was not the appearance of his daughter but having to see the reactions of family members who also initially reacted with shock. He did not feel critical of their behaviour as he feels it is a normal response even if one is prepared. Karen agreed but said that it hurt her to see people looking at Kelly and felt that when you see it through the eyes of others “You live through it all again.” She maintains that is the reason why they didn’t take Kelly out much during the early months.

The Lawsons agree that it is difficult to deal with comments from people who are uneducated. However, Karen says she is still not sure what is the right thing to say to people in a similar situation. Dennis feels that he has developed empathy and understanding from his experience and now can relate to others who have a disabled child. He says that he is more aware of what such people go through and takes the time to listen to them. Before his daughter’s birth he would think, “Geez, I’m glad it’s not me” and just move on. A colleague has a child with Down’s syndrome and Dennis feels empathy for what he is going through and grateful that their problem with Kelly is not so

severe. He acknowledges that meeting such people has helped him put their situation into perspective.

Karen's mother died when Kelly was two years old and she hinted at relationship problems, which were not fully resolved at the time of her death. Karen said that her mother had "her own issues to deal with and the birth of a grandchild with a facial disfigurement was experienced as 'justice' or 'punishment' on herself for not being a good enough mother." However she loved her granddaughter and did not reject her and was a strong support to both Dennis and Karen in the first two years. She was always available to help out with the children and this alleviated their stress immensely. Her death left a huge void that has not yet been filled. Karen says, "I think I suffered more from losing my mother than any other trauma I've had. Her father remarried when Karen was a child and although they are "not really hands on grandparents" they are becoming more involved as the children get older.

Dennis appears to be close to his mother and he spoke with much emotion when he related how he told her that Kelly had an orofacial cleft. "I think that affected me more than anything else…it was someone I could relate to and let go." While his parents are supportive they do not seem to be as involved as Karen's mother was. The children had spent the night before at their house so that Karen and Dennis could attend a function. Dennis said his parents, "love it" but Karen quickly responded, "They wouldn't like us to take advantage of them." There appeared to be slight undercurrents of tension between Karen and her parents-in-law, which she often hinted at during the discussion. She mentioned that she feels that they think she is too hard on Ryan so they try and compensate.

Karen is very protective towards Kelly. "For someone with no patience, I've got an incredible amount of patience with this little girl." She noted that in most families the father is usually softer on the daughter but in their family it is reversed. Dennis does not feel the same overwhelming need to be over-protective of Kelly and feels that Karen does sometimes spoil her. He therefore tends to be softer on Ryan to create a balance. They both feel that Ryan is quite accepting of the orofacial cleft and the experience has not negatively affected him. Dennis thinks that he has developed awareness and

empathy for others and goes out of his way to help a child who is in need of a friend. “He’s very sensitive.”

I did feel times of underlying tension or resentment from Karen towards Dennis. There were constant comments about the fact that she is the one who must deal with the practical aspects of childcare. In his own words, Dennis is “not very good at blood” so the hospital role tends to fall to Karen. She stresses that it does not bother her and she accepts this role. Dennis admits that he can distance himself to a certain extent by going to work when Kelly is undergoing hospital stays and just go and visit them at the end of the day. “For 15 minutes once a day!” retorted Karen with a laugh.

Karen seemed more affected than Dennis about the appearance aspect of the facial anomaly and didn’t feel comfortable taking her out before the cleft lip was repaired. Dennis responded by saying that it wasn’t an issue to him and she had instant tears in her eyes as she retorted, “Yes…but you were at work. I was….” At a later stage of the interview when we were discussing the future orthodontic operations that Kelly may have to have, she again said that “doesn’t really involve Dennis…. he’ll go to work and I’ll deal with it.” She was quick to then say that she was fine with that situation, as “I wouldn’t want him to be there because he’d be useless anyway.”

Both Karen and Dennis feel their relationship has changed since they became parents. Karen feels she used to be extremely dependent on Dennis but due to her responsibilities as a mother that has changed. Dennis agrees that she has “matured a lot in these past few years with having two children” but he doesn’t think it’s the facial cleft deformity that has caused this growth as much as parenthood in general.” Karen feels that if they didn’t have children at all “I’d have grown up anyway.” They both agree that they would like to spend more time together alone as a couple and enjoy it when such an occasion presents itself. They both feel they have a lot in common and still enjoy doing things together.

8.4. FAM-III RESULTS

Karen and Dennis were shown a list of statements and asked to rate their level of agreement with each statement. I administered the FAM-III to Dennis in his office and Karen in her home when I held the separate interviews.

Scores on the following dimensions were compared:
Task Accomplishment; Role Performance; Communication; Affective Expression; Involvement; Control, Values and Norms.

8.4.1. Task Accomplishment

Successful *Task Accomplishment* enables a family to achieve a variety of goals, which ensure family security, development, and autonomy of members and enables them to meet their environmental demands (Steinhauer *et al.,* 1984). There were large discrepancies on all three scales in this area, which is suggestive of differing perceptions in *Task Accomplishment* and problem solving between both members of this marital dyad.

Within the Lawsons family, the role of *Task Accomplishment* appears to be problematic in certain areas. Dennis had a rating of 64 on his *General Scale* (Figure 8.1) which suggests that he perceives his family unit as failing to achieve certain developmental tasks which are essential to it's achievement of basic objectives. He felt that they spend too much time arguing about their problems and it takes too long to work things out when things aren't going well (Items 1 & 31). Karen's score of 54 suggests that she feels the basic tasks for the family members to function effectively as positive members of society are satisfactorily met. They both agreed that they let problems pile up but they do try different ways of solving problems (Items 21 & 11). Dennis presents as a pragmatic individual who deals with problems in a practical, unemotional way. This was apparent in his reaction to the news of Kelly's orofacial cleft when he responded by saying, "Oh! Is that all? I thought it was worse".

Karen's higher score of 58 on the *Dyadic Scale* (Figure 8.3) is bordering on the problematic and indicates that she is less satisfied with *Task Accomplishment* within her

relationship. She agreed with her husband that they do see family problems the same way (Item 1) but felt that he does not help her enough when she has a problem and neither does he find a new way of finding a solution to a problem between them (Items 15 & 22). In the combined interview, Karen often commented on the fact that she has to cope with the medical issues alone as "…he'll go to work and I'll deal with it". Dennis acknowledges that this is true as he says, "She can cope with that sort of thing and I can't". However there are indications of underlying resentment on Karen's part at have to shoulder the major burden of the care. When Dennis said that he visited Kelly and Karen in the hospital after work she responded, "For 15 minutes a day!"

Karen's high score of 62 on the *Self-Rating Scale* (Figure 8.2) again reflect her dissatisfaction with this aspect of family functioning and may be indicative that she is frustrated with her own performance in this area. She disagreed with Dennis that they usually see family problems the same way and acknowledged that she has difficulty accepting someone else's answer to a family problem (Items 1 & 15). During the interview she was quick to stress that although the children spent the previous night at their grandparents it was not a regular occurrence and was due to the fact that they had just moved house. "If we'd been at the old house they'd have stayed at home". Both members of this dyad stated emphatically that they could be depended on in a crisis (Item 36).

8.4.2. Role Performance

Roles are "prescribed and repetitive behaviours involving a set of reciprocal activities with other family members" (Steinhauer *et al.,* 1984, p. 79). Dennis and Karen appear to successfully manage role differentiation and performance and they were in general agreement on most of the items on the *General* (Figure 8.1) and *Self-Rating Scales* (Figure 8.2). They acknowledged that they were in agreement as to who should do what in the family (Item 22 - *Genera*l S*cale*). They also agreed that they did not feel too much was expected of them (Item 2 – *Self-Rating Scale*). Dennis states he cannot cope with the practical realities of hospital care and Karen therefore assumes this role although there are indications of underlying resentment.

Although the results of the *Dyadic Scale* (Figure 8.3) were well within the norm, the 12-point discrepancy is indicative of possible problems in this area and Dennis's lower score suggests that he is more satisfied with role performance within this relationship. Dennis felt strongly that Karen takes her share of family responsibilities and does not expect too much of him. In contrast she felt that he does not take enough responsibility and *does* expect too much of her (Items 9 & 16).

These findings were confirmed during the interview where Dennis often praised Karen for her ability to cope with the medical issues which he could not deal with. "My wife is an absolute star". At times Karen hinted that she felt her husband does not take enough responsibility by saying that she was the one who had to deal with the reactions of strangers as he went off to work and she had to cope with the situation. When she referred to future medical procedures she again said, "That doesn't really involve Dennis. It's my problem".

Healthy relationships require a balance of power (Lauer & Lauer, 1997). There appears to be an uneasy consensus as to which roles each parent fulfills to ensure that they both assume necessary responsibilities for the survival of their family unit.

8.4.3. Communication

Communication can be described as "everything which one does to attempt to influence another's action and experience of the world" (L'Abate, Ganahl, & Chansen, 1986, p. 150). The results of the *General Scale* indicate that this couple is in accord as to the apparent success of their general communication process. They agree that family members always received straight answers, they know what is going on within the family and all family members are allowed to have their say (Items 3, 23 & 43).

Their scores on the *Dyadic Scale* (Figure 8.3) suggest Dennis may not be totally satisfied with the communication process within their relationship. He felt that Karen sometimes takes what he says the wrong way (Item 10 – *Dyadic Scale*). They agreed however, that their partner is available when they wish to talk (Item 24 – *Dyadic Scale*). Dennis's elevated score on this subscale may suggest that he is not totally satisfied with the communication process within their relationship. When he acknowledged that his

initial reaction to Kelly's facial anomaly was one of fright, Karen was totally surprised, as she had never heard him say that in the four years since the birth. "I realize now that maybe Dennis wasn't as prepared as I was". As a couple they appear not to discuss certain issues and when I asked them if their relationship had changed since their experience she responded by asking her husband, "I don't know. Did it?"

Karen's high score of 68 on the *Self-Rating Scale* as opposed to Dennis's 52 (Figure 8.2) is problematic and suggests that she may have concerns with her own ability to effectively communicate her wishes and she may experience an inability to seek clarification in case of confusion or may feel her ability is insufficient or masked. She stated that her family does not always know what she means when she says something, she often cannot find the words to say what she would like and she is not always available when other want to talk (Items 3, 24 & 31 – *Self-Rating Scale*).

The results of her communication difficulties on the *Self-Rating Scale* were confirmed in the discussion where there were indications that their communication is somewhat distorted at times and they are not always open in their dealings with each other. Incongruent communication results when individuals do not send each other straight messages (Becvar & Becvar, 1996). For example, Karen appeared to be resentful during the interview when she stated that she has to take on the heavier responsibility of the medical procedures but she then counteracts this by saying that, "I wouldn't want him to be there because he'd be useless anyway." For a marriage to thrive it is essential that both spouses must "have or learn good communication skills" (Lauer & Lauer, 1997, p. 256). When reference to her parents-in-law came up in the discussion there was underlying tension in her responses and she distanced herself from them to a certain extent, "I didn't notice with Dennis's family. He knows how they should react. I don't".

This aspect of the test had a number of conflicting responses. Dennis felt that Karen takes what he says the wrong way (Item 10 – *Dyadic Scale*) and Karen felt that Dennis does not help her when she has a problem (Item 15 – *Dyadic Scale*). Karen also felt they did not take time to listen to each other (Item 33 – *General Scale*). Both members of this dyad appear to send and receive conflicting messages in their verbal and nonverbal communication behaviour. Their shared messages, and particularly Karen's messages to her husband, do not encourage mutual understanding and shared meaning. There

are suggestions of underlying conflict in certain areas of their relationship in that Karen maintains that she does not expect Dennis to take a more active child-caring role but sends covert messages that she would like it. For example, when she was discussing the necessity to discuss the issue of the cleft with the children she said, "Dennis doesn't think about it…but I think it's important that every so often you do that so ….so they don't ask you a question that catches you unawares".

8.4.4. Affective Expression

Affective Expression is an essential element of the communication process and includes the content, strength and timing of feelings (Skinner *et. al*., 1995). If A*ffective Expression* is sound it can aid in *Task Accomplishment, Role Performance* and the *Communication* process. However, distorted or blocked expression of feelings can impede these processes and the presence of stress often causes a problem with the expression of feelings. The results of the *Dyadic Scale* (Figure 8.3) suggest that Dennis and Karen are satisfied with the expression of affect within their relationship. However Dennis's elevated scores on the S*elf-Rating* and *Dyadic Scales* (Figures 8.2 & 8.3) and the discrepancies between their scores suggest that he feels that there are problems in this area.

He stated that he did not always know if someone in the family was upset or angry (Item 4 – *General Scale*). He also stated that he did not feel his family knew what was bothering him when he was upset and admits he keeps it to himself if someone has upset him (Items 4 and 11 – *Self-Rating Scale*). Karen agreed that she does not get over things quickly (Item 18 – *Self-Rating Scale*).

In the combined interview she expressed surprise when Dennis said he had "a fright" when he first saw Kelly after the birth and up till then she had been unaware of his reaction. It has been found that in well-functioning families "both spouses are satisfied with the expression of affect that exists between them." (Greef, 2000, p. 959).

8.4.5. Involvement

Involvement refers to the quality of relationships within the family and may be either supportive or destructive (Steinhauer *et.al.,* 1984). The results of the FAM-III suggest

that this couple is satisfied with the level of *Involvemen*t they experience within their family unit and each perceive their own behaviour as nurturing and supportive. They both agreed that family members are allowed to be individuals and feel loved (Items 6 & 16 – *General Scale*). They also agreed that they care for their family (Item 26 – *Self-Rating Scale*).

However, there is an eight-point discrepancy between their scores on the *Dyadic Scale* (Figure 8.3) and Dennis's higher score indicates dissatisfaction with the *Involvement* he perceives within his marriage. He stated that Karen does not always trust him and she worries too much about him although he admits they are close and she cares when he is upset (Items 33, 40, 5 & 12 – *Dyadic Scale*). Again Karen does not appear to be aware of a problem and appears to be satisfied with the involvement generally and within her relationship with her husband. She stated that she feels Dennis loves her even when they argue (Item 19).

When asked in the interview how their relationship had changed after the birth of Kelly, Karen stated that, "We do a lot of things together. We have lots in common. It's not as if we…" She did not however give an example of what they actually have in common and Dennis immediately interrupted to justify that they rarely have a chance to spend time together due to the demands of parenthood.

There are suggestions that he feels a lack of involvement from Karen and may feel his emotional needs are not being fully met. While they both acknowledge that she is no longer so dependent on him and he may sometimes experience feelings of rejection, they dealt with this in a joking manner, "Oh, So you don't need me?"

8.4.6. Control

"Control is the process by which family members influence each other" (Skinner *et al*. 1995, p. 2). Family styles differ as to whether they are consistent or inconsistent, constructive or destructive, responsible or irresponsible in their functioning.

Karen's scores on these scales are well within the average, which suggests that she feels the family can adapt to changing demands and the family interaction is constructive

but flexible when the occasion warrants. Dennis's high score of 66 on the *General Scale* (Figure 8.1) and 60 on the *Self-Rating Scale* (Figure 8.2) contrasts strongly with his score of 48 on the *Dyadic Scale* (Figure 8.3). This may indicate that he does not see the family unit as adapting to changing demands and there may be overt or covert power struggles within the family unit.

As this couple was in agreement in their responses on the *Dyadic Scale*, the implication is that they are satisfied with the level of control within their marriage. They acknowledge their partner is reasonable when they make a mistake and they know how he/she will react (Items 6 & 20 – *Dyadic Scale*). There was a discrepancy of 10 points on the *General Scale* and Dennis's high score of 66 suggest that perceives problems in this area within his family unit. There was a six-point discrepancy on the *Self-Rating Scale* and again Dennis's higher score falls within a problematic range. Karen admits that she gets angry when others don't do what she wants (Item 13 – *Self-Rating Scale*) and Dennis admits that he is not as responsible as he should be (Item 27 – *Self-Rating Scale*). In his response to the *General Scale* Dennis stated that you don't know what to expect when you do something wrong (Items 17).

8.4.7. Values and Norms

Values of a family incorporate moral, religious, personal and social issues. Each family develops unique rules relating to acceptable behaviour to sustain their value system (Steinhauer *et al.,* 1984).

There are suggestions that Karen and Dennis's differing scores are in sync although there are certain discrepancies between certain responses. Generally both members of this particular dyad are in agreement as to the value system within their family unit. They believe they have the same views on what is right and wrong and family members are free to say what they think (Items 8 & 48 – *General Scale*).

While still within the norm, Karen scored six points higher on the *Self-Rating Scale* (Figure 8.2), which may suggest that she experiences certain components of their value system as dissonant. She agreed that she does not argue with family members about the importance of religion but stated that she thinks education is more important than

other family members do (Items 7 & 14 – *Self-Rating Scale*). This couple's results on the *Dyadic Scale* (Figure 8.3) were elevated although Karen's was just out of the norm, which suggests that they both may have conflicting feelings about their relationship value system. They both agreed that their partner is right about the importance of religion but Karen felt that there was sometimes a difference between Dennis's behaviour and what he expected from her (Items 42 & 35 – *Dyadic Scale*).

8.4.8. Social Desirability

The Lawsons scored well within the norm on this subscale, which suggests that they did not attempt to distort their responses to ensure that the family is reflected in a more positive light. They both agree that some families could get along better than theirs and their family could be happier (Items 9 & 19 – *General Scale*). Dennis stated their family was as well adjusted as any family could be and there are no things within the family that displeases him (Items 5 & 39). Karen presented as particularly honest and truthful in her responses during the interviews and acknowledged that it was difficult for her to take Kelly out in the early months to face the scrutiny of strangers. She spoke of an incident when she apologized to a customer because her daughter had a cleft and he responded with anger to her assumption that he would be shocked by the facial anomaly. She also freely admitted that she was afraid that her initial viewing of her child after the birth might repulse her.

8.4.9. Defensiveness

Again both Karen and Dennis scored well within the norm on the *Defensiveness* sub-scale, which appears to confirm the findings of the S*ocial Desirability* subscale and indicates that they do not feel the need to portray the family in a more favourable manner.

Both members of this dyad admitted that they are more easily annoyed on some days and sometimes they are unfair to each other (Items 10 & 20 – *General Scale*). However Dennis felt that family members always admit mistakes without hiding anything while Karen felt that they never let other family members down (Items 45 & 50). The only indication of any defensive behaviour was when Karen was discussing their marital relationship. "We do a lot of things together".

These discrepancies may indicate that this couple may not always share a common perception of their family. "A 10 point differential between how two family members rate the same aspect of family functioning the more likely the discrepancy is to be clinically relevant" (Skinner *et al*. 1995, p. 25). Many of Karen and Dennis's scores on various scales differ by 10 points or more, and others differ by five points or more, which is an indication of marital tension. By contrasting the *General, Dyadic* and *Self-Rating* scores we can compare how the individuals perceive both the family and his/her own functioning.

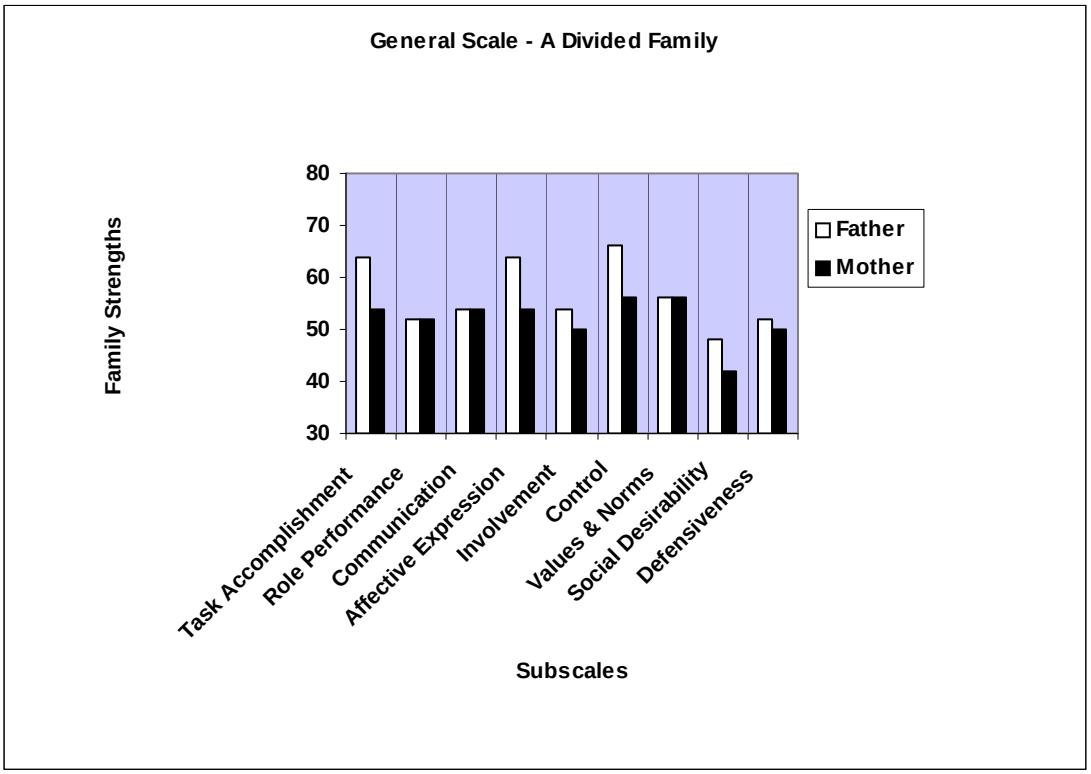

Figure 8.1: FAM-III scores for the different categories of the General Scale (Karen and Dennis)

On the *General Scale* they differed by ten points on *Task Accomplishment*, *Contro*l and *Affective Expression* and differed by six points on *Social Desirability*. They agreed on the rest. Dennis's scores of 64 (*Task Accomplishment*) and 64 (*Affective Expression*) suggests that he feels the family may not be satisfactorily resolving problems and also that members don't deal successfully with their feelings. His high score of 66 on *Control* suggests that there is conflict here and possible power struggles. The discrepancy

between the scores may point to the fact that the Lawsons may have differing views as to how well the family solves their problems and how well they actually meet each other's emotional needs.

Karen appears to be satisfied with how she perceives family functioning on the general scale although she rates *Values* and *Norms* as a possible potential problem. This may suggest value conflicts between the two, which may not be overtly expressed.

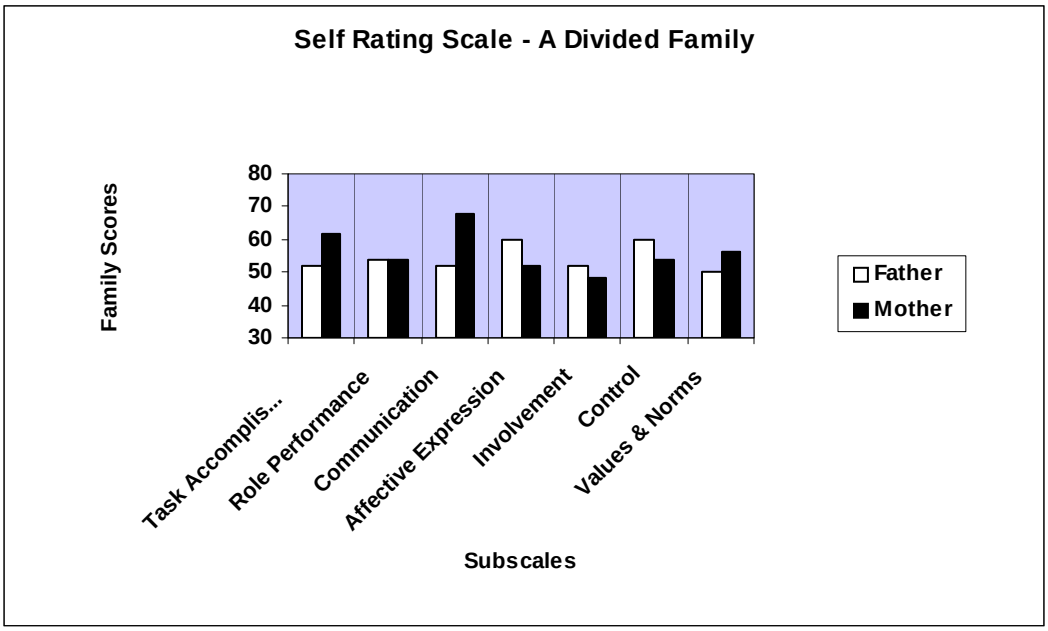

Figure 8.2: FAM-III scores for the different categories of the Self-Rating Scale (Karen and Dennis)

On the *Self-Rating Scale* Karen and Dennis differed by 16 points on *Communication* and 10 points on *Task Accomplishment*. Karen's high scores on these two areas suggest that she rates her functioning here as problematic. They differed eight points on *Affe*ctive *Expression* and six points on *Control* and *Values* and *Norms*. Dennis's elevated scores of 60 on *Affective Expression* and *Control* suggest he may be struggling over certain control issues and feelings of rejection or alienation. Karen's higher score on the *Values* and *Norms* suggests that she may felt that there are certain components of their values system, which are dissonant, and results in feelings of tension.

Her high scores indicate that she is not satisfied with her personal *Task Accomplishment* (62) and *Communication* (68). This could imply that she feels unable to adapt appropriately to changes and minor stresses may precipitate a crisis. She may also feel unable to identify appropriate tasks and generate possible solutions. Dennis's scores indicate that he is satisfied with his functioning generally although there may be problems with the areas of *Affective Expression* and *Control*.

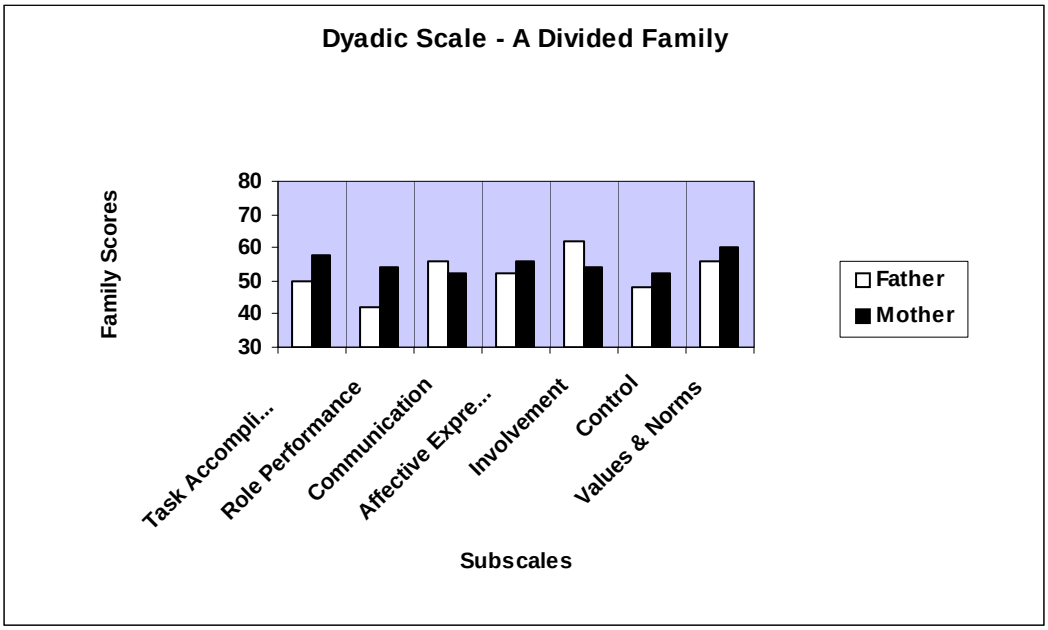

Figure 8.3: FAM-III scores for the different categories of the Dyadic Scale (Karen and Dennis)

On the *Dyadic Scale* they differed by twelve points on *Role Performance* and eight points on *Task Accomplishment* and *Involvement* and agreed on the rest. This suggests that certain aspects of their relationship are problematic and there is dissatisfaction with the level of involvement and possible feelings of alienation. Dennis's lower scores on R*ole Performance* and *Task Accomplishment* suggests that it is Karen who is dissatisfied with the problem solving within the family and does not feel that her expectations are being met. Dennis appears to be discontented with the emotional distance within their relationship.

8.5. DISCUSSION

The focus of family systems theory is that an individual is not an isolated being but lives and interacts as part of a social group and his interaction with his environment determines his experience. The family is a social group and as a member of such a group, the individual member influences and is influenced by this context (Minuchin, 1996). There is evidence of both complementary and symmetrical exchanges taking place within this particular family system, which suggests a 'parallel' style of interaction. Karen is the more emotional individual in this relationship and Dennis has a practical, analytical approach to most issues. As he states, "Not much fazes me in life anyway". An example of a symmetrical exchange would be the fact that they both love their children and take good care of them. However, there are indications of competitive aspects in their relationship where their individual actions influence the reactions of their partner in a spiraling effect. For example, Karen tends to spoil Kelly so Dennis reacts by being softer on Ryan.

Kaslow (1982) maintains that a healthy family exhibits a sense of mutuality, a clear and definite structure, shares roles and responsibilities and is open to change (cited in Becvar & Becvar, 1996, p. 125). On the surface, both Karen and Dennis appear committed to their marriage and family and accept the practical responsibilities that being the parents of a child with a facial deformity entails. They have both ensured that they are informed as to future medical procedures and are committed to providing Kelly with all necessary care and treatment.

In a study of families that had adapted well to the birth of a child with disabilities it was found that they enjoyed "a high satisfaction with the involvement and support exchanged with extended family members" (Trute & Hauch, 1988, p. 191). Karen and Dennis experienced help and support from immediate family and friends, which eased the adaptation process. As Dennis said, "Everyone knows…so it's not like it's a big gawping episode". At times they had to contend with hurtful comments from acquaintances. As Karen said, "You get some very ignorant comments". But generally they maintain that the experience allowed them to develop and grow and they acknowledge that they now are "more aware" of the feelings of others in a similar situation.

Adaptability refers to the ability of the marital and family system to change (Olson *et al.,* 1983). This particular family system succeeded in remaining apparently stable while undergoing necessary change and to also adapt to their unique situation. Although they were both initially shocked when they were informed of their daughter's condition, they adjusted to the new demands and dealt with each problem in an appropriate manner. As all parts of a system are interconnected change in one component results in change in all other components. (Bloch, 1984). Competent parenting encourages growth and development but unresolved conflicts may intrude into the parental subsystem when a couple cannot adequately separate spouse and parenting functions (Minuchin, 1996).

When Karen and Dennis first formed their marital unit, she was very dependent on him for emotional and practical support. But she had to change to meet the demands and needs of her children and her increasing independence resulted in a reciprocal change in her husband's attitude to her. "She has more pressing things to worry about". Autonomy and independence are overtly encouraged and both members of this dyad regard Karen's maturing as a positive factor. On the surface they present as a strong spousal subsystem with a well functioning family structure but at a deeper level there are indications of distrust, disengagement and evidence of a divided family. It is not apparent that this couple supports each other's functioning in all essential areas, which appears to be confirmed by the results of the FAM-III, particularly in the areas of *Affective Expression, Involvement* and *Control*.

Dennis states that he finds it more difficult to cope practically with a daughter and found it easier to parent his son. "Because I can relate to him…she's just too frail or whatever". He says that Karen in contrast copes better with her daughter. "She's softer on Kelly and she has no patience with Ryan and I think she sometimes spoils Kelly". They both agree that as a result of this dynamic that has developed they each are softer on one child and harder on the other to compensate.

The *boundaries* of a system "are the rules defining who participates and how" (Minuchin, 1996, p. 53). Each subsystem can only function effectively and develop specific role appropriate skills if it has clearly defined boundaries, which permits contact with other subsystems but does not allow interference. The Lawsons present as an *open system* in that they appear to have relatively flexible, permeable boundaries, which permit

transactions with their external environment. According to Fingerman & Bermann (2000) the family of origin continues to exert an influence over individual family members long after they have reached adulthood. Although this family system interacts with external subsystems in an open manner, there are suggestions of *disengagement* between Karen and her in-laws. There was underlying tension and defensiveness when she spoke of them during the interview and while Dennis seems to be close to his mother, Karen seems to feel that they are critical towards her. "I think they think…. I'm too hard on Ryan". She distanced herself from them by saying she did not know how they reacted to the news of Kelly's birth defect. "I didn't notice with Dennis's family. He knows how they should react. I don't". Dennis never reacted to her thinly veiled criticism of his family but spoke warmly of his mother and said that telling her of the cleft "affected me more than anything else" as he could relax, relate openly to her and know he would get support.

The boundaries between this particular spouse subsystem and the children subsystem within the family unit appear blurred and poorly defined. A functional spouse subsystem is characterized by mutual accommodation and supportive patterns of interaction (Minuchin, 1996). In this divided family the children appear to intrude into the spousal subsystem functioning. Karen appears over-involved with the care of her daughter and indifferent to her son while Dennis presents as disengaged from both his wife and daughter. During the discussion there was no evidence of a closeness between Kelly and Ryan and it is likely that the existing blurred boundaries present within this family system has had a detrimental effect on the sibling subsystem.

Two separate parent-child alliances comprising the mother and daughter and father and son appear to be present within this family unit. When the emotional distance between two people becomes too intense or distant, one member may attempt to restore the equilibrium to the system by means of triangulation. Triangulation is a process, which generally develops during periods of heightened stress when "one member of an unstable dyad will turn to a third person to secure additional support" (Lastoria, 1990, p. 47). This process allows a constructive balance within the family system to be maintained and acts as a stabilizing influence on the marital relationship (Lastoria, 1990). It is possible that Karen has become over-involved with her daughter in an attempt to gain a sense of closeness or control within her marriage. Although she states

that she has a close relationship with her husband she appears to have a need for understanding and support, which he is unable or unwilling to provide. When she speaks of her parents-in-law's lack of support he negates her covert message and says they are "wonderful". There is evidence of disengagement in their relationship as Dennis constantly under reacts to her pain and feelings. His response to her news of their daughter's cleft lip and palate was "Oh, is it only a cleft palate – that's not too bad". A healthy spousal subsystem supports members on practical, financial and emotional levels. Within this family unit there is evidence that there is a lack of emotional involvement and this couple appear to be emotionally disengaged.

Individuals, who are differentiated, retain their individuality while still being part of the family and are more self-sufficient and not as dependent on others. Differentiated individuals are more likely to successfully "weather the storms of life" (Lastoria, 1990, p. 46). Both Karen and Dennis state that she has matured since she has become a mother and is now "less dependent on Dennis". Karen acknowledges that she used to be totally dependent on her husband before the children were born and used to cry when he was late coming home. Although she has developed since then, there are strong indications that she is still very dependent on Dennis for emotional support despite both members of this dyad's claim that she has "grown up".

Differentiation implies that an individual has achieved a healthy level of emotional separation from the family (Kerr & Bowen, 1988). However there are suggestions that Karen has not yet fully differentiated from her relationship with her mother as she states, "I think I suffered more from losing my mother than any other trauma I've had". She appears to have transferred this pattern of interaction into her relationship with her husband and daughter and seems to need his constant reassurance that things are going to be all right. For example, she was devastated when she was told that Kelly was going to be born with a cleft lip and palate but Dennis's "practical, down to earth" response calmed her and made her realize the problem was not insurmountable. There are also indications that her over-protective behaviour may encourage the development of a similar dependent relationship with her own daughter.

"C*ircularity* refers to the "reciprocal, multi-directional relationship that occurs between individuals and systems" (Jonsson Jones, 2001, p. 109). As a result of Kelly's cleft lip

and palate, Karen found that she is much more patient in her mothering of her daughter. Dennis feels that his wife is too lenient in her attitude towards Kelly and as a result he feels that he must balance this by being 'softer' in his approach to disciplining his son. This circularity also extends to the sibling subsystem as both parents feel that Ryan, Kelly's older brother, has also developed an empathy and understanding for children who are in some way disadvantaged.

Circularity is also apparent in the interactions with extended family members, friends and acquaintances. Dennis experienced a feeling of acceptance and support from his mother when he told her of his daughter's facial cleft deformity and felt he could "relate and let go". The initial reaction from family members was one of shock and Dennis says the experience through their eyes was "…seeing it again and again". Circularity was also evident in the many guilt feelings experienced by Karen's mother as a result of her granddaughter's cleft. However, she adapted to the situation and Karen derived a comfort from the support and constant practical help she received from her mother.

Feedback is a process whereby information regarding past behaviour is fed back into the system and results in change or maintenance of the status quo. *Positive Feedback* encourages change and indicates that the system has accommodated this change (Becvar & Becvar, 1996). It occurs when Karen takes Kelly to her business and as a result of her interaction with a customer realizes that she should not hide her child from the reactions of strangers. Change as a result of *positive feedback* also occurs when Dennis interacts with empathy towards a parent who has a child suffering from Downs Syndrome and Ryan exhibits compassion to less fortunate children. The *positive feedback* resulted in an increased empathy in all members of this system towards others.

Negative Feedback maintains the status quo of the system and is evident by Dennis's reluctance to overcome his avoidance of involvement in both the medical procedures and Karen's emotional pain. As Karen deals with that aspect of the family responsibility he chooses to be less involved in the practical care as he says, "she can cope with that sort of thing and I can't". In response to his attitude she maintains that it suits her and she "wouldn't want him there because he's be useless anyway". The inability of this spousal subsystem to communicate in an open, honest manner regarding their feelings

about the appearance of their daughter inhibits involvement and an appropriate expression of affect and maintains the status quo of disengaged individuals. By focusing on Kelly's cleft lip and palate, this couple continues to avoid dealing with deeper, underlying conflict within their relationship.

Communication within this family unit does not appear to be open and there are indications of underlying conflict. Karen assumes the greater responsibility of childcare and maintains that she is content with the situation, "I wouldn't want him to be there because he'd be useless anyway". However, other comments she makes and her emotional reaction tends to suggest that this is not a true reflection of her feelings or wishes. When Dennis stated that taking Kelly to the shops was not an issue for him, she responded with tears in her eyes, "…you were at work. I was…" Dennis too avoids dealing with her covert messages and instead chooses to ignore them. For example, he presents his parents as warm, supportive grandparents and ignores his wife's comments, which contradict this impression.

Listening and supportive comments and problem solving skills are all positive communication behaviours that encourage family members to share their needs and feelings (Olson *et al.,* 1983). Although Kelly is now four years old, Karen was unaware of the depth of Dennis's experience and feelings until he verbalized them during our discussion, which suggests that such issues are never explored. "It never occurred to me that you got a big fright". Dennis's high scores on *Affective Expression* on the FAM-III scales indicate that he is dissatisfied with the expression of affect he experiences within this family unit and it is possible he does not feel supported or nurtured. This seems to be confirmed by the fact that the only time he showed strong emotion was when he spoke of telling his mother of his daughter's cleft lip and palate.

The results of the FAM-III indicate that both members of this dyad are generally satisfied with the communication process within their family and relationship. However, Karen scored extremely highly on the *Self-Rating Scale,* which suggests that she feels her personal communication behaviour is problematic. On first meeting she presents as an individual who is in control of her emotions and has no wish to communicate her feelings. However, when she felt comfortable in the interview situation she immediately dropped her mask and became very tearful and emotional when describing her

experiences. This appears to confirm other findings that she has not achieved a high level of differentiation and emotional detachment in her behaviour.

Spouses in well-functioning marriages have been found to attribute positive behaviour to each other (Forman, 1988). Both Karen and Dennis do appear to care for and support each other and they both made many positive references to their partner throughout the discussion. However, there was no real indication that they share their deeper needs and feelings with each other. Dennis's high scores on *Affective Expression* also suggest that he may be dissatisfied with his own ability to truly express his feelings. He admits on this subscale that when he is upset he keeps it to himself and his family does not know what is bothering him (Items 11 & 4). The fact that Karen never knew the extent of his shock when Kelly was born and how well he actually coped with the traumatic situation confirms his inability to share many feelings.

Both members of this marital dyad feel they share a sense of commitment and responsibility towards their family system. The discrepancy between their scores on the *Self-Rating Scale* suggests that Karen may feel there are certain areas, which are dissonant. She acknowledged that she has feelings of insecurity in social situations and he admitted that she does not always trust him, which seems to confirm her fears.

With the birth of their first child, this couple seemed to adjust to parenthood and restructured their family unit to accommodate the new member. However with the birth of their second child the rules changed and they formed coalitions. These coalitions negatively affected the spousal system, which resulted in a loss of integrity.

8.5 CONCLUSION

This family did not cope well with a child with a facial deformity. The family structure and functioning changed significantly with the birth and the spousal subsystem lost it's integrity as the mother formed a coalition with her daughter and the father formed a strong coalition with his son. The Lawsons presented as a divided family unit and it is clear that both Karen and Denis's emotional needs are not being met.

Karen is still very emotionally affected when she discusses her daughter's cleft lip and palate and the necessary medical procedures to correct the anomaly. She stresses how worried she is about future treatment her daughter must undergo and therefore justifies her 'softer' approach in her parenting of her daughter. She is aware that she is less patient with her son and although she states that "I hope it's not going to be detrimental in the long run" she does not appear concerned about the effect on her son as all her concentration is focused on her daughter.

It is likely that this family's avoidance of dealing with underlying conflict and unfulfilled needs may be problematic at a later stage of their family life cycle.

CHAPTER 9

CONCLUSION

9.1. INTRODUCTION

In the previous five chapters, I focused on the impact that the birth of a child with a cleft lip and palate has on five separate families. In this chapter I will integrate all the findings of the separate case studies as well as the FAM-III scales, and discuss them in relation to family systems theory. I will also relate my findings to the aims of this study as set out in chapter 1.

9.2. FAMILY STRUCTURE AND FUNCTIONING

The results of the FAM-III and the interviews reflect the different ways each couple deal with issues relating to family structure and functioning. All the husbands appear to be the main breadwinners, although as both Karen and Lesley run their own full time businesses it is to be presumed that they make an equal financial contribution. Jenny works part time and Ansie and Laura have chosen to be full time mothers at this stage of their family life cycle. Although all the families share the responsibility for childcare, the heavier burden appears to fall on the shoulders of the wives. The full time mothers who do not have work responsibilities are satisfied with this arrangement but the wives who have the added responsibility of work commitments appear to have a certain level of dissatisfaction. All individuals did however acknowledge that their partners do take sufficient responsibility. In her response to the FAM-III subscale, Karen indicated that she did not feel family duties were equally shared and she is expected to do more than her share. Interestingly, both Andrew and Rowan also felt their share of family duties was disproportionate.

As many well functioning families display a slight tendency to score higher on the *Social Desirability* subscale (Skinner *et al*., 1995), the quality of the family environment has a major effect on the styles of defensive behaviour that individuals develop and eventually make use of in adulthood (Thienemann *et al.,* 1998). There is therefore a possibility that some of the FAM-III results in this study may be invalid due to these responses and a

clinical assessment would be necessary to verify the responses as a true reflection of each individual's perception of their family functioning.

Although within the norm, Lesley, Ansie and Laura's higher scores on the *Social Desirability* and the *Defensiveness* subscale suggest that they attempt to portray their family in a more positive light. Throughout the interview, Laura made many defensive comments regarding her daughter's atypical facial appearance and maintained that, "For me it was nothing actually". However, her ongoing anger at the reactions of others may be contributing to her defensive reaction. Ansie stated that her family could not be happier than it is (Item 15 – *General Scale*) and unlike her husband, maintains that they do not try and avoid each other (Item35). The Lawsons differed by six points on the *Social Desirability* subscale but both scores were well within the norm and are not indicative of invalid responses. Karen presented as particularly honest in the interview and she agreed that the family is not as well adjusted as any family could be (Item 5 – *General Scale*).

Both Rowan and Lesley viewed *Task Accomplishment* as extremely problematic, which is perhaps due to the fact that their son was only two months old when the test was administered and they were still adjusting to parenthood and the added stress of a child with a cleft lip and palate. They both stated that they spend too much time arguing about their problems (Item 1- *General Scale*) and admitted that they let things pile up until they are more than they can handle. This couple is experiencing a crisis situation to which they are trying to adapt and it is probable that this situation is currently causing a high level of stress overload in their family system.

The Prinsloos appear satisfied with general task accomplishment but Ansie's scores indicate that she regards her personal functioning in this area as problematic. She stated that she and her family do not always see problems the same way (Item 1 – *Self-Rating Scale*). In the interview she was very expressive about many minor stresses, which precipitated a crisis, and this appears to be her normal pattern of interaction. She does not appear to be able to tolerate a high level of stress and has been hospitalized twice for depression. It was this intolerance of stress, which prompted her decision to give up work and devote herself to full time mothering.

Dennis viewed *Task Accomplishment* within the family unit as extremely problematic and it is likely he feels his family is not functioning, as it should. He agreed that they spend too much time arguing about what their problems are (Item 1 – *General Scale*). Karen appeared to feel that the family's overall functioning in this area is adequate but is dissatisfied with her personal functioning and the problem solving within their relationship. She does not feel she sees problems the same way as her family (Item 1 – *Self-Rating Scale*) and does not feel that Dennis tries to find a way to work out a problem between them (Item 22 – *Dyadic Scale*). This seems to confirm the underlying conflict that was apparent at various stages of the interview. However, neither spouse verbalized these feelings openly. Instead Dennis constantly praised Karen's coping abilities which seems to suggest that he would prefer to avoid dealing with the issues which are bothering his wife.

The Standers both appear to be extremely satisfied with the task accomplishment within their family. Kobus admits he has trouble accepting someone else's answer to a family problem (Item 15 – *Self-Rating Scale*) and stated in our discussion that he would rather do something himself than ask for unnecessary help.

Overall the Parkers presented as the most competent family in this study but Jenny's elevated score on the *General Scale* is indicative of dissatisfaction in this area. She appears satisfied with her own functioning but does not appear to share her husband's perception that this family is successfully accomplishing basic tasks. During the interview there was no indication of dissatisfaction and both Jenny and Andrew agreed that they work together to solve problems. "We compliment each other whenever possible and support each other if possible".

Although most of the scores of these couples were within the norm on *Role Performance,* many had discrepancies, which is suggestive of possible conflict. In contrast to his wife, Rowan appeared to be the most dissatisfied with this area of family functioning. Karen and Jenny do not have scores, which are problematic, but the discrepancies between their scores and those of their spouse suggest different expectations and levels of satisfaction regarding family roles. Although Jenny maintains that her husband is always supportive she states that he has difficulty dealing with illness, "Andrew doesn't like it. He can't handle them being sick". Karen too accepts this

similar trait in her husband, which results in her carrying the main responsibility of childcare. " I mean you were at work. I was…."

Family satisfaction is related to the quality of communication that exists between parents and children (Scabini *et al.,* 1999). The FAM-III scores for *Communication* indicate that four of the couples have problems with this process, as there are large discrepancies between their scores on the various subscales. Three of the men (Rowan, Dennis and Leon) and two of the women (Karen and Ansie) appear dissatisfied with this area of family functioning. Dennis and Ansie are content with their own ability to effectively communicate and the dissatisfaction is centered on the communication process within their separate family units. Ansie feels they argue about who said what in the family and she doesn't always get a straight answer (Items 13 & 3 – *General Scale*). Rowan rates both his personal own communication ability and the process within his relationships as problematic. He stated that he feels that Lesley often takes what he says the wrong way (Item 10 – *Dyadic Scale*). In contrast to her husband, Karen only views her own communication ability as problematic and is satisfied with the process within their relationship. She agreed that family members don't always know what she means when she says something (Item 3 – *Self-Rating Scale*). The Parkers were the only marital dyad that appears to be satisfied with shared communication at all levels.

Affective Expression is an important aspect of the communication process and implies the ability to communicate one's emotions and feelings (Skinner *et al.,* 1995). Four of the couples were dissatisfied with *Affective Expression* within their family and relationship and again the discrepancies between the spouse scores suggests they do not share a similar perception in this area. Kobus' high scores on this subscale and on the communication subscales differed vastly from Laura's. He appears to feel satisfied with his personal functioning in these areas so the conflict appears to be in his interaction with his wife. However, there was no indication of this in the interview and he appeared content to allow her to dominate the discussion and never showed irritation if he was interrupted.

The Wiltshires appear totally comfortable with the expression of affect within their relationship which appears to conflict with the findings of the *Communication* subscale. Throughout the interviews Rowan expressed dissatisfaction with many areas of his

marriage, which seems to conflict with these healthy scores on the *Dyadic Scale*. It is possible his present adaptation to parenthood is being experienced as stressful and problematic.

The Lawsons results on the *Dyadic Scale* do not indicate dissatisfaction with the expression of affect within their relationship. Karen presents as an inhibited individual who is reluctant initially to express her feelings. When discussing Jenny's reaction to the news of Peter's cleft lip and palate she said, "I don't think it had less of an impact on me but I think I'm not as emotional as Jenny…" However, she appears to have little emotional control and becomes very tearful when discussing personal issues. Her high score on the *Self-Rating Scale* in this area suggests she is aware of her inability to effectively communicate affect. This appears to be confirmed by her equally problematic *Communication* score on the *Self-Rating* subscale. Dennis's scores suggests that he does not experience the expression of affect within his family unit as appropriate and may be experiencing either too inhibited or too intense emotions within his family interactions. These findings tend to conflict with his results on the *Dyadic Scale.* He stated that when Karen was upset he could not always tell if she was angry or upset (Item 4) and agreed that they do not always tell each other about things that bother them (Item 14).

Leon's higher score on *Affective Expression* and the eight-point discrepancy on *Communication* on the *Dyadic subscale* suggest that he is exceedingly dissatisfied with the expression of affect within his marital relationship. He too stated he did not always know if Ansie was upset (Item 4). Throughout the interview he did not show irritation at her expressiveness but appears to take the role of constantly calming her down when she "throws her toys out of the cot". His depression following this stressful period of their lives may be an indication of the high level of stress he was coping with.

The Parkers were entirely satisfied with the expression of affect within their relationship but Jenny's higher score on the *General Scale* is bordering on the problematic. She admits she was very shocked when Andrew told her that he "now he's got a son" when Peter's cleft lip was surgically repaired as she had had no inkling as to his true feelings. She had a similar problematic score on the *Involvement* subscale which seems to suggest she has feelings of isolation or rejection and may desire a higher level of

closeness within her family unit. Andrew's higher score on the *Involvement* aspect of the *Self-Rating Scale* indicates he rates his behaviour as problematic in this area. His work commitments are high and he is away from the home for extended stays so this may explain the lack of involvement. However, this couple appeared consistently warm and supportive in their interactions with each other during the interviews and there were no indications of underlying conflict.

Both Kobus and Rowan have problematic scores on the *General Scale* in the area of I*nvolvement,* which suggests they both may be experiencing feelings of insecurity and a lack of autonomy within their family unit. Lesley's problematic score on the *Dyadic Scale* suggests she too is experiencing similar emotions. At the time of the administration of the FAM-III, all were adapting to the recent birth of their child and were anticipating corrective surgery so it is likely that the stress of their situation affected these results. In contrast to his wife, Dennis's score suggests that he experiences difficulties in this area of his relationship and he stated that he did not feel Karen really trusts him (Item 33).

The remaining respondents appeared to be generally satisfied with the overall involvement they experience within their family unit and do not appear to be aware of any spouse dissatisfaction.

The Lawsons appear to be experiencing the most problems in the area of *Control* with Dennis's high scores suggesting that he is very dissatisfied with this aspect of their relationship. He may be experiencing feelings of rejection or alienation from his wife or sense that he is in a power struggle. In response to her comment that he may perceive her as rejecting he jokingly said, "Oh, so you don't need me?" Although both members of this dyad indicated in the interview that Karen had grown and developed since their marriage, there were strong feelings of unresolved tension and conflict. This was particularly apparent when the discussion centered on the child caring responsibilities or interaction with Dennis's parents. He stated that he didn't know what to expect if he did something wrong (Item 17 – *General scale*) and admits he is not as responsible as he should be (Item 27 – *Self-rating scale*).

Lesley and Rowan's scores suggest they do not share the same perception of family functioning in this area and the level of control within their relationship may be

problematic. Lesley's score on the *Self-Rating Scale* is high and seems to confirm her admitted 'perfectionist' tendencies. At the time of this study, their child was only two months old and many parents experience an initial loss of control over their lives when confronted with an unexpected deformity (Van Staden & Gerhardt, 1994,b).

The Standers, Prinsloos and Parkers appear to be generally satisfied with this aspect of family functioning although Andrew admitted he has problems in his personal functioning in this area, which was not reflected on the *Self-Rating Scale*. He stated in the discussion that he does not like the feeling of not being in control and spoke of feelings of helplessness that he experienced because he had to trust the doctors to make most crucial decisions. "I'm a bit of a control freak when it comes to that. I like to know what's going on".

The Wiltshires appear to share a similar value system and the discrepancy between their scores may be a reflection of a dissonance within their value systems, which may be due to their differing attitude to involvement with extended family members. He stated that they are not free to say what they want in the family (Item 48 – *General Scale*). This was confirmed in the interview in that he was not open with expressing his feelings regarding his wife and extended family members until she was not present. Lesley expressed a fair amount of defensive behaviour in her responses on this subscale. She maintained that they are never unfair to each other and have never let down other family members (Items 20 & 50 – General scale).

The Lawsons have a discrepancy on the *Self-Rating Scale* and problematic scores on the *Dyadic Scale*, which suggests a discord between their value systems. Dennis stated that they argue about how much freedom they have to make their own decisions (Item 28 – *General Scale*) and Karen stated that there is a big difference in how Dennis behaves and what he expects from her (Item 35 – *Dyadic Scale*). The Standers, Prinsloos and Parkers all seem to share a strong and similar value system. Kobus states that he trusts his wife implicitly, Leon verbally supports Ansie's protective behaviour when dealing with their son, and Andrew said that he and Jenny were friends at school, "So the base of our relationship is friendship".

9.3. THE IMPACT OF APPEARANCE ON FAMILY FUNCTIONING

Of all the families, only Karen and Dennis were informed during the pregnancy that they would have a child with a facial anomaly. They stated that they were pleased to be prepared and felt this lessened the eventual shock. None of the other families knew of their child's condition in advance and only Lesley and Ansie would have preferred to have been prepared. The others maintained that they would have imagined a much worse deformity than the reality as once they began researching the literature they learned of syndromes associated with the condition. As Rowan said, "Seeing what can go wrong…It will *completely* freak us out!" Also, two of the mothers felt that they would have worried so much about what could be wrong that the stress would have been more harmful to their child.

As most parents are unprepared for the birth of a child with a facial anomaly and are also not familiar with the condition, the manner in which they are told of the defect is of vital importance for future adaptation and acceptance (MacDonald, 1979). Only two couples (The Parkers and Wiltshires) felt that their gynaecologists supported them and broke the news to them in an empathic manner. The other three couples felt that their doctors lacked sensitivity and they were angered at their approach. As Leon stated, "I actually thought the casualness was sort of arrogant". Crying is a normal reaction and too often they are told not to cry (MacDonald, 1979). Karen particularly experienced the birth as traumatic and vividly remembers the lack of empathy and understanding she received and being told "Don't cry". Laura maintains that her doctor was blunt and unfeeling and she feels that her anger is focused on the way he broke the news to her and also on the fact that he was the 'messenger' and she hated him because he was the first person to tell her of her daughter's condition.

Mothers of children with facial clefts have been found to report more difficult pregnancies than those who have 'normal' children (Clifford & Crocker, 1971). Two of the couples (The Wiltshires and Standers) had unexpected pregnancies as they had medical problems and were told they would need medical treatment to fall pregnant. But of all the mothers in this study, only Jenny appeared to have had a difficult pregnancy in which she did not gain weight. Lesley had the hardest time with adapting to the change in her

life circumstances as she is a self-confessed perfectionist who likes to plan her life and she had not planned to have a child for another two years.

The birth of a child with a defect is experienced as a traumatic event by parents who undergo a period of mourning "for the perfect baby that was expected and hoped for" (Rosenstein & Schulman, 1990, p. 47). Many couples admitted that they felt they had let everyone down by producing a less than perfect child. As the Parkers said, "Everyone is expecting this…perfect child and you can't even do that right". Lesley felt that "there were such great expectations" which were shattered when they realized their son was not 'perfect'.

Parents of children with a facial anomaly have to deal with the conflict of the "idealized image of what their infant will look like and the realities of the infant's actual physical appearance". To successfully bond with their child, such parents must adapt (Hildebrandt & Fitzgerald, 1981, p. 60). All couples admit that the initial appearance of their child's cleft was a shock and each individual varied as to the time it took to adjust to the condition. Both Jenny and Andrew used the term 'decent' to describe Peter's appearance once his cleft lip was repaired.

Jenny and Lesley admitted to initially experiencing feelings of rejection towards their child. However, Jenny said that once she recovered from the shock she was able to form a fiercely protective bond that remains to this day. Lesley admits to strong feelings of anger when she sees a child with a 'normal' facial appearance and says, "I felt angry! I wanted to throw all the prams out!". Some mothers of children born with a facial cleft regard the anomaly as a reflection of their own inadequacy and imperfection and this perception can negatively affect their relationship with their child (Tisza & Gumpertz, 1962). Three months since the birth of her son, Lesley has not yet worked through her feelings of anger and frustration. It is possible that her future relationship with her son will be affected if she does not receive appropriate support. Anger, anxiety and depression are common reactions to the birth of a child with a facial deformity. However, these emotions diminish in time if parents receive empathic social support from extended family members, friends and medical professionals, which aid in the development of essential coping skills (Van Staden & Gerhardt, 1994b).

Societal reaction to the physical appearance of a cleft places a high level of stress on parents of such a child (Van Staden & Gerhardt, 1994b). All of the couples have experienced negative and "ignorant" comments from outsiders in relation to their child's appearance, which increased their levels of stress and anxiety. Some, like Andrew chose to stay in his "comfort zone" and he refused to go to the shops with his son as he "wanted to take the heads off" individuals who stared or made unthinking comments. Others, like Ansie, decided she would not be cowed but would show the world she was not trying to hide her son. Even well intended comments from friends and acquaintances meant to reassure, were experienced by most of the parents as irritating and not based in reality. Studies have found that most parents of a child with a facial cleft initially resent well-intentioned comments even when spoken by medical professionals (MacDonald, 1979). The participants felt that no one could possibly understand what they were going through and they felt angered that they presumed to comment. As Jenny said, "How can you tell me it's going to be fine when I don't know that it is?"

Many extended family members initially reacted with shock and denial at the news and this response intensified the stress levels of the parents. Most of the parents say the initial reaction of family members was very hard for them to accept. Rowan said their reaction was, "Shocking! It wasn't great!" and Dennis said that each time he watched someone's reaction it was "Like you're seeing it again and again".

Fathers of 'imperfect' children have been found to react by attempting to "make a complete man out of their sons" (Tisza, Irwin & Scheide, 1973, cited in Rosenstein & Schulman, 1990, p. 48). All the men in this study admitted to feelings of shock at the birth but all felt that they accepted and bonded with their child. Rowan is already planning his son's sports future and intends to encourage him to play golf as he feels he will be unable to play rugby when he is older due to the danger of injury to his face. Andrew openly admitted to being bothered about his son's appearance and he felt that Peter was "born all over again" after the surgery to correct his lip.

Interestingly, Ansie was the only mother who voiced the opinion that the operation made her feel that he now looked as he should have at birth although she tells her son that he had a 'split lip' "because you are special". Andrew is irritated when Jenny also refers to

the cleft as “Peter’s special lip” and maintains that he is actually harder on his son to ensure that he is not treated any differently from a ‘normal’ child. Jenny said her husband did not tell her of the depth of his feelings until after the operation when her son was four months old and she was shocked that she was unaware of his true feelings. Karen too was unaware of the depth of Dennis’s feelings and only realized what he had fully experienced during our interview. As Kelly is now four years old, this appears to confirm the FAM-III findings of problems in this family functioning in the area of communication and affective expression.

Research has found that “the effects of the original impact continue unabated for relatively lengthy periods of time – months and years” (Clifford & Crocker, 1971, p. 298). At the time of the study, Kelly was four years old and Peter was five and yet both mothers were extremely emotional and tearful as they discussed their early experiences, which did not seem to have lessened with the intervening years and the successful corrective surgery. At the stage of the interviews three of the five couples had undergone corrective surgery for their child’s condition. The Wiltshires and Standers were anticipating the first surgery in the following few months. They both maintained that they were now used to the appearance of the cleft and Rowan stated, “If we look at it now we don’t even see it”. The remaining three couples all spoke of their relief at how ‘normal’ their child looked after the surgery. Jenny and Karen both said that they actually missed the cleft and the ‘wide smile’ but Ansie emphatically declared that she didn’t miss it at all and after the surgery “I couldn’t stop looking at him in the hospital with his mouth closed and his little nose.”

Mothers of babies with facial anomalies report higher levels of parenting stress than mothers with non-disabled infants (Speltz *et al*., 1990). The birth of a baby is a stressful transition for all new parents but this stress is heightened when the child has a defect. In this study, some of the parents said they did not enjoy the early months of their child and were much more relaxed with their other children who had no physical problems. Ansie said that her eldest son was an easy child who slept through from four weeks and Jenny stated that the first months of her daughter’s life “was a breeze”.

Genetic counseling enables couples to deal with feelings of guilt and allow them to “plan realistically for the future (Barden, 1990, p. 365). Most of the couples in this study stated

that the birth of a child with a facial anomaly did not prevent them from having another child. Those who had a subsequent pregnancy admitted that they were very fearful during the pregnancy and relieved at the birth of a healthy child. However, they felt they did not want their fear to prevent them enjoying another experience of parenthood or to deprive their child of a sibling. Kelly was the Lawsons second child and Karen admitted she would not have another child, as she was too fearful that the experience would be repeated. Laura says she had always only planned to have one child and Chantal's condition does not affect her decision. The Wiltshires feel that it is too early too even think of another child at this stage as they still are trying to adjust to the pressures of their current situation.

Many parents feel that they are responsible for 'causing' the condition and suffer feelings of guilt and anxiety. Some feel that God is punishing them and others feel intense anger or depression at the perceived unfairness (Rosenstein & Schulman, 1990). All couples in this study acknowledged feelings of anger and guilt regarding their child's condition. The Wiltshires admitted that they found it difficult to look at children with 'normal' faces and it made them want to "throw all the babies out on their heads and faces!" Jenny felt that all her pregnant friends were discussing her when she was not present and she was offended when she heard they all wanted the doctor to test if they too could be carrying a child with a cleft lip and palate deformity. Laura said she felt irrational anger towards an Indian baby with a cleft whom she had seen when she was pregnant as she felt "that baby gave it to me". Most of these couples felt that they had 'let people' down by having a child who were not perfect and admitted it was experienced as a reflection on themselves.

Parents of a child with an orofacial cleft have been found to want to discover the cause of their child's malformation and so determine why it 'happened to them'. There is a need to be reassured that they did not cause the condition (Tisza & Gumpertz, 1962). None of the couples in this study assigned blame. Once they adjusted to the initial shock they were all more concerned with anticipating possible future complications than determining the cause. All five couples ensured that they were educated and informed as to the condition and all are therefore aware of possible causes as stated in the literature. For example, Jenny feels that the fact that she did not take folic acid during her pregnancy may have been a contributing factor and Lesley has guilt feelings that she

may have inadvertently taken some medication, which caused the condition. The Standers feel the cleft lip and palate is due to the high level of pollution in their area.

Two of the couples had a family history, which may be significant in the development of the condition. Jenny had a miscarriage before the birth of her second child, as did her sister-in-law. Her sister had a stillborn child when she was five months pregnant who had anacephally and spina bifida. Laura's sister gave birth to a child with a malfunctioning fontanelle, which necessitated surgery as a 'cone' developed. However neither couple associated these factors with their own child's birth defect.

9.4. FAMILY SYSTEMS THEORY AND FAMILY FUNCTIONING

Family system's theory focuses on relationships between individuals within a system and how they interact and influence each other's behaviour. The mutual interaction and influence of Individuals and events is the focus of study (Becvar & Becvar, 1996). All families are systems that function through repeated transactional patterns, which regulate the behaviour of members. The family structure establishes the ways in which members interact to meet the functional demands of the system and thus enables it to maintain itself (Minuchin, 1996). The participants in this study have evolved their own unique patterns of interaction, which ensures the stability of their particular system. Most of the wives in this study 'permit' their husbands to state that they cannot deal with the intricacies of childcare and so they shoulder the heavier burden of responsibility. Laura claims that to ask Kobus to participate in childcare would be "…like telling him to cook. I don't do it. This is my responsibility". Karen and Jenny feel that their husbands do not tolerate illness well so they feel that they cannot be expected to deal with the medical problems concerning their children. The husbands effusively praise their wives for being 'strong' and 'a star' and the status quo is maintained. Participants within a relationship are mutually responsible for maintaining their unique pattern of interaction (MacKinnon & Miller, 1987).

The birth of a child with a facial deformity produces *disequilibrium* within the family system, which necessitates change and adaptation. Initially many families respond with family disorganization and disruption (Van Staden & Gerhardt, 1994b). The Wiltshires are currently in a state of system disequilibrium. Their family structure must adjust to the

new demands and introduce alternative transactional patterns into their system in order to survive. At this stage they appear to be resisting change and clinging to their familiar roles and functions and as a result they are experiencing 'role overload' and a sense that their partner is not totally meeting their expectations.

Reorganization is a process whereby a family system "acknowledges the demand and enters into a process of communication and negotiation to reorganize the system and to establish new routines to cope with the new situation" (Jonsson Jones, 2001, p. 140). Members of the other marital dyads adapted to their crises by changing their transactional patterns. For example, Karen 'matured' and became less dependent on her husband's support. However, her need for emotional support, which is not present within her marital relationship, has resulted in the development of an enmeshed relationship with her daughter. Jenny accepted her need to function as a mother with less dependence on her own mother. In contrast, Ansie insisted that the extended family members actively support her family unit while 'allowing' Leon's role to remain essentially unchanged during the crisis period. As she stated, "I actually insisted on help. I said, 'I'm sorry. I need your help. I need you to look after Leon and Pieter for me'".

Many parents experience a loss of control in 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 & Gerhardt, 1994b). The fathers in this study commented on their frustration and feelings of helplessness at having to 'hand over' their child to the expert care of professionals. The support these couples received from external subsystems was very important to enable them to adjust to their situation.

The formation of a new spousal subsystem entails a strengthening of boundaries around the dyad and a lessening or certain level of separation from previous relationships and subsystems. If the structures of the family of origin do not accommodate this change, the new spousal unit becomes threatened (Minuchin, 1996). Lesley was the most dependent on the support of her older sister and appears reluctant to separate at this early stage. Instead she encourages her extended family subsystems to intrude into her marriage. The stress of their situation is such that Rowan appears to have limited capacity for significant emotional involvement with his wife and their present dysfunctional pattern of interaction inhibits mutual support, which could otherwise

strengthen their spousal boundaries (Minuchin, 1996). In contrast, Jenny realized that she was now the mother of a child and had to deal with her problems without the help of her own mother and modified her behaviour to meet her new parenting demands. She asked her mother to stay away for a period while she dealt with the situation on her own.

Parental reaction to the birth of a child with a handicap often includes overprotective or indulgent behaviour due to high levels of anxiety (Barden, 1990). The *circularity* between over-protective maternal behaviour and a child with a facial deformity is evident in the responses of all of the mothers in this study. Jenny stated that she is not naturally assertive but became that way as she dealt with her son's medical problems. Karen developed an enormous level of patience with her daughter and is very protective of her, as is Ansie towards her son. Laura is naturally shielding of her husband due to his disability and interacts in a similar manner with her daughter. At this stage, Lesley appears to be still adjusting to her son's condition and there was no overt indication of over-protective behaviour. Anger seems to be the dominant emotion she is currently experiencing which was evident when she spoke of babies with 'normal' facial features.

A positive *communication* process is essential for the healthy functioning of a family system and becomes dysfunctional when individuals do not send each other straight messages (Becvar & Becvar, 1996). Good communication skills are vital for a healthy marital relationship (Lauer & Lauer, 1997). There was evidence of underlying covert messages within the communication patterns of four of the couples in this study, as the majority appears to have problems in this area. Even the Parkers, who present as the healthiest dyad with open communication processes, do not always communicate effectively. Jenny was shocked to learn of the intensity of Andrew's feelings regarding his son's facial deformity, which he only disclosed when it had been repaired.

As Becvar and Becvar (1996) maintained, individuals cannot *not* communicate. Even silence is a form of communication. During the discussions, all dyads were constantly communicating with each other by means of both verbal and non-verbal behaviour. They would make or avoid eye contact with their partner or nod or shake their heads in response to a comment. For example, although Karen verbally stated that she did not mind Dennis's lack of involvement in the medical procedures, she contradicted this overt message by stating that he only visited for 15 minutes a day. When she made this

statement she glanced briefly at her husband and then stared at the floor. Dennis chose to ignore her covert message that his parents were not as involved as they could be by stating, “Oh they love it!”

The content and order of family communication express its dynamics and structure (Minuchin, 1996). Only the Standers and Wiltshires sat next to each other on the same couch during the interview. However, while this suggested a solidarity and support between the Standers, the stiffness of the Wiltshires body language negated their physical closeness and communicated a sense of distance between them. This seemed to be confirmed by the verbal expressiveness of Rowan once Lesley had left the room. Most of the couples interrupted each other during the interviews but only Andrew showed any irritation towards his wife when she did so. For the most part, most individuals interrupted to agree with a point their partner was making. With the exception of Rowan, the mothers were the most expressive and their husbands tended to back down and let them take over. This was particularly apparent in the interviews with Kobus and Leon and interestingly it was Ansie whose results on the FAM-III scales indicated dissatisfaction in this aspect of their relationship. One could hypothesize that she feels frustrated at Leon’s lesser verbal ability.

When a couple form a new spousal subsystem and family unit, one essential adjustment for the family of origin is to partially separate from the grown child while accommodating the new spouse into the family structure (Minuchin, 1996). Most individuals in this study were close to their own mothers and had varying levels of closeness with their spouse’s parents. Generally mothers were experienced as the most important source of emotional and practical support by both husbands and wives. Dennis stated that it was very hard for him to tell his mother that Kelly had a cleft lip and palate and said, “It was someone I could relate to and let go”. While the men all acknowledged the support of their mothers-in-law, the women were less effusive in their praise of their husband’s family members. Jenny agreed that her mother-in-law is helpful but “you have to ask” and Karen said that her in-laws were also willing to help as long as it doesn’t “affect what they’re doing”.

Most of the grandparents initially reacted to shock at the news of their grandchild’s condition. The *circularity* of affecting and being affected by the birth of a child with a

orofacial cleft was however very apparent in their subsequent adjustment. Ansie's parents felt they could not go through the whole process a second time and were very angry when they chose to have another child. Many grandparents also suffered with their own feelings of guilt. Karen's mother thought it was 'justice' as she had not been a good enough mother for Karen and Jenny's father felt he was being punished for derisive comments towards an acquaintance with a cleft lip deformity.

Rules, which express the values of a system, form its boundaries and are its unique relationship patterns (Becvar & Becvar, 1996). All the families in this study appear to have firm rules and a shared set of values although there are indications of dissonance in some cases. Ansie was very vocal in describing behaviour that is expected within her family when she stated that her child can "speak for those who have Down's syndrome as…at *our* house we know about things like that!" Rowan does not feel that he is free to express his true feelings and Karen states that Dennis's behaviour is different from what he expects of her. The Standers, Parkers and Wiltshires appear to share similar views and values but Laura appears to be less accepting of society's reaction to disabilities and this aspect appears to be a problem for her.

All families in this study are *open* systems although there is variation along the continuum. *Boundaries* of a subsystem are comprised of rules which define who participates and how. It is essential that these boundaries are clear and permeable and allow members to satisfactorily carry out their specific functions while still tolerating access between members of the subsystem and external subsystems (Minuchin, 1996). Firm but flexible boundaries are evident in the Parkers home. Their parental subsystem is strong, they interact with but are differentiated from their families of origin and there is a healthy balance between support and individuation.

The Wiltshires present as a family system with blurred boundaries between the marital dyad and Lesley's sister and mother. There is a high level of *enmeshment* between Lesley and her extended family members, which seems to adversely affect the relationship with her husband. There is also evidence of diffuse boundaries in the Prinsloos home as Ansie is over protective in her parenting and there "is an extreme of hovering and providing support even when its not needed: (Becvar & Becvar, 1996, p. 192). She fights all the family battles and does not allow her children to develop

sufficient independence and autonomy. As she is an emotional person who by her own admission is a "crying person", her behaviour impacts negatively on her older son who "didn't want to go to school because he was so worried about me". Thus the child feels the need to act as the parent to protect his crying mother. Ansie admits that she tells strangers in the supermarket not to come near her trolley when her children are with her and phoned the teacher at school to tell her to ensure that Johan was not bullied or "I'll come and sort it out!" The Lawsons present as a family with blurred boundaries which impact on the integrity of the spousal subsystem.

Systems theory maintains that the quality of the dyadic relationships within a family is closely related to the functioning of the family as a whole and positive parent-child relationships are related to positive family functioning (Shek, 2001). The Lawsons present as an open system who interact well with external subsystems but it does not appear that Karen has achieved a sufficient level of differentiation from her relationship with her late mother and appears to have transferred this pattern of interaction into the relationship with her husband. There is also evidence of intergenerational coalitions forming between Karen and her daughter and Dennis and his son, which may be problematic in the future. Karen admits that she differs in the parenting of her children and has an abundance of patience only when interacting with her daughter. To counter this imbalance, Dennis states that he adopts a more tolerant approach to parenting Ryan.

The concept of *circularity* can also be extended to the sibling subsystems within this study. The Prinsloos agree that their older son, Pieter, is a gentle child who seems to have been adversely affected by the loss of parental attention since the birth of his brother. He appears to have a lowered self esteem and tends to withdraw when Johan is present and demanding of attention. However, both the Lawsons and the Prinsloos feel that their older sons have an increased level of empathy for disadvantaged children, which has developed since the birth of their siblings.

Feedback is a key concept of family systems and is a process that regulates the stability of a system. It is "the regulating mechanism by which a system maintains homeostasis" (Jonsson Jones, 2001) and is apparent in the varying responses of these couples in dealing with their child's condition. *Positive feedback* allows flexibility and change and

negative feedback maintains the functional stability and integrity of the system. Many of the couples adjusted to their situation and chose not to 'hide' their child from the reactions of others (*positive feedback*). Positive feedback was also evident in change within most of the husbands who felt that as a result of their experience they developed a new awareness and empathy for other parents of disabled children.

As a response to *negative feedback* of the children crying for their father in the evenings, the Prinsloos devised a system where Leon could take his supper from the postbox before continuing to the University for his night courses. Although she maintains that she does not 'see' her husband as a blind person, Laura responds to the negative feedback of his helplessness by calling on her mother-in-law to help her with the care of Chantal. Most of the other wives also responded to the negative feedback of their husband's stated inability to deal with illness by shouldering the greater part of the childcare responsibility.

Increased mutual emotional support and sharing between spouses has been found to strengthen the marital relationship and couples have been found to have an increased level of maturity and openness. Individuals who have persistent feelings of depression, blame and resentment have been found to experience a straining of their marital bond (Van Staden & Gerhardt, 1994b). The Parkers appear to have the healthiest relationship, which they say is based on friendship and sharing. They both maintain they have grown from the experience and have a stronger bond. The Lawsons do not feel the experience has negatively or positively impacted on their relationship as Karen feels she would have matured and developed in a similar manner whether she had children or not. The Prinsloos appear comfortable in their marriage but there is evidence that the experience took a heavy toll on their individual lives. Ansie has been hospitalized twice with depression and feels that Leon too suffered a depressive incident after the whole experience. At this stage it is too early to determine long-term positive or negative effects on the other two couple's relationships.

It has been found that parents of a child with a cleft lip and palate do not experience the long-term level of stress and adjustment problems as those parents of children with more severe conditions such as Down's syndrome or congenital heart disease (Pelchat *et al*., 1999b). The fathers in this study were particularly grateful that their child had a

treatable and relatively minor condition once they were aware of other more severe conditions. As Dennis stated, “This is the best thing that *could* be wrong. It’s nothing permanent or serious”.

In times of stress or crisis, a family system must develop new coping skills to meet increased demands. Lewis, Beavers, Gossett and Phillips (1976) determined that competent families exhibited no single quality, which differentiated them from less well functioning families. The strength of the parental coalition was felt to be of prime importance in establishing a high level of functioning and serving as a model for subsystem relationships in which feelings were openly communicated (Goldberg & Goldberg, 1985).

In the present study, the parental coalition appears to be strong in most of the couples as they are all committed to their children’s well being and the maintenance of their family system. However, there are apparent problems with the communication of feelings in most of these family units, which appears to be responsible for varying levels of underlying conflict. Dysfunctional families tend to respond to each other with defensiveness and hostility and family members do not feel free to voice their opinions (Goldberg & Goldberg, 1985). This pattern of interaction was mainly apparent in the discussion with the Wiltshires and Lawsons.

A study by Trute and Hauch (1988) found that families who adapted positively to the birth of a disabled child scored significantly higher on the scales of the FAM-111 relating to strong family involvement and affective expression. Four of the couples are experiencing dissatisfaction with the expression of affect within their family units and Kobus, Dennis and Jenny seem to be also dissatisfied with the level of family involvement. Three of the couples, notably those with the older children, acknowledged positive aspects of the experience of dealing with a child with a facial cleft anomaly. Both the Lawsons and Prinsloos feel that their older sons have an empathy and understanding for children with disabilities. None of the parents perceive their child with the cleft lip deformity as having been negatively affected by the condition but feel they too have increased empathy for others.

The negative impact appears to be the effect of Johan's cleft deformity on the social development of his older brother and the accompanying feelings of guilt that the parents experience. Another negative impact appears to be the alliance forming between Dennis and his son and between Karen and her daughter. Dennis, Kobus and Andrew feel they too have increased empathy for parents in a similar situation and acknowledge a new awareness, which was not present before. As Dennis said, he now listens with interest to a parent who has a child with Downs syndrome where before he would think, "I'm glad it's not me".

Family systems theory acknowledges the many issues involved in the adaptation of parents faced with a child with a facial deformity. Society's response to appearance is such that a facial cleft anomaly impacts on the functioning within a family system on many levels.

In this study, the findings of the interviews and the results of the FAM-III measurement scale appear to confirm previous research studies that state that the birth of a child with a cleft lip and palate is a stressor, which has an impact on healthy family performance. These results also highlighted the multifaceted factors, which interact to impact on family functioning. These include individual family coping skills, family rules and boundaries, interactive patterns between family members and the cohesion existing in each family system.

9.5. LIMITATIONS OF THE STUDY

The small sample of participants chosen for this study allowed the researcher to explore the feelings and experiences of a small group of individuals but in the process the opportunity to study a large sample of respondents was forfeited.

The instruments used in this study were predominantly self-report measures and therefore the results are restricted by the individual's personal assumptions and feelings regarding their family and relationships and what they are willing to reveal.

Interviewer bias is a strong possibility when dealing with in-depth interviewing and a small sample size. However, I was aware of this possibility and made a concerted effort to guard against subjectivity within the interview situation.

It is important to acknowledge that an endeavor to describe a holistic perspective of the effects of a child born with a facial anomaly on family functioning will always exclude certain fundamental factors. The complexity of such a study is such that it is not possible to include all relevant factors and it is necessary to focus on the essential ones.

9.6. SUGGESTIONS FOR FURTHER RESEARCH

The small sample size of this study prevented the exploration of many factors that are highly likely to impact on the functioning of a family coping with a child with a cleft lip and palate. These include socio-economic status, geographical location, religious beliefs, race and stage of family life cycle. Such factors have possible significance and further research, building on the results of this and other studies, would be of interest.

Future studies making use of random heterogeneous samples would verify the validity of the findings of this study. A longitudinal study in which the FAM-III was administered to a similar sample over a period of time would enhance our understanding of family functioning as the family continues to adapt to the changing needs of a child born with a facial anomaly. It would also identify those factors that contribute to healthy functioning in families who have a child with a facial cleft deformity.

The results of the FAM-III appeared to be confirmed by the interview findings in this study and it would be of interest to see if similar findings could be replicated using a less homogenous sample.

To date, research in this area has focused on the effects of the birth of a child with a cleft lip and palate on the mother. The literature indicates that the effects on the father and sibling subsystems have been largely ignored. When a family system is in a state of disequilibrium due to the birth of a child with a physical defect, it is not always able to adequately support all family members during the crisis. In the process, family members such as siblings may experience feelings of rejection and isolation (Van Staden &

Gerhardt, 1994b). There is a great need for further research focusing on these individuals as preliminary research indicates that although mothers generally shoulder the heaviest burden of childcare, the impact on fathers and siblings cannot be negated and ignored.

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ADDENDUM

DISCUSSION GUIDE

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JOINT INTERVIEW WITH THE PARENTS OF A CHILD BORN WITH A CLEFT LIP AND PALATE

I am going to be discussing your experiences with coping with a child who was born with a cleft lip and palate. I would like you to just tell me your experience and how you felt it impacted on both your family life and your marriage. (Throughout the discussion I noted who dominated the discussion and the response of the partner to this domination). The following areas were focused on:

1. Family Structure and Functioning

How many people are there in this family unit?
Who are they? Names and ages?
What position is the child with the cleft anomaly?
Who is responsible for the care of the children?
How extensive is the support system?
How is conflict resolved?
Do you feel communication is open between family members?
Are family activities shared? Do you have time alone as a couple?

2. Impact of the Cleft Lip and Palate on Family Functioning and Lifestyle

Did the birth of this child affect your decision to have other children?
Who has the greater responsibility for childcare? Is this role equally shared?
Did the increased stress and responsibility result in greater conflict?
Do you feel your family has made a successful adjustment?
Who is mainly responsible for the financial aspect?
How did the birth of a child with a cleft lip and palate negatively impact on your life?
How did the birth of a child with a cleft lip and palate positively impact on your life?
Do you feel you have grown from the experience?

How did you feel your partner coped with the experience?

Did you discuss your feelings and fears?

Are you more protective towards this child?

How did you experience the reactions of others? Family members? Acquaintances and strangers?

3. Support System

Did you experience positive support from health professionals? Hospital staff? Doctors?

Were extended family members supportive?

Were friends supportive?

Did you experience positive support from your partner?

Did you feel you could also play a supportive role when necessary?

How would you now support someone in a similar situation?

4. Severity of the Cleft Lip and Palate

How severe to you regard the extent of the cleft lip and palate?

Do you feel it could be worse?

Do you feel that surgery will be (or has been) successful?

What unexpected outcomes have you experienced?

5. Parental Attitudes towards a Child with a Facial Deformity

Had you seen a child with a cleft lip and palate before your child was born?

Did you have knowledge of what a cleft lip and palate involved?

Were you aware of the possible causes and long-term prognosis?

What emotions did you experience when you were first informed of the disability?

Did you feel anger/ resentment towards parents with a child with no disability?

Did you feel you were to ‘blame’?

Did you ‘blame’ your partner?

How do you visualize your future and that of your child?