THE INTERACTION BETWEEN PAEDIATRIC ASTHMA AND FAMILY FUNCTIONING

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SUMMARY

The present study explored the interaction between paediatric asthma and family functioning, within the context of family systems theory. Eight families, each with an asthmatic child between the ages of 8 and 15, were included in this study. In each case, the parents were interviewed and completed a quantitative measure, the Family Assessment Device. The results indicated that each family has a unique way of functioning and of integrating the child's asthma into its lifestyle. Factors found to be involved in the mutual impact of paediatric asthma and family functioning were the size of the family, the severity of the child's condition, the ways in which the family copes with the stress of asthma, communication patterns between parents, compliance with family rules and boundaries, and the affective responsiveness and involvement of family members.

Key Terms:

Paediatric asthma; Family functioning; Family structure; Family systems theory; Family Assessment Device (FAD); Parental attitudes; Severe asthma; Circularity; Feedback; Healthy families.

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AN INTRODUCTION TO CHILDHOOD ASTHMA

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1.1 BACKGROUND

Asthma is a chronic inflammatory condition of the bronchial tubes (airways). Narrowing of the airways (bronchoconstriction) as well as inflammation of the lung tissue occurs, and this impairs breathing. In response, the bronchial tubes secrete more mucus, further limiting airflow. As breathing becomes more difficult, emotional anxiety – sometimes changing to panic – impairs breathing even more.

Medication used to treat asthma dilates the bronchioles (bronchodilators) or prevents the inflammation (anti-inflammatories, steroids), and is usually delivered directly into the lungs with the use of an inhaler. However, control of the disease is complicated by the fact that adherence to medical regimens does not mean that the patient is symptom free. Thus, although asthma is a chronic condition, acute attacks (exacerbations) still occur even with the most compliant of patients (Barnes & Newhouse, 1994).

Acute asthma is defined as an acute exacerbation of wheezing (a whistling sound caused by air passing through the narrowed tubes), which is unresponsive to usually effective therapy and necessitates care in an emergency room or hospital ward. An acute asthma attack is characterized by narrowing of the airways as well as inflammation, hyperventilation, impairment of pulmonary function, alteration of alveolar ventilation and hypoxaemia (difficulty in breathing out and poor lung function) (South African Childhood Asthma Working Group, 1993).

Severity of the disease depends on the frequency and intensity of attacks. In terms of frequency, *mild asthma* can be defined as infrequent and easily controllable asthmatic symptoms. *Moderate asthma* can be defined as asthma attacks, which require medication or occasional hospitalization for the control of symptoms. *Severe asthma* can be defined as wheezy episodes occurring once a week to every day as well as frequent hospitalization or emergency room visits for the treatment of acute asthma attacks four to six (or more) times per year. Asthma symptoms are present even if the person is not doing any exercise and are

not returned to normal by bronchodilator inhalers (Barnes & Newhouse, 1994; Khampalikit, 1983; McLean & Ching, 1973).

In terms of intensity, the severity of asthma is commonly measured by means of a peak flow meter, which is a portable apparatus, easily used in home settings. The patient gives a sharp blow into a tube-like device and then reads off the measurement of the peak flow rate during exhalation. This provides an objective measure of pulmonary tissue dysfunction. Severe asthmatics would have a reading of 40% to 50% or more below their normal or best achievable value (Barnes & Newhouse, 1994).

Scarce at the beginning of the 20th century, asthma is now the most common chronic disease and the major reason for hospitalization (Gregerson, 2000). Asthma prevalence increased dramatically in the 1980's (USA figures) and by 1992 it was the most common reason for seeking medical treatment. World wide there appears to be an increase in the prevalence of asthma (Bloomberg & Strunk, 1992; Busse & Holgate, 1995; O'Byrne & Thomson, 1995; Warner, 1993). This increase is thought to be related to the presence of house dust mites and cockroaches which trigger asthma in cities; an increased consumption of processed foods; socio-economic deprivation; high levels of ozone and ultrafine particles (soot, cigarette smoke) in the air; energy-efficient buildings that trap pollutants; and, ironically, a decrease in other respiratory diseases such as tuberculosis which, it is thought, has changed the immune response in the lungs in ways that increase the likelihood of asthma (Bateman, 2000; Ehrlich et al., 1996; Steinman, Le Roux & Potter, 1993; Van Niekerk, Shore & Weinberg, 1977).

Asthma is more likely to be diagnosed during childhood than at any other stage during the lifecycle. Asthma is the most common chronic illness of childhood, accounting for 25% (USA statistic) of school absences related to chronic illness (Steiner, Fritz, Hilliard & Lewiston, 1982). Asthma affects between 4% and 10% of children world wide (Madsen, Storm & Johansen, 1992). In South Africa, studies show a prevalence of asthma in urban children comparable to, or higher than, those in other countries (Terblanch & Stewart, 1990).

Ehrlich and Bourne (1994) published an epidemiological paper covering asthma deaths among coloured and white South Africans aged between 5 and 34 years, from 1962 to 1988.

They found that the number of asthma related deaths in the population approximated those of England and Wales and exceeded those of the USA (in 1980 the South African and UK figures were 0.9 and the USA figure was 0.4 per 100 000). The coloured figure for the same years was much higher than the international figures: 2.0 per 100 000. In 1985 the white figure remained at 0.9 and the coloured figure had risen to 2.6 per 100 000. The authors concluded that the difference in prevalence was related to inequalities in medical care and were a strong indicator to institute more preventative strategies in the Cape Town coloured community.

In another study, Ehrlich and Weinberg (1994) studied the trends in hospital asthma admission at the Red Cross Children's Hospital in Cape Town between the years 1978 and 1990. They found that, with about 900 asthma admissions annually, asthma was the most common chronic disease requiring admission to the hospital. Of interest was the sharp increase in asthma admissions between 1978 and 1984, which the authors attributed to changes in medical practice and parental behaviour.

In a further study conducted by Ehrlich, Du Toit, Jordaan, Volmink, Weinberg and Zwarenstein (1995), the authors compared prevalence of reported wheeze in young schoolchildren (age 7 to 10 years). The percentage of South African (Cape Town) parents reporting that their child had a wheeze was 26.8%. This was compared with figures from Australia (23.1%), Chile (16.2%) and Great Britain (16.7%). The prevalence of recent wheeze in Cape Town was at the high end of the range. While recognizing that self-report measures are not an exact science, the comparison of figures is interesting. This, together with the finding of a relatively low frequency of recognition and diagnosis of asthma made the authors conclude that paediatric asthma represents an important public health problem in Cape Town.

The aetiology of childhood asthma is perceived to be multicausal, with heredity, infection, allergy and psychological factors all combining to produce asthmatic symptoms (McNichol, Williams, Allan & McAndrew, 1973; Warner, 1993). As previously stated, the condition is treated pharmacologically but most clinicians recognise the psychosomatic aspects impacting on the disease. In particular, there is the general concession that emotional stress can contribute to the trigger factors or even precipitate an attack (Jariwalla, 1988; Kuzembo, 1980).

Childhood asthma tends to begin before the age of five and occurs more frequently in boys than girls with the male to female ratio being approximately 2:1 (Busse & Holgate, 1995). Although the prognosis is good and many children recover when reaching puberty, the experiences of illness during the school going years may have considerable impact on the individual. Asthma can effect the child's physical growth and strength, school achievement, social life and psychological state (Khampalikit, 1983). Asthma not only affects the individual but can create major burdens, both in financial and functional terms, on the family and society (Busse & Holgate, 1995).

Although doctors and other health care practitioners are important in the management of asthma (Bloomberg & Strunk, 1992; Henry, Fitzclarence, Henry & Cruickshank, 1993; Reddihough, Landau, Jones & Rickards, 1978), parents' active and effective involvement is also essential (Christie, French, Weatherstone & West, 1991; Clarke, 1989; Eiser & Town, 1988; Ellis & Friend, 1985; Howell, Flam & Lung, 1992; McNabb, Wilson-Pessano & Jacobs, 1986; Spykboer, Donnelly & Thong, 1986; Staudenmayer, 1981; Tal, Gil-Spielberg, Antonovsky, Tal & Moaz, 1990; Tettersell 1993; Wade, Holden, Lynn, Mitchell & Ewart, 2000). This places a heavy burden on the parents and families of asthmatic children and, although pharmacological management of the disease has improved (Spykboer, Donnelly & Thong, 1986), the quality of life of patients and their families may still be adversely affected by this condition (Eiser & Town, 1988; Townsend, Feeney, Guyatt, Furlong, Seip and Dolovich, 1991).

Children and their families do not live in isolation and there is an interaction between family members. The child's asthma both affects and is affected by the family (Marteau, Bloch & Baum, 1987). Thus, the asthmatic child's family impacts on the child's psychological and physiological functioning and the asthmatic child contributes to the family's stress experience and impacts on the way that the family copes with these chronic strains. Further, because it is a chronic disease and exacerbations (asthma attacks) occur despite good management, asthma tends to place a greater strain on family living than most chronic illnesses do.

Review of the literature indicates that although many studies have been conducted to find out the impact which the family, and the ways in which it functions, has on the child's asthma, very few have looked at the impact which the child's asthma has on family

functioning and lifestyle. That this is an important area is highlighted by studies such as that conducted by Dubo, McLean, Ching, Wright, Kauffman and Sheldon (1961) who found that in many homes with an asthmatic child major housekeeping and other physical changes were necessitated, long hours of otherwise useless drudgery imposed on mothers, many sleepless nights exacted, and numerous and often expensive trips to doctors and hospitals called for. As well as these physical demands there was anxiety – in some families severe and ever present – and a sense of frustration because the trouble seemed to have no end regardless of what was done. Many parents, in the above-mentioned study, expressed feelings of frustration and disappointment, and sometimes even of anger or martyrdom. These factors of fatigue, irritability, anxiety and financial strain all impacted on the family's lifestyle. Dubo et al. (1961) were impressed with the degree to which family dynamics and family life had been altered because of the presence of a chronically ill child.

In a more recent study, Svavarsdottir, McCubbin and Kane (2000) focused on the relationship between family demands, care giving demands, sense of coherence, family hardiness and the well-being of parents with a young asthmatic child. The most time-consuming task identified by mothers was providing emotional support for the child. For fathers, it was providing developmental as well as emotional support for the child. The most difficult care giving tasks for the mother were managing her own fatigue when caring for the child with asthma, handling an asthma episode and managing the discipline and behavioural problems of the child. For the father, it was handling an asthma episode. Because of the challenges that families with asthmatics face in their family life, Svavarsdottir et al. advocated a more holistic health promotion focusing on both the parents and the child.

One of the factors that my study recognizes is the impact of the severity of the child's condition on family functioning. But, rather than focusing on just one or two aspects of the child's asthma that may impact on family functioning, as many studies do, I have chosen to approach the family situation holistically. I have therefore allowed parents to communicate what their unique experiences have been in an attempt to get a better understanding and a broader perspective of the ways in which a child with asthma impacts the functioning of the family. With the increase in the prevalence of asthma there is an urgent need for studies such as this, which will improve our understanding of the impact that the disease has on the family. Understanding how families with asthmatic children function and live will enable

clinicians dealing with these families to optimize the way that they function and, therefore improve the management of paediatric asthma.

1.2 AIM OF THE STUDY

Paediatric asthma can be studied from a number of points of view. Events take place at multiple levels: molecular, biochemical, cellular, organic, organic systemic, psychological, familial, institutional and societal. It is impossible for any study to include all of these aspects, and it is impossible for clinicians to stretch their knowledge and treatment techniques all the way from molecular-biological to societal levels. In this study I will concentrate on the psychological and familial aspects of paediatric asthma.

The primary aim of this study is to investigate the interaction between paediatric asthma and family functioning. The following factors were investigated:

1. Family structure and functioning.

The way in which the family functions as regards:

1.1 Number of people comprising the family unit and its impact on the child's asthma.

1.2 Boundaries that exist within families, and the strength of these boundaries.

1.3 Family rules.

1.4 Shared activities (including shared child care between parents).

1.5 Other interactions between parents, such as economic management, support for the primary child caregiver and resolution of conflict.

2. The interaction between the child's asthma and family functioning

2.1 Stress experienced in the family in relation to the child's asthma.

2.2 The restrictions which the child's asthma places on the child's school activities, exercise/sporting activities, play and social activities.

2.3 The ways in which the restrictions placed on the child impacts on the family.

2.4 Ways in which the family copes with the child's asthma, with a particular focus on self-limitation, denial and re-organisation

2.5 The impact of the child's asthma on the family in terms of finance, time, emotional life and social activities.

2.6 Positive impacts of the child's asthma on family functioning.

3. ***Severity of the child's asthma***

The impact that the severity of the child's condition has on family functioning.

4. ***Parental attitudes about their asthmatic child.***

Attitudes that parents express about their asthmatic child, including:

4.1 Behavioural disturbances in the asthmatic child, and its perceived relationship to the child's asthma.

4.2 Parents' experience of anxiety in relation to the child's asthma.

4.3 Similarities and differences in parents' view of the asthmatic child and other children in the family.

This study is exploratory and no attempt is made to establish causality or the relative importance of the various factors. In any study, it is difficult to determine whether family functioning is specific to asthma, whether it is a consequence of asthma or precedes its development, or whether it is the result of disturbed family relations. These are important questions, but are outside of the scope of this study and can be answered only by specifically designed prospective studies in which asthmatic and control samples of both healthy children and children with chronic illness are randomly selected and the clinical, physiological and allergic aspects of the asthmatic samples clearly defined.

1.3 ORGANISATION OF THE PRESENT STUDY

Systems theory, and its relevance to understanding paediatric asthma, is discussed in Chapter 2. Research that has been conducted on paediatric asthma, and particularly research that focuses on the relationship between paediatric asthma and family functioning, is discussed within the framework of family systems theory.

The research design is presented in Chapter 3. I chose to use the exploratory case study methodology to best meet the objectives of the research. Eight families are included in the study, all of whom had an asthmatic child between the ages of 8 and 15 as a family member. The FAD scale was chosen as a statistical tool to provide a quantified measure to support and add value to the qualitative research.

The case studies are presented individually from Chapters 4 to 11. The interview and the Family Assessment Device (FAD) scores precede a discussion on the findings that were unique to each family.

In Chapter 12, the findings are discussed in the context of family systems theory. Limitations of the present study are discussed as well as suggestions for future research.

CHAPTER 2

ASTHMA AND THE FAMILY:

A SYSTEMS APPROACH

CHAPTER 2

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2.1 INTRODUCTION

A child, living in a family, is influenced by and influences other family members. There is an ongoing interaction between the child and the family in which the child exists. Because of the chronic nature of the condition, the child with asthma introduces an ongoing stressor into the family system. In this chapter, I discuss the interaction between paediatric asthma and the way in which the family functions, from the perspective of system's theory.

2.2 THE INTERACTING SYSTEM

Family systems theory, pioneered primarily by Minuchin (1974) through his work with children with chronic conditions such as diabetes, asthma and anorexia nervosa, postulates an ongoing process of *mutual accommodation* between the system in transformation and the individual's predispositions, vulnerabilities and potential for psycho-social growth. He focussed on the organization of the whole family, i.e. on the rules, boundaries and coalitions, that characterize its structure. However, the roots of family systems theory go back much further as it is the model of the shaman, the traditional healer and the folk healer (Hurd, Pattison & Mansell, 1981).

In primitive society, if a member became sick or was unable to function optimally, it impacted on the entire community. The loss of one worker in a small community would affect each individual in that community. Thus, it was in everyone's interests to restore the person to full function within the social system. The goal of healing was shared by the community and the shaman. The healing procedures were known and understood by everyone and involved the healer, the patient and the community.

Keeney (1979, p.120) postulated the following generalizations relative to systems theory:

- Difficulties in any part of the relationship system may give rise to symptomatic expression in other parts of the system.

- Symptomatic relief at one point of the system may result in the transfer of symptomatic expression to another site.
- Significant change in any part of the system may result in changes in other part of the system.

2.2.1 Systemic versus linear thinking

Researchers, working from a traditional psychology point of view attempted to establish a cause-and-effect link between the family in which the child lived and the development of the child's asthma. These researchers argued that asthma developed as a result of interactions between the child and the family, that the mother was particularly implicated in the development of the child's asthma and, further, that the child's personality had a direct impact on the development of his/her asthma (Creer, Stein, Rappaport and Lewis, 1992; Wood, 1993). One of the problems in cause-and-effect logic is trying to establish the direction in which the primary influence operates. Various research studies have been conducted with the primary objective of challenging the direction of influence. For example, Sarafino (2000) studied the relationship between early temperament and asthma and found that there was no support for a psychogenic aetiology of asthma. Sarafino concluded that associations between asthma and temperament resulted mainly from having asthma.

Although past experiences are acknowledged, family systems thinking is primarily concerned with current relationships, and symptomatic behaviour is understood as performing a function in relation to an unresolved family dilemma. Systems theory is not interested in cause and effect (as the individual psychologies are) but in the current, contextual patterns that exist. Systemic thinking allows us to escape linear-type thinking. It allows us to consider more than straight line, cause-and-effect logic. Linear logic assumes that we can objectively identify discrete events with set beginnings and endings. Systems thinking recognises that we are a part of the events. We influence the drift of events, as we are influenced by other events (Anderson, Lufton & Romney, 1986; Bardill, 1997; Bertonaffly, 1968; Goldenberg & Goldenberg, 1991; Hetherington & Clingempeel, 1992; Keeney, 1979).

Gregerson (2000) discussed two basic subsystem components located both inside (i.e. psychological and physical dimensions) and outside the asthmatic (i.e. social and physical environments). Thus, analysis of the asthmatic person moves from the macro physical surroundings (e.g. impact of smoke and house dust mite) to the interpersonal and group social environments (e.g. ethnicity and socio-economic status), to the micro physiological level (e.g. diagnosis and treatment). It seems clear that asthma may permeate every system in a person's life. Effects can reverberate on all levels, simultaneously on some levels or perhaps on all of them systematically. This begs the question of whether we need to know the cause of asthma to understand and manage the disease and in order to control its effects on family functioning.

In linear terms, A causes B, which acts upon C, causing D. In human relationships this "billiard ball" model, which proposes that a force moves in one direction only and only affect objects in its path is seldom, if ever, relevant. So, searching for the ultimate cause of an interpersonal event is pointless. A does not cause B any more than B causes A. Rather, A and B impact on each other. One needs to look at the system holistically rather than at the actions of the individuals within the system. A child may experience that his mother's anxiety exacerbates his asthma. She, in turn, may feel that his asthma causes her to become anxious. From the perspective of systems theory, the interaction is circular and it makes little difference whether his asthma results in her anxiety or her anxiety results in his asthma. The child's symptoms can be conceptualized as both the cause and the effect of the affective quality of marital, parental and sibling relations. One person's behaviour will reverberate throughout the system, causing changes and responses in other family members. ***Circularity*** then, 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; Keeney, 1979).

Recent studies recognize the complexity of understanding asthma within the context of the family. In their study, Svavarsdottir et al. (2000) established a relationship between resiliency factors (sense of coherence and family hardiness), family demands and the well-being of parents of young children with asthma. Svavarsdottir et al. did not attempt to establish a direction of influence but recognized the complexity of interactions that occur within families. The factors that were included in the study were not perceived to be the only, or the most important, factors interacting in families with asthmatic children. What

this study did, however, was to establish a mutual interaction between the factors under scrutiny.

Williams (2000a and 2000b) focused on another aspect of reciprocal interaction, i.e. gender and asthma management. She concluded that the interaction of gender and health is a complex two-way process. Specifically, in one study (2000b), Williams found that aspects of gender impacted on management of the illness, and that aspects of the condition impacted on the child's construction of their gender. In another study (2000a), Williams found that there was an interaction between the mother's perceptions of the self-care abilities of their asthmatic sons, and their son's gender.

Some studies have focused on the reciprocal influence of emotional factors that exist within families with an asthmatic child. For example, Gupta, Mitchell, Michael Giuffre and Crawford (2000) found that children with asthma had more fears and anxiety than children with either congenital heart disease or no chronic disease, and that increased maternal anxiety correlated with increased child anxiety, fears and behavioural problems. The authors concluded that maternal anxiety may contribute to the child's anxiety but the concept of circularity opens up the possibility of a reciprocal pattern of interaction between mother and child.

Other studies have also focused on the interactional relationship between the mother/primary caregiver and the asthmatic child. Bleil, Ramesh, Miller and Wood (2000) found that the relationship between mother and asthmatic child impacts on the functional status of the child's asthma as well as depressive symptoms in the child. In another study, Wade et al. (2000) found a relationship between caretakers' ineffectual problem-solving and the child's poor asthma function, as well as a relationship between the positive expectations of caregivers and the child's better functional status (severity of the child's symptoms).

Even at a physiological level, there appears to be a complex interaction between factors. Ritz, Claussen and Dahme (2001) studied the effects of emotion induction on total respiratory resistance and their relationship with cardiac vagal activity and facial muscle activity in asthma. They found that stimulation increased respiratory resistance and cardiac vagal activity, and that facial muscle activation during emotional stimulation reduced vagal activity. Thus, moving away from cause-and-effect logic and on to a more inclusive view of

mutual interaction and accommodation highlights the complexity of influences between paediatric asthma and family functioning.

2.2.2 Mutual interaction and mutual influence

Systems theory does not ask why something happened, but rather what is going on, in an attempt to describe the patterns in the exchange of information and the process of relationships between people (Bardill, 1997; Becvar & Stroh Becvar, 1982; Minuchin, 1974). The focus is on the interactions occurring here-and-now rather than on looking to history for antecedent causes. People and events are studied holistically within the context of mutual interaction and mutual influence. The individual is not examined in isolation. Rather, relationships are studied and particularly how individuals interact and influence each other. Each person's behaviour becomes reinforcing feedback for the behaviour of the other. So, the behaviour of one individual is the logical compliment of the behaviour of another individual, and vice versa. We see each member of a family in relation to other family members, as each affects and is affected by the other persons. There is an attempt to transcend either/or dichotomies by acknowledging the necessity for and complementary aspects of both sides of the coin. The focus is on the processes or context that gives meaning to events instead of only on the individuals or events in isolation. Not only do individuals reciprocally influence each other, but relationships within families influence each other. For example, there is a positive connection between the affective quality of the marital and parent-child relationships (Cox, Owen, Lewis & Henderson, 1989). Also, there is evidence that change induced in one relationship subsystem provokes change in other subsystems within the family (Mann, Borduin, Henggeler & Blasske, 1990).

Systems can be defined according to the concept of "*equifinality*", or "*equal ending*". Thus, regardless of where one begins, the end will be the same (Becvar & Stroh Becvar, 1982; Bertonaffly, 1968). People tend to develop habitual ways of behaving and of communicating with one another, which results in redundant patterns of interaction. The complementary of this concept is "equipotentiality", which states that different end states may be arrived at from the same initial conditions. One of the basic assumptions of family systems theory is that you cannot make deterministic predictions about developmental processes. All one can predict is that intervention produces change. One can never

determine precisely what that change will be. The focus is on the here-and-now, on the ongoing interaction and organization and not on the origins of these characteristic patterns and processes (Goldenberg & Goldenberg, 1991; Keeney, 1979).

Systems theory takes the entire *environmental context* of human beings into consideration. Systemic thinking allows us to see the breadth of an event or situation. It moves us forward into the complexities of life. This wider framework does not view behaviour as being independent of environmental conditions or as the product of intrapsychic processes but as the result of the interplay of reciprocal processes between interactional partners. Miller (2000) studied the relationship between poverty, race/ethnicity, asthma prevalence and rates of hospitalization and emergency room use for asthma (in the USA). He found that poverty and Black race were important determinants of emergency room use for asthma but that other factors, particularly marital disruption and a larger number of siblings were also important determinants.

The environmental context is perceived to be a "*unitary interactive system*" (Keeney, 1979) that operates synergistically. This means that the components operating together have a greater total effect than the sum of their individual effects (Bertonaffly, 1968; Keeney & Sprenkle, 1982; Walsh, 1993). The components interact so that each influences and, in turn, is influenced by other component parts, together producing a whole that is greater than the sum of the interdependant parts. This synergism occurs because of interaction. Thus, each individual within a person-event system is functionally and reciprocally related to every other person and environmental factors. This synergism is illustrated by a longitudinal study conducted by Klinnert, Mrazek and Mrazek (1994) to identify risk factors for the onset of asthma. They found that, independently, maternal stress and parenting risk were not significant predictors of asthma onset. However, the synergistic effect of both maternal stress and parenting risk was a significant predictor of the onset of asthma in the child.

The assumption that the individuals within a system, once combined, produce a whole that is greater than the sum of its parts means that systems cannot be understood adequately or fully explained if they are broken down into their component parts. Thus, no element within a system can be understood in isolation since it never functions independently.

There has been a movement towards advocating a more *holistic* approach to help families cope with the stress of asthma. Campbell (1993), in a review of literature on the impact of family factors on childhood respiratory disease (cystic fibrosis and asthma), found that childhood chronic illness was enormously stressful for families. He also found the coping mechanisms that the family used impacted on the course of the illness, and that family psycho-education could provide specific coping skills for parents and lead to better health outcomes.

Richards (1994), in a review of literature focusing on the effect of asthma on the psychological well-being of the patient and the family, highlighted a number of behavioural consequences of asthma. He concluded that there were many ways in which asthma may adversely affect family functioning depending on the severity of symptoms, the family's ability to cope and how the family copes. These included parental anxiety, parental over-protection, parental guilt, parental hostility, attention deprivation of siblings, and fatigue caused by sleep disturbance. He advocated a holistic approach to helping the family cope including disease management, parenting techniques and minimizing family stress and tension.

2.3 INTERACTION WITHIN THE FAMILY SYSTEM

At a *physical level*, the respiratory system and the immune system consist of different organs and perform different functions. At the physical level, they function autonomously. But, at the next higher order system, they operate synergistically to maintain the human body. Even at a physical level, asthma effects and is affected by more than one system. As described earlier, during an asthma attack, the airways narrow and the lung tissue becomes inflamed. Breathing is impaired and the bronchial tubes secrete more mucus, further limiting airflow. The person having the asthma attack starts to panic because they can't breathe and this impairs breathing even more.

In a similar way, the person-environment system is organized in a series of increasingly *inclusive system levels* (Bardill, 1997; Bertonaffly, 1968; Bowen, 1978; Hetherington & Clingempeel, 1992). Each system is identified functionally and qualitatively but is intrinsically related to those systems above and below it in terms of complexity.

The family is a subsystem of the larger surrounding culture. So, society sets the broad outlines for family structure and functioning, yet each family develops its own unique family form and style (Keeney, 1979). Therefore, to understand each family, one must study how that family is in relationship with other families in their broader societal and cultural contexts.

In systems theory, families can also be viewed *horizontally* (Bardill, 1997; Bowen, 1978; Hinde, 1989). There are systems at the same conceptual level, such as families interacting with other families. Radtke and Van Mens-Verhulst (2001) described women with asthma as living in three overlapping discursive worlds: home, work and the world of illness and receiving care. Children with asthma would also live in at least two different systems: the 'normal' healthy world and the world of being sick. Within the family subsystem, brothers and sisters interact with each other. As more people become part of the family system, the system may become a series of interlocking triangles. The concept of wholeness means that a family of five is a very complex system, that comprises five persons, ten relationships (dyads) and twenty-seven triangles, making a total of forty-two units.

Irrespective of whether one views families horizontally or vertically, systems theory has helped us to become more sensitive to the *contexts* in which families function, and how these contexts impact on the environment that parents are able to construct. For example, parenting style has been associated with marital satisfaction, with parents who are maritally dissatisfied being described as less sensitive to their children (Dickstein & Parke, 1988; Erel & Burman, 1995; Goldberg & Easterbrooks, 1984; Jouriles, Pfiffner & O'Leary, 1988; Pratt, Kerig, Cowan & Cowan, 1992). Dyadic marital intimacy has also been associated with interaction patterns of larger family systems, where the level of intimacy between parents is reflected in the intimacy patterns within the family (Waring & Patton, 1984). In the context of family mealtimes, family functioning has been found to correlate with parenting style and sensitivity. Thus, the way in which the family functions at mealtime can be seen as a metaphor for the way in which it functions generally (Pettit & Bates, 1990). A controlling parenting style has been found to be most prevalent in low-functioning families, and teaching and positive social themes were most prevalent in higher functioning families (McFarlane, Ballissimo & Norman, 1995). Finally, parental self-reports of family functioning are related to the dyadic marital satisfaction, and healthy marital relationships

are related to healthy family functioning (Akister & Stevenson-Hinde, 1991; Stevenson-Hinde & Akister, 1995).

The family is a system in which the member components are organized into a group forming a whole that transcends the sum of its separate parts. So, understanding the dynamic relationships among the family members is more illuminating than simply describing the individual members. Relationships between family members are complex, and factions, coalitions and tensions exist. *Causality*, within a family, is circular and multidirectional. Causality is a reciprocal concept to be found in the interface between individuals and between systems. Thus, paediatric asthma is affected by more than one system. For example, Meijer (1976) studied the impact of inter-generational relationships on childhood asthma. He compared generation chain relationships in sixty asthmatic and non-asthmatic children with similar personal and familial backgrounds. He found that asthmatic girls did not show many significant differences from non-asthmatic girls in terms of their generational relationships. He did, however, find significant differences between asthmatic and non-asthmatic boys. The mothers of asthmatic boys had a close relationship with their own mothers and felt rejected by their fathers. The asthmatic boys showed a significantly strong denial of feeling towards their parents and tended to be anxious-depressed like their mothers. Meijer concluded that the combination of feelings that mothers had towards both their parents seems to have influenced their relationship with their asthmatic sons, expressed in dominating over-involvement, irrespective of these children's needs.

Prest and Protinsky (1993), in a paper reviewing co-dependency literature within the framework of systems theory, highlighted the importance of being aware of intergenerational influences within the context of dysfunctional families. Their discussion focused on addiction, particularly alcoholism, but may be relevant to paediatric asthma. The intergenerational family systems model of co-dependency rest on three basic premises: relational patterns are learned and passed down through the generations; current individual and family behaviour is a result of these patterns; and the family system is homeostatic. In families where the members are not well differentiated (the degree to which a person operates in an autonomous manner, especially in the presence of high anxiety) another person will be used as an anxiety-binding mechanism. Eventually the triangle itself becomes pathological, resulting in decreased differentiation as well as one of the members developing a symptom (e.g. asthma). Thus, the symptom may be seen as manifestation of

the family emotional process. It is this process, involving difficulties in developing intimacy and identity that is called co-dependence. These patterns are passed on to future generations when the separating young adult unconsciously seeks out a partner who is at a similar level of differentiation and who manifests complementary relationship patterns. The intergeneration processes are reinforced and transmitted through current relationship functioning.

System levels are not confined only to the human-environment arena but can be identified from the smallest atom to outer space (Bloch, 1984; Keeney & Sprenkle, 1982). On a human level, system levels extend from physiological functioning to the community and society at large. The finding that there was a relationship between individualism and illness-producing immune activity (including asthma) led James (2001) to conclude that a circularity of impact exists in allergic people: the occurrence of immune-related illness could lead to changes in peoples' self-perceptions; an underlying genetic difference could shape both the nature of the psychological self and the tendency towards immune over-activity in some coordinated way without there being a causal relationship between the two; or the cerebral cortex representations of self could exert influences on the immune system.

Given the range of systems interacting within the human arena, selection of the systems levels relevant to a specific problem is a crucial first step. This dissertation focuses on the family system, which is not to say that physiological, intra-psychic and community systems are unimportant.

The family system was chosen as the point of departure because it is a complex system that extends *mutually reciprocal* behaviour from physiological, individual and paired interactions to patterns involving three or more individuals. Family members have an enduring relationship with one another, and actions, changes and events within the system exert effects throughout. Although empirical research based on systems theory is still in its relative infancy there is mounting evidence that examining the complex, interacting, contextual nature of families provides richer, more meaningful insight than any single measures are able to do (Hayden, Schiller, Miller, Keitner, Sameroff & Rasmussen, 1998; O'Connor, Hetherington & Reiss, 1998).

2.3.1 Feedback processes in family systems

Family systems theory was influenced by the development of *cybernetics* in the 1930s and 1940s. It involved many disciplines, including psychology, medicine, physiology, anthropology and economics, and concerned itself with organization, pattern and process rather than matter, material and content. Proponents of cybernetics focused on feedback mechanisms (the process whereby information about past behaviours is fed back into the system in a circular manner), information processing and patterns of communication, and compared living organisms with inanimate objects in an attempt to understand and control complex systems. Gregory Bateson (1979) was one of the most influential cybernetic thinkers, with his ongoing theme of "the pattern that connects". He focused on a common system, a metapattern, which can be applied to all of nature, including families; the pattern of connection. One of the impacts of Bateson's thought was his redefinition of conditions such as schizophrenia that had formerly been viewed purely in intra-psychic terms, as intra-personal, relational phenomenon.

Cybernetics also introduced the notion that we are not outside observers analyzing inputs to and outputs from a system. Rather, as observers, we exist within the larger context and become participants of what is observed. This notion is called cybernetics within cybernetics (Bateson, 1979; Keeney, 1979).

As a system, the family unit balances its need for internal organization and stability with outside demands for adaptation and change. A *dynamic equilibrium* is maintained by making use of positive and negative feedback loops (Bertonaffly, 1968; Brown & Christensen, 1986; Goldenberg & Goldenberg, 1991). Negative feedback is used to maintain family functioning within acceptable normal limits by countering deviation from normal or expected behaviour. Negative feedback indicates that the status quo has been maintained, and it maintains the functional integrity of the system. Positive feedback allows for flexibility and for change in the family system by encouraging new behaviour. It acknowledges that a change has occurred and has been accepted by the system. This is essential to the family's ability to adapt to new situations and conditions (Jasnoski & Schwartz, 1985).

Feedback processes are self-correcting mechanisms. They indicate variation and fluctuations in the system, which serve to increase the probability of survival of the system. Both are important because change and stability are necessary. There are no value judgments associated with positive and negative feedback. For example, a positive pregnancy test and a positive cancer test would have different implications for the individual concerned, as would a negative pregnancy or cancer test.

In a healthy family, *positive and negative feedback* loops work together to maintain stability and promote flexibility to changing conditions (Brown & Christensen, 1986). There is a balance of diverse forms of experience and behaviour, and between the resources available in the family and the individual's physical and emotional needs. Interventions with asthmatic families that take this circularity into account have been found to be successful. For example, Weinstein, Faust, McKee and Padman (1992) reported on the outcome of 44 severely asthmatic children who, together with their families, participated in twice-weekly family sessions that focused on specific behavioural coping techniques. The family was viewed as an essential resource, and the interaction was successful on a number of measurements. These included a reduction in the number of emergency room visits and hospitalization, a reduction in the use of steroids, improvement in lung function, and improvements in family functioning.

Stroh Becvar and Becvar (1988) give *three basic principles* governing family systems theory:

- One cannot not behave: Whatever we do, even if we are sitting still, we are still behaving.
- One cannot not communicate: All behaviour, whether verbal or non-verbal, has message value.
- The meaning of a given behaviour is not the true meaning of the behaviour; it is, however, the personal truth for the person who has given it a particular meaning: reality is subjective and not objective, and all behaviour may be interpreted in more than one way with no one interpretation being more correct than any other.

In a healthy family, *communication* is clear and direct, with a balance between individuals asking for what they need and a fair distribution of resources. Explicit values and sufficient rewards maintain family cohesion. Parental agreement is crucial to healthy family

functioning. If parents have the same goals and agendas their behaviour reinforces each other. Parental disagreement may cause severe strain within the family system and impact negatively on the child (Gardner, 1982).

A number of studies have focused on poor communication patterns in families with an asthmatic child. For example Wikran, Faleide and Blakar (1978) studied the impact of poor parental communication on the family. They focused on the communication patterns of parents of asthmatic children, when a communication conflict was induced. They found that two thirds of the couples studied showed communication that was as efficient as that of the control couples (parents of children with severe chronic heart disease) but one third demonstrated extremely inefficient communication in that they were unable to cope with the experimentally induced communication conflict. These spouses were found to be highly egocentric and demonstrated limited abilities to take each other's perspective. They did not seem to listen to what the other person said, their tolerance for unclear and vague communication was high and they had a tendency to pretend to understand each other. In short, they avoided conflicts. Their communication was "inactive" in that these couples asked fewer questions and had fewer proposals than other couples, and did little to find the causes of their communication difficulties. Wikran et al. (1978) concluded that, for some asthmatic children, pathology in the parents, and particularly regarding their communication patterns, impacts on the child's condition.

Other unhealthy communication patterns, particularly parental criticism, have been studied. Hermanns, Florin, Dietrich, Rieger and Hahlweg (1989) studied the differences in parental criticism and parent-child interaction between families with an asthmatic child and matched controls. They found that significantly more mothers and fathers of asthmatic children were critical of their children than were the control parents. They concluded that maternal criticism could act as a chronic stressor in asthma. However, the authors acknowledged that one cannot determine cause and effect, and that there may be a circularity of behaviours in the family. That is, the stress of asthma in the family may cause more negative and critical family interaction.

Wamboldt, Wamboldt, Gavin, Roesler and Brugman (1995) investigated the relationship between parental criticism and medical treatment outcome across inpatient hospitalization in adolescents with severe, chronic asthma. They found that parental criticism was related to a

clinical presentation of severe chronic asthma but that adolescents responded promptly and significantly to treatment. Thus, this study established the relationship between parental criticism, parent-child conflict and asthma outcome, without establishing the etiology of any factor.

The complexity in understanding poor communication patterns in families with an asthmatic child is highlighted in a study by Gupta et al. (2000). In studying anxiety, fears and behavioural problems in children with asthma, the authors found that the anxious child found it difficult to communicate feelings of anxiety. In another study, Brook and Shemesh (1991) found that overall communication between parents and children with chronic prolonged asthma may decrease.

Stroh Becvar and Becvar's (1988) *third principle* of the influence of the personal meaning that individuals give to behaviour is illustrated by Khampalikit (1983), who studied the child's perception of their illness. He found that those children who perceived their asthma to be moderate or severe were more dependent than those children who perceived their asthma to be mild. Children who viewed their asthma as severe were likely to look to other persons for help in solving problems rather then trying to overcome their problems themselves. These children also seemed to require more emotional support and assistance from their parents in anxiety-provoking situations than children who perceived their asthma attacks as less severe. Thus, not only the asthma per se, but the intra-psychic effects of the asthma impacts on family functioning.

The ways in which parents interpret their child's illness also impacts on the quality of their experience of the illness. Barmettler and Fields (1976) studied parents that attended support groups for parents of hospitalized asthmatic children. They focussed on the psycho-dynamics of the groups rather than on giving information about asthma to parents, believing that parents' active search and request for medical data was an overlay for deeper psychological conflicts and fears. The parents in the groups reported a number of common attitudes and experiences: feelings of duty and resentment; feeling controlled by the child and resentful of the manipulation; feelings of panic, helplessness and fear for the survival of the child with every asthma attack; and feelings of regret and guilt about their inability to help their child. Fathers expressed their hurt at being "left out" but felt powerless to make the situation better for the mother and child. Mothers expressed resentment toward the

fathers for having left them to shoulder the burden alone and feelings of frustration at being unable to communicate with and express affection for their children. Barmettler and Fields' (1976) work has highlighted the complexity of feeling that parents of asthmatic children have to deal with, as they live on a day-to-day basis with a severe and potentially life-threatening disease.

Drummond (2000) gives support to the notion that reality is not external to us but is constructed by us as we bring our own personal perceptions to bear on it and give meaning and order to it. In his study about the quality of life of asthmatics, Drummond found that intrinsic to respondents' conceptualization of quality of life were what they themselves perceived to be important emotional experiences associated with social relationships. He concluded that the existential (i.e. subjective and intuitive) and aesthetic (i.e. emotional engagement with beauty, happiness or goodness) both inform each other and provide a psychological and emotional context for the experience of quality. Drummond thus gave a systemic understanding of quality of life within the context of asthma, as being a complex bundle of relationships, incorporating values, expectations of benefit and experience of happiness or pleasure.

The inability of parents to cope with asthma could be explained, in part, by their misconceptions about the disease. Spykboer et al. (1986) interviewed the parents of 128 asthmatic children and found that a significant number of parents had misconceptions about asthma. For example, one third believed that swallowing a hard object or touching a poisonous plant could set off an asthma attack. Spykboer et al. concluded that providing knowledge to parents about how to manage asthma had limited success, and that programs aimed at parents to improve asthma management would have to include strategies aimed at dispelling myths and misconceptions about asthma. Further, that misconceptions about a disease would not only impact on compliance and other management behaviour but also on the type of coping strategies that parents develop.

Other studies that had similar findings and conclusions were conducted by Kling, Ebrecht and Gie (1997) and by Moosa and Henley (1996). These studies highlight the importance of understanding the personal meanings that people attach to what they experience, rather than what medical science "knows" to be fact.

2.3.2 Response to change

The extent to which a system screens out or permits the input of new information into the system refers to the *openness or closedness* of the system (Bertonaffly, 1968; Goldenberg & Goldenberg, 1991; Simon, Stierlin & Wynn, 1985; Stroh Becvar & Becvar, 1988). At either extreme, the system is said to be in a state of entropy, i.e. tending towards maximum disorder and disintegration. When there is an appropriate balance between openness and closedness the system is said to be in a state of negentropy (or negative entropy), i.e. tending towards maximum order. The more-or-less free exchange of information within a family and between the family and the outside world helps reduce uncertainty, thus avoiding disorder. The exchange of information is essential to all living, ongoing systems, as more information is fed back and alterations in output are made in response to the new input. The more open the family system is, the more adaptable and open it is to change. Open systems have the ability to change their internal structure by incorporating new information into the system. Such a system tends not merely to survive but to thrive, to be open to new experiences and to alter or discard patterns that are no longer viable. Closed systems run the risk of sealing themselves off from all but necessary exchanges with the outside world, and will eventually become dysfunctional because of insufficient input.

Gupta et al. (2000), in their study on the anxiety, fears and behavioural problems of children with asthma, found that newly diagnosed children were more anxious than those with long-standing illness. The authors concluded that most families go through a 'grieving process' as they change lifestyles and accept the disease. Thus, most families have the ability to change their internal structure and incorporate the ramifications of the asthmatic child's illness into the system. But it is not just the family that learns to cope. The individual with asthma appears to go through a similar process. Huberty, Austin, Huster and Dunn (2000) studied schoolgoing children with asthma and found that they improved in academic performance and adaptive functioning behaviours over time.

In a healthy family system the rules and procedures necessary to carry out such family functioning as child-rearing are consistent and are reviewed when circumstances change. *Rules* are characteristic relationship patterns within the system (Bertonaffly, 1968; Simon et al., 1985; Stroh Becvar & Becvar, 1988). They express the values of the system and the appropriate behaviour within the system. Rules form *boundaries* and denote the

separateness of a system or subsystem. Neither the rules nor the boundaries are visible. Simon et al. (1985) refer to rubber boundaries, i.e. boundaries that help family members to maintain a sense of tolerable relatedness and to decrease the threat of divergence from within and intrusion from without. Boundaries are inferred from the repeated patterns of behaviour within a system. Within the family, boundaries circumscribe and protect the integrity of the system, determining who is considered as an insider, and who remains outside. A system with a high level of information flow to and from the outside is considered to be an open system, while one whose boundaries are not easily crossed is considered a closed system.

Within the family, boundaries differentiate subsystems, helping define and separate sub-units of the overall system. Such units must be sufficiently well defined to allow subsystem members to carry out their tasks without undue interference, while at the same time open enough to permit contact between members of the subsystem and others (Minuchin, 1974). Boundaries thus help safeguard each subsystem's autonomy, while maintaining the inter-dependance of all of the family's subsystems. Most families fall somewhere along the continuum between enmeshment (rigid boundaries) and disengagement (diffuse boundaries). Enmeshment refers to an extreme form of proximity and intensity in family interaction in which members are over-concerned and over-involved in each others' lives. Disengaged families have members that may function separately and autonomously with little sense of family loyalty. As Minuchin (1974) illustrates the parents in an enmeshed family may become very upset if a child does not eat dessert, where a disengaged family will be unconcerned about the child's hatred of school. Minuchin's discussion gives insight into the way that different families respond to stress, whether it is a minor or a major change in the system.

Wolf Tatem and DelCampo (1995) discussed a major change in the system, i.e. selective mutism in children, within the context of family systems theory. They found that literature supported the notion that selective mutism in children is a family problem, and that family structure, role distribution and modeled behaviour contributed to its occurrence and maintenance. The symptom in the child (mutism, asthma) could therefore be an indication of rigid boundaries and compliance to family rules. For example, if the spousal dyad is weak and unsupportive, a mother-child subsystem could become overly strong while the father continued to withdraw. A family rule could be "mother is the one who really cares

about the child; the child will not cope away from the mother". So, the child, in compliance with this rule and to reduce anxiety when separated from the mother, does something to make separation less likely, i.e. the child becomes symptomatic in the mother's absence.

Further, in healthy systems there is a balance between morphostasis and morphogenesis (Bray & Williamson, 1987; Goldenberg & Goldenberg, 1991). *Morphostasis* is the system's tendency towards stability, and it serves to maintain the system in a state of dynamic equilibrium. *Morphogenesis* is the system's enhancing behaviour that allows for growth, creativity, innovation and change (Stroh Becvar & Becvar, 1988). *Homeostasis* refers to the concept of dynamic equilibrium, i.e. the system's ability to self-regulate, and to maintain a steady state despite the changes in the outside environment. It refers to the family's ability to maintain internal balance and a stable environment. Goldenberg and Goldenberg (1991) make the analogy between balance and a thermostat, which is set to cause the furnace to respond if the temperature in a house drops below a predetermined level. If the temperature drops below the set point, that information is fed back into the system activating the furnace. When the desired temperature is reached that new information is fed back into the system, which is deactivated until the temperature drops again. The system achieves balance by maintaining a dynamic equilibrium around a set point. Thus, homeostasis refers to the state in which stability and equilibrium is achieved between the need for change and the need to control change in order to maintain the integrity of the system. Feedback is the regulating mechanism by which a system maintains homeostasis whilst, at the same time, monitoring attempts to achieve goals. Feedback loops are circular mechanisms that feed information about a system output back to its input in order to alter, correct and govern the system's functioning.

Systems theory emphasizes a *developmental perspective* (Goldenberg & Goldenberg, 1991). Families go through different phases, i.e. marriage, the arrival of children, the school going years, children leaving home. Each milestone causes a crisis, which has to be dealt with within the family system. These are common crises to all families but other disruptions occur, such as divorce, moving, death and illness. External demands for adaptation and change also places stress on the family system. For example, changes in the national economy, periods of stress at work and school and other changes affect the availability of resources and demands made on family members. The family must attempt to deal with developmental tasks as well as the crises that require mastery at each stage. Thus, every

family lives in an ever-changing context, and certain key transitional points are universal. Both continuity and change characterize the family system as it progresses through time. The changes may be orderly, gradual and continuous or they may be sudden, disruptive or discontinuous. Both call for organizational transformations within the family system.

Those families that can successfully *adapt* to these changes experience less disruption. Wasilewski et al. (1988) interviewed 228 low-income Black and Hispanic mothers of children with asthma. Their aim was to find out whether participation in the care of asthma by the father would reduce maternal stress due to childhood asthma. Wasilwski et al. found that families who moved outside the traditional paradigm of the mother as the sole caregiver experienced less stress. In particular, they found that when fathers shared the task of caring for chronic childhood asthma, whether or not they were living in the home, mothers experienced less disruption in their daily lives. Thus the healthy family is creative and resilient in adapting to changing conditions, crises or periods of stress in which resources are diminished. This study also demonstrates that not all the difficulties that a family experiences in coping with change need result in symptomatic behaviour. The stress on the family system may provide an opportunity for the family to break out of its customary coping patterns and develop more productive and growth-enhancing responses to change.

In discussing the integration of managing the child's asthma into the family's everyday functioning, Fiese and Wamboldt (2000) emphasized the importance of recognising that families are organized systems that develop and undergo change. Children are often diagnosed with asthma during their preschool and early school years and management of their asthma must change to meet the needs of the developing child and their family. Thus, effective management strategies are sensitive to development changes in the family and involve multiple family members. Further, adherence to management strategies improves the child's disease status and thus supports healthier psychosocial and physical functioning.

The findings in a study conducted by Markson and Fiese (2000) supported the complexity of impacts in paediatric asthma. They examined the relationship between family rituals and the child's personal report of anxiety in families with a child with asthma. They found that family rituals did not operate any differently in families that had a child with asthma and those that did not. They did find, however, that when multiple indicators of family health were considered (i.e. life stress, family health and child health), family rituals may protect

the child from anxiety. Thus, their findings point to the interrelationship of factors in the adjustment of an asthmatic child: family rituals may play an important role in stabilizing the family and providing meaning in the face of life events and daily stressors involved in the management of a chronic illness; family rituals may serve as a guide for families as they cope with the challenges of disease management; families that have already organized their lives around daily routines may be better equipped to integrate disease management into their lives; and families that experience more chaos in their lives may find that implementation of daily routines serve to stabilize their lives. They conclude, "... we cannot claim that rituals themselves protect children. Likely, family rituals are only one component of the complex system of family effects on child adjustment" (p. 478).

2.3.3 Circularity

Within the frame of reference of the family, problems are reconstructed to take into consideration the fact that an individual family member's behaviour cannot be understood without attention to the context in which the behaviour occurs (Brown & Christensen, 1986; Goldenberg & Goldenberg, 1991). The appearance of symptoms is not viewed as emanating from a single 'sick' person, but rather the individual is perceived as a symptom bearer, expressing the family's disequilibrium or dysfunction.

The malfunctioning family could be both a cause and a sustainer of problem behaviour (Sundberg, Taplin & Tyler, 1983). The breakdown of any of the family functions produces a state of imbalance or disequilibrium. As the family becomes increasingly dysfunctional, symptomatic or irrational patterns of behaviour may be employed by family members in an attempt to maintain the marginal stability of the imbalanced system. Thus, asthma can be viewed as a symptom of the dysfunctional family, as reflective of the state of the family, determined by the family history, by the processes at work within it and the challenges to which it must adjust. The child is not disturbed but the child's behaviour is the result of the complex interactions between the child and the family system in which it is occurring. The child's symptomatic behaviour is thus functional within a dysfunctional family system. For example, if there were repeated conflict between parents this would represent a serious imbalance in the system and although the child could not correct the source of the conflict he or she could display behaviour that disrupted the cycle each time it occurred. However, in doing so the child would take onto himself the stress of the family imbalance in an

attempt to maintain the stability and survival of the family system. The functionality of chronic childhood illnesses has found support in the observation of families with a chronically medically ill child. Gerson (1993) notes that when the child's illness remits or is cured, previously "psychologically well-adjusted" siblings often become psychologically symptomatic.

One study that illustrates this *reciprocity* was conducted by James and Arnold (Stern, 1981). They found that parental attitudes vary from rejection and intolerance of the disease to overprotection and cosseting, and that the asthmatic child was over-dependent on his/her mother. They concluded that the child was unable to express hostility towards the parents and turned this hostility inwards. The asthma attacks occurred in compliance with the mother's desire to control the child and the mother's over-protective attitude sought to bind the child in a dependent situation. This study also highlights the problem of blame. The child's behaviour can easily be misinterpreted as the source of marital and family problems.

Family systems theory does not apportion blame (Auerswald, 1985). In the same way that the child is not to blame for the deviance occurring within the family system, so the family is not to blame. Family systems theory does not suggest that families instead of individuals be considered disturbed. The family does not intentionally "create" the symptom because it "needs" it to function. Rather, this model rejects any linear interpretation and postulates a circular model with the symptomatic child and family involved in a transaction of mutual accommodation. Individuals within a family are not seen in isolation but rather as interacting and influential members within a family context. There is an interactional relationship between the physiological aspects of asthma, the interrelationships in the asthmatic child's family, the child's physical environment as well as other contexts such as the hospital and school environment. The parents both affect and are affected by the child's asthma and vice versa. In studying another chronic disease, i.e. diabetes, and its impact on family life, Marteau et al. (1987) concluded that there was an undeniable relationship between family and illness and that a specific illness will both affect and be affected by the family context. Thus, it appears to be necessary to think of a complex of mutually interacting factors, i.e. biological, psychological and social, that contribute to the child's asthma and the way in which the family functions.

The *circularity of interrelationships* between mother and child is well illustrated by a study by Marcuse (1976). Marcuse was interested in a repeated observation that asthmatic children vary significantly in the degree to which emotions can be implicated as precipitants of their symptoms (EP). She found that mothers of high EP (emotion precipitants) asthmatic children were less responsive to their children's displays of emotional distress and more responsive to their symptoms than mothers of low EP asthmatics. Marcuse postulated that high EP asthmatic children learn that their feelings are ignored but that wheezing gains rapid maternal attention and nurturance. This finding suggests a circularity of relationship, where family members accommodate other family members in order to achieve their objectives.

In another study, Byrne and Murrell (1977) asked 65 mothers of asthmatic children to complete a self-description questionnaire. The results confirmed the obsessional, anxious and over-protective characteristics of mothers of asthmatic children that previous researchers had found (Block, 1969; Williams, 1975). However, Byrne and Murrell interpreted these results within a cyclical model and postulated that these maternal behaviors are a response to the child's illness and, further that these behaviours reinforce and therefore prolong the occurrence of the asthmatic symptoms in the child.

The asthmatic child's family impacts on the child's physiological and psychological functioning, and the asthmatic child contributes to the family's stress experience and impacts on the way the family copes with these chronic strains. Carson and Schauer (1992) studied 41 mothers of asthmatic children. They found that perceived parenting stress was greater, the quality of mother-child relationship was more problematic and children were perceived to have more behavioural difficulties amongst the mothers with asthmatic children than for a comparison group of mothers with healthy children. They concluded that mothers and their asthmatic children may be at risk for a variety of individual and relational problems.

Circularity is also demonstrated in another study conducted by Hilliard, Fritz and Lewiston (1985). They studied functioning amongst families of asthmatic, diabetic and healthy children. They found that differences between parents of chronically ill children and parents of healthy children were not inevitably associated with psychopathology and, in fact, may be adaptive in coping with the child's illness. Rather than interpret these findings to mean

that mothers who were over-concerned and over-protective, in some way caused their child's asthma, these researchers concluded that the child's behaviour and the mother's reaction was a response to a long-continuing illness.

The impact of asthma on the family is even more profound if the child's asthma is *severe*. Staudenmayer (1981) studied the effects of childhood asthma on parents (159 mothers and 70 fathers) and found that the degree of parental anxiety experienced was related to the frequency of hospitalization required. In other words, the amount of debilitation experienced by the child and the more severe the child's asthma, the worse the parent's quality of life.

Other studies have also focused on the impact of the severity of the child's asthma on the family's functioning and quality of life. McNichol et al. (1973) studied asthmatic children and compared them with control group children. The children were assessed at 7, 10 and 14 years of age, and the focus was on behavioural disturbances in the child, the mother-child and family relationships, and the family social structure. They found that behaviour disturbances occurred more often and at statistically significant levels only in the small group of children with severe and continuing asthma, i.e. those children with severe chronic airways obstruction as assessed physiologically and also with the most severe allergic manifestations. Mothers of children who continued to have severe asthma at 14 years of age were found to be over-concerned and over-protective. Thus, it appears that the greater and the more prolonged the stress, the more reactive the system will become.

Further, the families of the very severely affected groups of children showed evidence of more stress than other families. In particular, McNichol et al. (1973) found greater resentment between the parents; fewer fathers taking responsibility for the family's economic management or sharing it with mothers; and fewer joint family activities, compared to the control group. Thus, the symptoms could be perceived as metaphors for the ecology of the relationship system. There is no individual, group or etiological factor to blame; i.e. neither the child, the parents, the siblings nor the asthma is to blame. The symptoms are expressions of dysfunctionality throughout the system.

Not only the family but also the child with asthma experiences more stress if their asthma is severe. In a study conducted by Gupta et al. (2000), it was found that children with severe

asthma have to face greater physical and emotional challenges: there is a reduction in physical activity, diminished stamina, difficulty in keeping up with peers, having to cope with the side effects caused by long-term medication, absenteeism from school, sport and social activities, and feeling left out of their peer group.

Klinnert, McQuaid, McCormick, Allen, Adinoff and Bryant (2000) studied asthmatic children as well as healthy children all aged six years old. They established a relationship between severity of the child's asthma and behavioural disturbances in the child. These behavioural disturbances included reported behavioural functioning (e.g. "The child has nightmares"), as well as observed negative reactions to tasks that induced anxiety and frustration (e.g. withdrawal, aggression). Interviewers and raters were blind to the child's group status (asthma or control) as well as the clinical severity of the asthma. These findings are consistent with the findings of Mrazek, Klinnert, Mrazek and Macey (1991), who described negative affect and emotional dysregulation among pre-schoolers with severe asthma.

Duvdevany and Harel (2000) also established a relationship between severity of the child's asthma and severity of the behavioral problems of children with asthma. In their discussion as to why there was this relationship, Duvdevany and Harel described the following experiences that may impact on the behaviour of severely asthmatic children: numerous periods in hospital, stressful medical treatment; separation from home and families, physical discomfort and allergic symptoms.

However, it would be simplistic to conclude that the severity of the child's asthma has the major influence on family functioning and coping. Baron, Veilleux and Lamarre (1992) studied 34 asthmatic children and found strong associations between certain personality traits and an excessive use of medication, and between personality traits and family structure. Regardless of the severity of their asthma, children with high levels of anxiety and dependence were more likely to live with highly cohesive families and to use greater quantities of cortisone than children with better adapted personality structures.

A number of studies have focused specifically on the circularity of the relationship between asthmatic children and their families. McLean and Ching (1973) studied the relationship between family situation and asthma ten to twelve years after an original investigation. The

original study (1961), in which McLean and Ching collaborated with Cubo, Wright, Kauffman and Sheldon, established that there was no relationship between the family situation, the severity of asthma and response to treatment. However, they did demonstrate a close relationship between family situation and the child's adjustment. That is, a significant number of children with labile asthma came from families with poor inter-relationships. In the 1973 study McLean and Ching focused on asthmatic children requiring hospitalization. They found that only one of the eight patients, referred to a children's psychiatric hospital because of asthma and severe emotional problems, came from a family who was regarded as having good interfamilial relationships. They also studied a second group of asthmatic children whose emotional problems required psychiatric hospitalization. They found that fifteen of the 27 patients suffered from chronic, severe asthma. The findings led McLean and Ching (1973) to conclude that the deciding factor was not the child's asthma but the emotional status of both child and family, with the recognition that the asthma may add a new problem requiring therapeutic intervention through the coordinated efforts of allergists, child psychologists and case workers.

2.3.4 Healthy and dysfunctional families

Many theorists have devoted much time describing healthy families (Goldenberg & Goldenberg, 1991; Minuchin, 1974; Stroh Becvar & Becvar, 1988). Healthy families care for each other, support each other, share rituals and traditions and celebrate each other. They enjoy uniqueness and togetherness as individuals and as a family. They may fight but, because they know that they belong, they have the courage to be imperfect.

In a healthy family the *symptom* moves from one member to another. A whole, integrated personality is not necessarily one who is always symptom-free. The healthy person may be a bit symptomatic (e.g. depressed) at times. What is pathological is to be symptomatic or symptom-free consistently. In a healthy family, no one member is stuck with carrying all of the family's anxiety all of the time. This is a potential problem for families who have an asthmatic child. Asthma is an ever-present, potentially fatal condition and by its very nature would focus attention on the sufferer, possibly more than would be healthy.

Stroh Becvar and Becvar (1988) go into some detail about the *characteristics of healthy families*, within the context of family systems theory. These characteristics include:

- a hierarchical structure with a strong parental/marital coalition and appropriate generational boundaries
- a caring and nurturing atmosphere supportive of both individual differences and family growth 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 all feelings
- a systemic 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.

This framework accommodates interactional processes as well as structural and cultural variations in families. Stroh Becvar and Becvar (1988) assert that this model may be used to assess and understand families in terms of their unique characteristics and contexts.

It appears that the *coping mechanisms* used by the family impacts on the child's experience of asthma. Meijer and Oppenheimer (1995) compared 20 families with a child suffering from controlled asthma to 20 families with a child suffering from uncontrolled asthma. The results showed significantly more cohesion and structure in the group with a child suffering from controlled asthma. They concluded that the occurrence of cohesion and a structured form of adaptation in families with a child suffering from asthma must be seen as a coping mechanism employed by the family in the interests of the sick child, and should not be interpreted negatively.

There are a number of ways in which the family can respond to the stress of asthma. Faced with change, the family system may respond with self-limitation, denial or reorganization. *Self-limitation* involves the choice to avoid the environmental demand by limiting one's activities or potential. So, an asthmatic child may choose not to take part in sport because of the potential risk of an attack with its consequent disruption on the family. Second, the

family may *deny* the existence of the demand. This involves establishing a consensus of unreality by convincing the affected family member that there is no problem so that no change is necessary. So, the family of the asthmatic child may refuse to make any concessions or changes because of the child's asthma. Thirdly, the family could acknowledge the demand and enter into a process of communication and negotiation to *reorganize the system* and to establish new routines to cope with the new environmental situation. So, the parents of an asthmatic child may decide to share the child-care load so that no one person is fully responsible for caring for the asthmatic child. The success of shared responsibility has been illustrated by a study conducted by Wasilewski et al. (1988).

Thus, the ways in which the family system copes with the child's asthma impacts on the asthma itself as well as on family functioning. Mailick Holden and Walther (1994) explained the effects of asthma on families and the coping strategies used by caretakers. Childhood asthma was found to impact on the family in the areas of financial burden, social and familial isolation and personal strain. Caretakers reported a number of ways in which they coped with the strains on them. The authors interpreted the coping mechanisms as helping the caretakers to redefine asthma and to reduce its effects.

2.4 CONCLUSION

It is apparent from the above discussion that family systems theory has moved the study of the asthmatic child outside the realms of traditional intra-psychic psychology, with its focus on the individual. Family systems theory has allowed us to study the child's asthma within the context and complexity of the systems within which it operates, the most important of these being the family system. Families have a defining and formative effect on the individual members. Many of the descriptions that researchers give of families with an asthmatic child appear to be pathological. However, it is important to note that what looks like pathology may be the stress of readjustment to a new structure, and of accommodation to change. According to Minuchin (1974) pathology must be reserved for those few families who, in the face of stress, increase the rigidity of their boundaries and resist any exploration of the alternatives. What makes families with an asthmatic child so fascinating is that they constantly have to adjust to an ever-present stressor, over which they have little or no control. Families with an asthmatic child offer a unique situation of study because their adjustment to stress is a day-to-day challenge.

CHAPTER 3

RESEARCH METHODOLOGY

CHAPTER 3
RESEARCH METHODOLOGY

3.1 INTRODUCTION

While recognising the complexity of interactions that occur in a family with an asthmatic child, this study focuses on the specific interactions that occur between paediatric asthma and family functioning: family structure and functioning; the impacts of the child's asthma within the family; parental attitudes towards the asthmatic child; and the impact of the severity of the child's asthma on family functioning. In this chapter, I discuss the methodology chosen to best meet the objectives.

3.2 BACKGROUND: IN SEARCH OF A RELEVANT METHODOLOGY

The step-by-step study of cause and effect sequences and the breaking down of phenomena to their most basic elements, as in traditional methods, are not relevant to the study of families within the paradigm of family systems theory. With systems theory came a shift in thinking that was more holistic, and the realization that families cannot be reduced to the smallest common denominator. Traditional experimental design imposes a definition of reality on the data that may be convenient but may also fail to untangle the complexity of systemic phenomena. By breaking phenomena down to the smallest unit in order to make investigations more precise, scientists may inadvertently destroy the possibility of ever really knowing the phenomena they set out to study. The complexity of relationships that occur within families has to be acknowledged and an attempt made to study the family systemically.

The assumptions of traditional scientific methodology are incompatible with the following underlying assumptions of family systems theory:

- Many viewpoints of what constitutes reality exist, rather than a single "objective" reality.
- Multiple causalities account for most events, not simple cause-and-effect sequences.

- The wholeness of the system should be the unit of study, not smaller and smaller units to ensure "scientific" rigor.
- The researcher must search for systemic connections, not explanations based on linear causality.
- The researcher must recognise their subjective involvement (cybernetics of cybernetics), and make no attempt to be an "objective" observer of events.

Early studies on families attempted to compare family interaction patterns in "healthy" and "disturbed" families (Riskin & Faunce, 1972). These studies did not deal adequately with the complex methodological issues involved (e.g. comparable sampling).

Ideally, research should be based on observations of family members interacting. However, this approach has a number of disadvantages: it is very time-consuming for both the family and the assessor; the behaviour of families in the observation setting may not generalize to their behaviour in the real world; family observations generate vast amounts of data, which are both difficult and expensive to reduce to clinically meaningful dimensions; and families would need to be studied over time, i.e. family observations would have to include patterns that anteceded the onset of disorders as well as observations of the accommodations that members made to the presence of the disorder. Further the family may not be perceived in the same way by observers with different points of view. There could be differences of opinion among family members, and family members are likely to perceive things differently from observers (researchers).

Another approach would be to collect information on each family member (and on dyads and triads in the family as well). The information on these sub-units could then be combined to provide a description of the family system as a whole. Like family behaviour observation, this approach has the disadvantages of being time-consuming and expensive.

To be in line with systems theory, it must be acknowledged that families can never be understood in any important degree without investigating their ongoing processes in real time, through repeated observation, and over the span of developmental time. This is clearly unattainable, but this ideal must not preclude researchers from attempting, within the limitations of time, space and finance, to extend our knowledge of family functioning and interaction.

3.3 THE EXPLORATORY CASE STUDY METHOD

The most appropriate method to investigate the interaction between the child's asthma and the family's functioning is the exploratory case study method. This method was used in this study, and the data was collected via in-depth, face-to-face interviews with parents who had an asthmatic child. In the words of Lofland and Lofland (1984, p. 258), these interviews were, "a guided conversation whose goal is to elicit from the interviewee rich, detailed material that can be used in qualitative analysis...the intensive interview seeks to discover the informant's experience of a particular topic or situation."

A case study is an excellent method for examining the behaviour of a few individuals in great detail. Case studies are important because they are exploratory in nature. New, and perhaps important, hypotheses may be revealed that could not have been uncovered in a more controlled investigation. The very lack of control that characterizes case studies and allows circumstances to vary, increases the method's potential for revealing findings that might not otherwise appear.

Jean Piaget (1952) used the case study method to investigate the intellectual capacities of preschool children. Previous studies that he had conducted were formal and focused on pre-selected measures. They provided a descriptive account of the growth of children's abilities but they led to relatively little understanding of the underlying processes of intelligence. Piaget used his own children in an unstructured case study method. He gave little attention to control and allowed situations to wander in an effort to get the greatest possible grasp of the intellectual processes involved in the child's answers to various questions. Piaget's discoveries about children's thinking have subsequently been replicated in extended and more systematically controlled studies (e.g. Elkind, 1961; Flavell, 1963). These studies would probably not have been initiated without Piaget's original non-directive, open approach and his reliance on uncontrolled case studies.

3.4 SUBJECTS

Subjects were the parents of asthmatic children between the ages of 8 and 15. All respondents were English or Afrikaans-speaking, had at least a high school education and lived in the Gauteng (South Africa) area. Children and their parents had no history of

psychiatric treatment and were free of physically handicapping conditions. Apart from asthma, the children were free of any chronic illness. Three paediatric pulmonologists in the Gauteng area were approached to supply the names of potential respondents. A total of 8 couples (i.e. 16 respondents) was randomly selected from a total list of 52 couples. The child's doctor furnished an objective measure of the severity of the child's asthma.

3.5 PROCEDURE

All interviews took place in respondents' homes. This gave the interviewer an indication of some of the behavioural parameters that existed in the home setting as a result of the child's asthma. The interviews took between one and two hours and took place outside of working hours, i.e. in the evening or on Saturday afternoon. Couples were interviewed together. The interviews were tape-recorded and later transcribed for analysis. All the couples interviewed were the biological parents of the asthmatic child. The names of the respondents are not their real names, and pseudonyms have been used.

Eight interviews were conducted. All but one of the asthmatics were boys, which is a higher proportion of boys than the worldwide epidemiological male:female ratio of 2:1 (Busse & Holgate, 1995). As diagnosed by their paediatric pulmonologist, one asthmatic was mild, four were mild to moderate, one was moderate to severe and two were severe. Three of the asthmatics were only children, one had a brother and four came from families with three children.

The interview was conducted in two parts. Initially, each of the parents was given the McMaster Family Assessment Device (FAD) questionnaire to complete (see Section 3.6.2). Couples did this exercise on their own with no discussion between the partners. Once the FAD questionnaire was complete, the interviewer put them to one side and continued with the in-depth interview. Questions in the qualitative interview (see Section 3.6.1) generated information about the current thinking and perceptions of the respondents as regards their personal experience of asthma. Because of the flexibility inherent in the technique additional valuable information, not included in the discussion guide, was solicited. Transcripts of the interview are available on request.

3.6 INSTRUMENTS

In order to fully understand the impact of paediatric asthma on family functioning and lifestyle, the following instruments were used: in-depth, face-to-face interviews with parents who have a child with asthma (see Addendum A for a copy of the discussion guide); and the McMaster Family Assessment Device (FAD) (see Addendum B).

3.6.1 The interviews

The discussion guide focused on a number of issues that the literature suggested were of importance to the asthmatic child's family. Parents were asked about:

a. Family structure and functioning

The ways in which the family is structured and functions are discussed on a number of levels:

- The number of people comprising the family unit.
- The boundaries that exist within families.
- Family rules.
- Shared activities (including child care).
- Economic management.
- Support for child caregiving.
- Resolution of conflict.

b. Impact of the child's asthma on family functioning and lifestyle

Parents' perceptions of the ways in which the child's asthma has impacted on the family are discussed:

- Stress experienced in the family.
- Restrictions on the child's school, exercise/sporting, play and social activities.
- Ways in which the family copes with the child's asthma.
- Impact of the child's asthma on the family in terms of finance, time, emotional life and social activities.
- Positive impacts on family lifestyle and functioning.

c. Severity of the child's asthma

Parents' perceptions of the severity of their child's asthma, and the impacts that the child's condition has on family functioning and lifestyle. Similarities and differences in families with severe, moderately severe and mildly asthmatic children are discussed.

d. Parental attitudes

Attitudes that parents express about their asthmatic child are discussed, including:

- Behavioural disturbances, and its perceived relationship to the child's asthma.
- Stress and anxiety related to the child's asthma.
- Comparison between the asthmatic child and their siblings.

3.6.2 The Family Assessment Device

The McMaster Approach is a comprehensive model of family theory assessment and treatment. It consists of three assessment instruments: the Family Assessment Device (used in this study), the McMaster Clinical Rating Scale and the McMaster Structured Interview of Family Functioning. The McMaster Model of Family Functioning, of which the FAD is a self-report questionnaire, is based on systems theory. Crucial assumptions that underly both systems theory and the McMaster model are (Miller, Ryan, Keitner, Bishop & Epstein, 2000):

- All parts of the family are interrelated.
- One part of the family cannot be understood in isolation from the rest of the family system.
- Family functioning cannot be fully understood by simply understanding each of the individual family members or subgroups.
- A family's structure and organization are important factors that strongly influence and determine the behaviour of family members.
- The transactional patterns of the family system strongly shape the behaviour of family members.

The Family Assessment Device (FAD) describes structural and organizational properties of the family group and the patterns of transaction among family members which have been found to distinguish between healthy and unhealthy families (Akister & Stevenson-Hinde,

1991; Epstein, Baldwin & Bishop, 1983; Stevenson-Hinde & Akister, 1995). For this study, the purpose of the FAD was to explore functioning that was unique to families with an asthmatic child and to establish possible differences in family functioning. It also offered a quantitative measurement, to support and challenge the qualitative interviews.

The McMaster Model of Family Functioning consists of six dimensions of family functioning, as well as a general functioning scale, which assesses the overall level of family functioning (i.e. a total of seven dimensions). Mean norms for the general population have been established, and any score above the norm is considered to be unhealthy. These seven dimensions may be assessed by (a) the Clinical Rating Scale (CRS) (Epstein et al., 1982), designed for observations made during a semi-structured interview of the whole family, or (b) by a self-report questionnaire, the Family Assessment Device (FAD) (Epstein et al., 1983). The FAD scale was used in the current study and the following dimensions of family functioning were investigated: problem solving, communication, roles, affective responsiveness, affective involvement, behaviour control and general functioning. An explanation of each of these dimensions follows (see Addendum B for the questionnaire):

a. Problem solving

Problem solving (mean norm = 2.3) refers to the family's ability to solve problems at a level that maintains effective family functioning. Five dimensions are identified, and these include statements that relate to the mechanical problems of everyday life (e.g. "We usually act on our decisions regarding problems"), as well as those related to feelings and emotional experiences (e.g. "We resolve most emotional upsets that come up").

b. Communication

Communication (mean norm = 2.3) is defined as the exchange of information among family members. The focus of the six communication items is on whether verbal messages are clear with respect to content (e.g. "When someone is upset the others know why"), and direct in the sense that the person spoken to is the person for whom the message is intended (e.g. "When we don't like what someone has done, we tell them").

c. Roles

The measurement for Roles (mean norm = 2.4) focuses on whether the family has established patterns of behaviour for handling a set of family functions. Eight items were used to establish the provision of resources (e.g. "We discuss who is to do household jobs"), nurturance and support (e.g. "We make sure members meet their family responsibilities"), support for personal development (e.g. "There's little time to explore personal interests"), and maintenance and management of the family systems (e.g. "When you ask someone to do something, you have to check that they did it").

d. Affective responsiveness

Affective responsiveness (mean norm = 2.4) includes six items, and assesses the extent to which individual family members are able to experience appropriate affect over a range of stimuli. The quality and quantity of feelings are considered. Quality relates to the full spectrum of feelings in human emotional life as well as the appropriateness of these feelings (e.g. "We express tenderness"). Quantity focuses on the degree of response (e.g. "Tenderness takes second place to other things in our family"). For an effective affective family life, there should be the potential for the full range of affective experiences that are appropriate in quality and quantity of response.

e. Affective involvement

Affective involvement (mean norm = 2.2) is concerned with the extent to which family members are interested in and place value on each other's activities and concerns. The seven items included on this dimension focus is on how much, and in what way, family members show an interest and invest themselves in each other. It does not simply refer to the extent to which the family does things together (e.g. "We are too self-centered") but to the degree of involvement among family members (e.g. "We show interest in each other when we can get something out of it personally").

f. Behaviour control

Behaviour control (mean norm = 2.0) includes eight items, and assesses the way in which a family expresses and maintains standards for the behaviour of its members. Behaviour in different situations are considered, as are different patterns of control. Three types of situation are considered: physically dangerous situations where the family monitors and controls the behaviour of its members (e.g. "We don't know what to do when an emergency

situation comes up"); situations that involve meeting and expressing psychobiological needs or drives such as eating, drinking, sleeping, eliminating, sex and aggression (e.g. "We have no clear expectations about toilet habits"); and situations involving interpersonal socializing behaviour among family members and with people outside the family (e.g. "Anything goes in our family").

g. General functioning

General functioning (mean norm = 2.2) is an independent encapsulation of the above six dimensions. It includes twelve items, and indicates overall health or pathology. (e.g. "Individuals are accepted for what they are"; "Making decisions is a problem for our family"; We confide in each other").

The FAD is a paper and pencil questionnaire, which can be filled out by all family members over the age of twelve. For the purposes of this dissertation, it was completed by the parents of asthmatic children. The items on the questionnaire are statements a person could make about his or her family. So, like other family assessment questionnaires, it measures people's perceptions of their families. Each family member (in the case of this dissertation, the parents) rates his or her agreement or disagreement with how well an item describes their family by selecting among the four alternative responses: strongly agree, agree, disagree, strongly disagree. The FAD is scored by summing the responses for each subscale (negatively worded items are reversed), and dividing this figure by the number of items in each scale. Higher scores than the FAD means reflect worse family functioning, and the higher the score the less healthy the functioning. Thus, individual scores range from 1.0. (best functioning) to 4.0 (worst functioning)

The FAD can be used to identify particular areas of difficulty within the family (e.g. problems with communication) and between husband and wife, as identified by significant differences between the individual rating scores.

3.6.2.1 Reliability of the FAD scale

The FAD was developed by Epstein, Baldwin and Bishop (1983), from a sample of 503 individuals (including 112 families), and originally contained 240 items. In its current form it contains 53 items, which make up seven scales. Table 3.1 (Epstein et al., 1983) shows the

number of items, reliability levels, means and standard deviations for each of the seven scales based on the responses of the 503 individuals in the original sample. The internal consistencies of each scale range from .72 (Roles) to .92 (General Functioning).

Table 3.1 Reliabilities, Means and Standard Deviations of the Seven Scales of the FAD (N=503)

	Number of Items	Reliability (Chronbach's *alpha*)	Mean	Standard Deviation
Problem Solving	5	.74	2.3	.47
Communication	6	.75	2.3	.51
Roles	8	.72	2.4	.43
Affective Responsiveness	6	.83	2.4	.61
Affective Involvement	7	.78	2.2	.50
Behaviour Control	9	.72	2.0	.41
General Functioning	12	.92	2.2	.58

Items were selected on the six dimension scales (excluding general functioning) according to three criteria. First, the items had to be written for the relevant dimension. Second, the set of items making up the scale had to be as highly correlated as possible so that the scale had maximal internal consistency. Third, the items in the scale had to correlate more highly with that scale than with either the General Functioning scale or the other five dimension scales. The scale construction process was a recursive one. Each time the set of items making up a scale was modified, the correlations between that scale and the individual items, and the scale and other scales changed. The item selection process for a scale stopped when the scale reliability was over a specific minimum (alpha = .70), and either there were no items to add which would increase reliability, or an item, which might increase the scale reliability, would also increase the correlation of that scale with one of the other scales. This procedure resulted in a scale consisting of between five and twelve items. The scales are different sizes because the number of items in a scale is only indirectly related to the selection criteria.

Table 3.2 (Epstein et al., 1983) shows the correlation between the seven dimension scales, including the General Functioning scale. Correlations range between 0.4 and 0.6, and thus the scales are moderately independent.

Table 3.2 Pearson product moment correlations among the seven FAD scales (N= 503)

	PS	CM	RL	AR	AI	BC	GF
PS	-	0.66	0.49	0.62	0.54	0.43	0.76
CM	0.66	-	0.50	0.67	0.57	0.38	0.75
RL	0.49	0.50	-	0.50	0.55	0.37	0.60
AR	0.62	0.67	0.50	-	0.61	0.41	0.76
AI	0.54	0.57	0.55	0.61	-	0.42	0.71
BC	0.43	0.38	0.37	0.41	0.42	-	0.48
GF	0,76	0.75	0.60	0.76	0.71	0.48	-

PS = Problem Solving; CM = Communication; RL = Roles;
AR = Affective Responsiveness; AI = Affective Involvement;
BC = Behaviour Control; GF = General Functioning

The partial correlations between the dimension scales approach zero when General Functioning is held constant. Table 3.3 (Epstein et al., 1983) shows that the variance shared between the dimension scales is for the most part accounted for by the variance that each shares with the General Functioning scale. Thus, each dimension scale measures an independent variable, and correlates with the General Functioning scale.

Table 3.3 Partial correlations among the six dimension scales, with the effect of general functioning removed (N = 503)

	PS	CM	RL	AR	AI	BC
PS	-	0.23	0.08	0.12	0.01	0.11
CM	0.23	-	0.10	0.23	0.08	0.03
RL	0.08	0.10	-	0.10	0.23	0.12
AR	0.12	0.23	0.10	-	0.16	0.08
AI	0.01	0.08	0.23	0.16	-	0.13
BC	0.11	0.03	0.12	0.08	0.13	-

PS = Problem Solving; CM = Communication; RL = Roles;
AR = Affective Responsiveness; AI = Affective Involvement;
BC = Behaviour Control

3.6.2.2 Validity of the FAD scale

Epstein et al. (1983) compared the FAD scores of individuals from families, which presented with psychological symptoms with those that did not. They found that the means on the seven FAD scales for individuals in the non-clinical group was lower (more healthy) than the means for the clinically presenting group. Overall the results were highly statistically significant ($p < 001$).

In another study, Epstein et al. (1983) interviewed a random sample of 178 retired couples, to look at retirement adjustment. They collected data using the FAD, the Philadelphia Geriatric Morale Scale, and the Locke Wallace Marital Satisfaction Scale, and used regression analysis to study concurrent validity. The FAD predicted 28% ($r = 0.53$) of the variance on the Lock Wallace for both husbands and wives analysed separately. Thus, the two measures were assessing related phenomena. In a test of predictive validity, the FAD also predicted 22% ($r = 0.47$) of the variance in the morale scores for husband and 17% ($r = 0.41$) of the variance for wives. In a parallel analysis the Lock Wallace predicted only 11% ($r = 0.34$) of the variance for husbands and 13% ($r = 0.36$) for wives. Epstein et al. concluded that the FAD was the more powerful predictor.

Luescher, Dede, Gitten, Fennel and Maria (1999) assessed problem areas within family functioning studies of families with ill children, and found that the FAD appeared more sensitive in detecting dysfunction than global family assessment measures such as the Family Environment Scale. The FAD compares favourably with the Family Unit Inventory and FACES II, which also measure family functioning (Akister & Stevenson-Hinde, 1991). Further, it has some cross-cultural validity and has been used in families receiving therapy in the UK (Goodyer, Nicol, Eavis & Pollinger, 1982) and in Hungary (Keitner, Ryan, Fodor, Miller, Epstein & Bishop, 1990).

Kabacoff, Miller, Bishop, Epstein and Keitner (1990) applied factor analysis to the six subscales and found that 92% of the items loaded highest on the factor that they were hypothesized to represent. The General Functioning Scale was considered separately and found to correlate highly with the principal component of the other items, supporting its use as a global index of family functioning. The results provide strong support for the validity of the instrument.

3.6.2.3 FAD scale analysis

The FAD questionnaire was completed by all the respondents. Husband and wife completed the questionnaire separately. For each family, individual scores mapped around the FAD mean are given to show the level of agreement and/or disagreement between the mother and father. A family score was obtained by summing the mother and father's rating and dividing by two. These scores have been included to identify those couples who are 'at risk' according to two criteria. The first criterion is to have a family score above the cut-off point established for each dimension by the authors of the FAD (Kabacoff et al., 1990). The second criterion is to have large mother/father disagreement on any of these scores, which are particularly significant if they lie on either side of the norm. Because of the small sample, it was not possible to compute statistical significance for the scores. Large differences between couples, and scores that lie in the 'unhealthy' range formed the basis of the discussion on the families' FAD scores.

3.7 CONCLUSION

The FAD measurement offers a simple quantitative scale that is easy to administer and score. The in-depth interview and the results of the FAD are discussed in conjunction, with each adding value and insight to the other. The FAD scale was included with a view to offering statistical support for the findings from the qualitative interview.

Chapters 4 to 11 cover the case studies, and are each presented in a separate chapter. For each family, a paraphrasing of their story (the interview) and the findings of the FAD scale precede a discussion of the unique findings relevant to the family.

A discussion of all the findings follows in Chapter 12. In this chapter, the general findings as well as those insights unique to specific families are discussed within the context of family systems theory.

CHAPTER 4

THE SNYMANS:

A CHILD-CENTRED FAMILY

CHAPTER 4
THE SNYMANS: A CHILD-CENTRED FAMILY

4.1 FAMILY BACKGROUND

George and Jean are in their early forties and have three boys: Andrew, who has asthma, is ten years old, Stephen is nine years old and Kevin is five. George and Jean thought that Andrew's asthma was mild and the paediatric pulmonologist agreed with this assessment, saying it was mild to moderate.

4.2 THE INTERVIEW

My interview with George and Jean took place on a Saturday afternoon, after the boys' club soccer and before afternoon sports on television began. The three boys were playing in the garden with the dogs and Jean's parents were visiting but we went straight through to the dining room, closed the door and were interrupted only once, when 'granny' brought us some tea.

George was eager to talk and answered most of the questions, even if I addressed them to Jean. Often, he would allow her to answer first and then add his answer. George answered all of the questions about finance and claimed to handle all the finances himself.

Child-care was primarily Jean's responsibility. George worked longer hours than Jean did, and she undertook the majority of the child-care during the week, with George getting involved after-hours and over weekends. It was clear that the family spent most of their leisure hours together, with the parents being intimately involved in their children's school and sporting activities. Apart from her husband, Jean received support from her maid and from her parents and sister. Thus, the extended family was closely involved with the family's life.

Time spent together, as a couple, was minimal. Jean and George said that their only time together was when the boys were asleep. Both would like to spend more time together but

felt that it was a period in their lives and would improve when the boys were a bit older. Before their children were born, they enjoyed seeing movies together, and occasionally saw one now, but not as often as they would like. Topics of conversation between the couple ranged from education to friends and the state of the country. George specifically said that they did not talk about work, particularly his, because Jean found it boring. Their main shared interest was friends and socialising, usually at their home or at the homes of friends. Both of them were interested in sports and involved in their own sports (he played golf and squash, and she swam and went to gym) but they did not do any sports together as a couple. Family activities centred round the older boys' sports, playing in the garden at home and socialising with friends. Most of their friends had children the same age and Jean, in particular, saw this as an opportunity for her boys to socialise, particularly with girls. Thus, this couple portrayed themselves as being very family-centred, with their children being the main focus of their time spent together and being an integral part of their social lives.

Jean and George found it difficult to talk about how they resolved conflict. Replies were very short, with little detail. George said, "We are very bad about that. Jean won't talk to me for days." Jean did not comment but George said that they eventually talked through problems.

Andrew, who is ten years old, was diagnosed with asthma at the age of seven. His major symptom is coughing and it was a coughing spell during a swimming lesson that alerted a friend to the possibility of asthma. This friend referred them to her husband, a paediatrician, who confirmed the diagnosis.

Management of Andrew's asthma appears to be Jean's responsibility. George's attitude was that it is a treatable disease and any exacerbations that Andrew experiences are because Andrew is not managing his condition properly, i.e., he does not take his medication, he eats or drinks something that he should avoid or he exercises too much. Some of the comments that George made were, "It was a worry initially but now it is a case of 'its treatable so let's treat it.'" And, "His attacks seem to be brought on by not taking his maintenance medication, so it is self-induced, so he gets little sympathy."

Jean, too, was anxious to perceive her son as "a normal little boy". Although, she claimed, "I protect him to the nth degree", she did not want to restrict his activities because of his

asthma. She did, however, check that he had taken his medication, particularly before he took part in athletics and other sports that could exacerbate the asthma.

For Jean, the major negative effect of Andrew's asthma was that he was difficult to manage after a night spent coughing. Lack of sleep made Andrew tired, irritable and lethargic. The first word she used to describe Andrew was "difficult", and this response was related to those occasions when his temper was short due to lack of sleep.

Emotionally, neither Jean nor George seemed to experience major stress because of Andrew's asthma. They both talked about feeling worried initially but once they realised that Andrew's asthma was not serious or life threatening their anxiety disappeared. Thus, their attitude appears to be related to the perceived severity of the condition.

Financially, the family experienced little real stress. Although medical aid limits were reached by the middle of the year, this did not create major financial problems for the family. Although they were not happy about the medical bills, they were able to meet them.

The perceived positive impact of Andrew's asthma was focussed on two aspects, both of which were practical and not emotional. The first aspect, and this was spontaneously brought into the discussion early on in the interview, was that there was no smoking in the house. George smokes but he no longer smokes inside and visitors are not allowed to do so. The other aspect was dietary. Jean has taken Andrew to see a kinesthesiologist, who advised her on a diet for Andrew. This has made Jean more diet conscious and she felt that the benefits have been passed on to all the family members. It is clear that Andrew finds it difficult to be compliant to the dietary restrictions even though they have a positive impact on his condition. "He has things like weak black tea but every now and then I walk into the kitchen and he's glugging down a litre of milk. And five minutes later he'll be coughing."

Both George and Jean were adamant that their attitude toward Andrew was not affected by his asthma. His position in the family, as the oldest child, was perceived to be much more important than his condition. "I don't think there is even a little bit of difference in my head because he is asthmatic. He does have a few privileges because he is older, like going to bed half an hour later than Andrew. But there are no differences because he is asthmatic."

Andrew was perceived to be different to his younger brothers in that he liked to be inside and preferred sedentary occupations, such as playing computer games, to playing outside and participating in sport. George said that Andrew's greatest punishment was to deprive him of his computer. For both Jean and George, the similarities between their children was greater than the differences were. They were all competitive, demanding and sometimes naughty. In other words, "they were little boys."

George expressed his concern that Andrew was a high achiever who has learned how to cope with not coming first but was still stressed by his need to achieve. Physically, George would like Andrew to get more exercise. Neither George nor Jean were particularly prescriptive about their aspirations for Andrew. "He must just keep on doing what he is doing but he must go back to doing some sport." "I think that he must be happy in whatever he chooses to do. Long-term, that he is well adjusted and responsible."

As far as Andrew's asthma was concerned, George and Jean do not expect it to get better or worse. They do not expect Andrew to outgrow his asthma. For them, Andrew should get to know his own body and adjust to his life-long condition.

George and Jean perceive their son to be generally serious but, occasionally, a comedian. They are proud of the fact that he questions a lot and does not take anything at face value. He prefers the company of girls because, they think, he is more mature than his peer boy friends. He has a competitive relationship with his brother Stephen, who is a year younger than he is and a protective relationship with his brother Kevin, who is five years younger than he is.

The words that Jean used to describe Andrew were 'difficult' and 'caring'. George said he was 'moody', 'easy' and 'bright'.

George and Jean, thus perceive their asthmatic child, Andrew, to be a normal little boy, who happens to have a condition that is treatable and that they have under control. The paediatric pulmonologist assessed Andrew's asthma as mild to moderate, and Andrew's parents felt that his asthma had had a minimal impact on their lives as a couple and as a family.

4.3 THE FAD SCALE

Jean and George were shown a list of statements and asked to rate their level of agreement with each statement on a four-point scale (strongly agree, agree, disagree, strongly disagree). George and Jean completed the FAD questionnaire separately, without discussing it with each other. Figure 4.1 shows the *individual mean scores* for George and Jean as well as the FAD norm. Individual scores for George and Jean are to be found in Addendum C. Figure 4.2 shows the *family mean score* (the combination of George's and Jean's scores) and the FAD norm. Scores on the following dimensions were compared: problem solving, communication, roles, affective responsiveness, affective involvement, behaviour control and general functioning. High scores on the FAD scale mean unhealthy functioning.

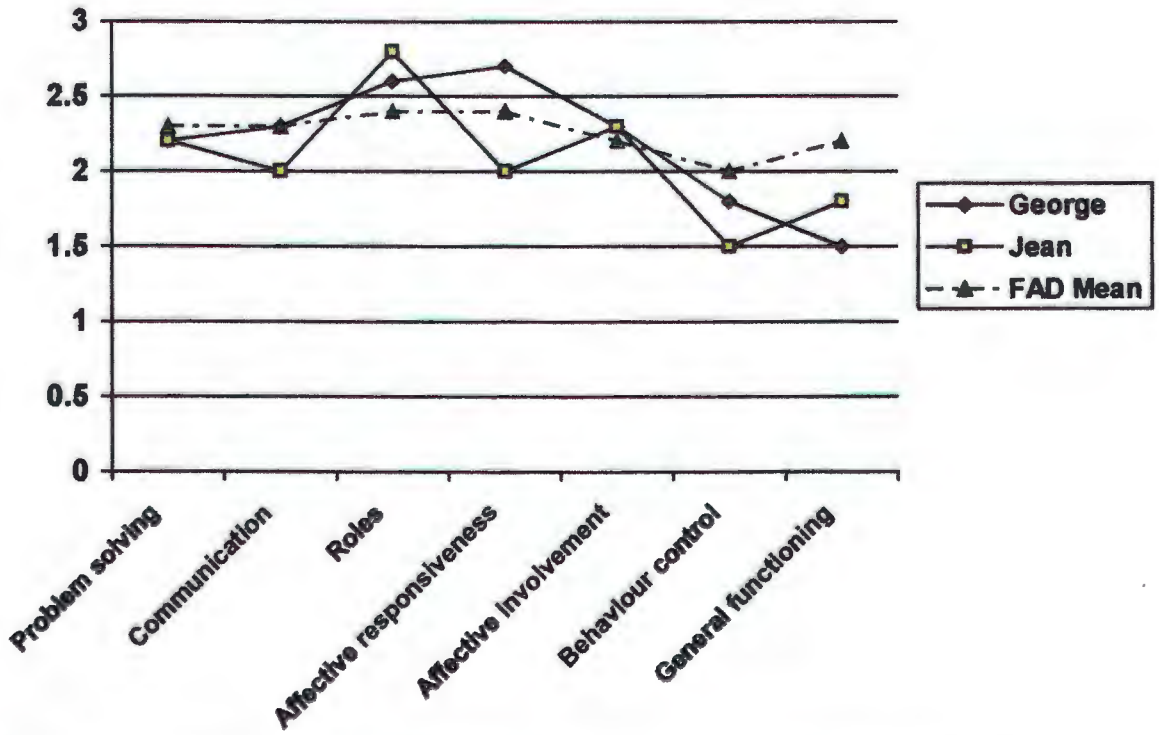

Figure 4.1 Comparative individual mean scores for the different categories in the FAD scale: George and Jean

The joint family scores (Figure 4.2) were all below the FAD norms (i.e. they were all in the healthy range) except for one dimension: *'Roles'*. For this dimension, Jean (2.8) and

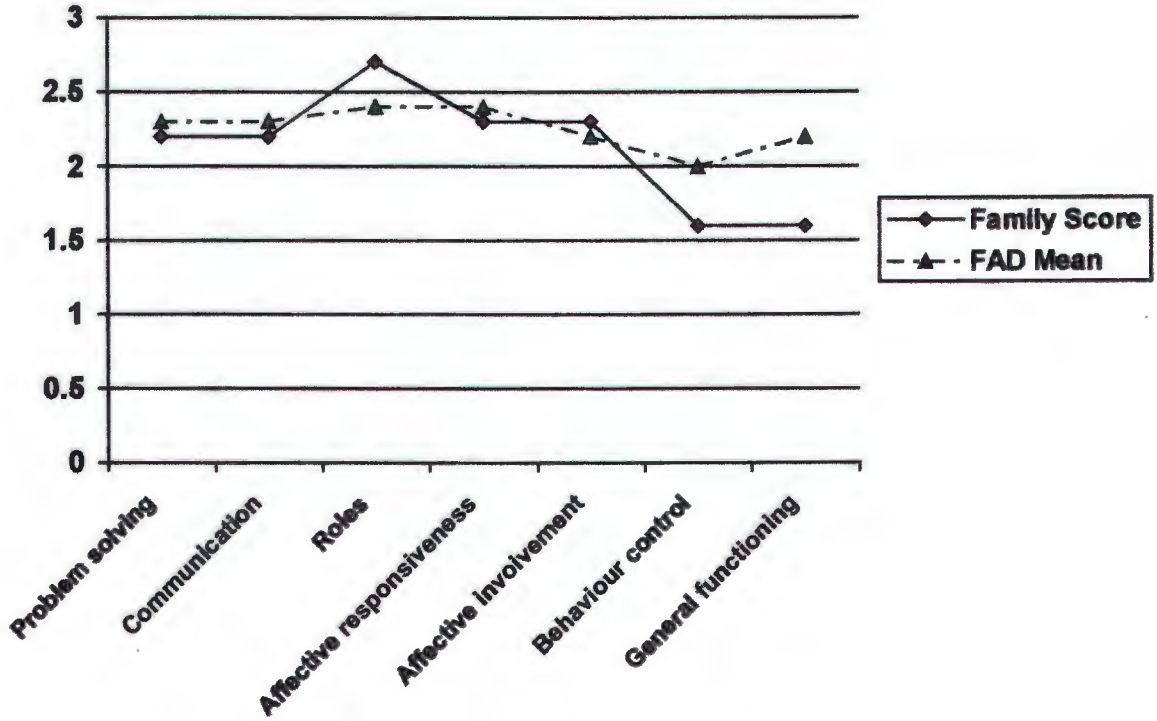

Figure 4.2 Comparative family mean scores for the different categories in the FAD scale: the Snyman family

George (2.6) both gave a higher rating than the FAD mean (2.4) on the individual scale (Figure 4.1), indicating that this couple felt less effective in establishing responsibility for family tasks. This score could be an indicator of the age of their children, with both parents feeling burdened by the responsibilities of a young family.

Certainly, their description of family functioning during the interview indicated that they put their children's needs and interests ahead of their own but expected that there would be a shift in focus as their children grew older.

On *affective responsiveness*, the joint family score (2.3) was below the FAD norm of 2.4 (Figure 4.2), which means that the joint score for George and Jean was in the healthy range. However, there was a significant difference between George's score (2.7) and Jean's score (2.0) on the individual scale (Figure 4.1), and their scores were on either side of the norm. This indicates that George is less accepting than Jean of the emotional demands existing in

the family. George's comment during the interview that he gives little sympathy to Andrew when he has an asthma attack because he believes they occur when Andrew does not take his maintenance medication is an indicator of his lack of emotional empathy with Andrew. However, George's higher score may well be associated with the demands of a younger family, and may not persist over time.

On *affective involvement*, the joint family score (2.3) was just above the FAD norm of 2.2 (Figure 4.2), which means that the joint score for George and Jean was just within the unhealthy range. George and Jean's individual scores were the same (2.3), meaning that there was agreement on the level and degree of involvement that they each wanted. Further, the interview did not uncover any major problems in this area and George and Jean's scores are so close to the healthy norm that one cannot draw any conclusions about unhealthy functioning in this area.

On *problem solving*, *communication*, *behaviour control* and *general functioning*, George and Jean's individual and joint scores were on or below the healthy norm, indicating that this couple solve problems constructively, communicate effectively and agree on the control of behaviour in the family. The general functioning score, which lies within the healthy norm, means that although this couple shows some disagreement, there is consensus on important issues and the family functions in a healthy way.

4.4 DISCUSSION OF THE EFFECT OF ANDREW'S ASTHMA ON THE SNYMAN FAMILY

The concept of *circularity* (Bardill, 1997; Becvar & Stroh Becvar, 1982; Minuchin, 1974) is well-illustrated at a number of levels in the Snyman family. Briefly, circularity allows us to look outside of cause-and-effect logic and to view a system holistically (Bertonaffly, 1968; Keeney, 1979). The focus is on looking at the current situation, and specifically at the processes or contexts that give meaning to events. Jean and George's response to the perception of the severity of their son's asthma is an example of circularity. When Andrew was initially diagnosed with asthma, both parents reported feeling anxious. When they were told that his asthma was not life threatening, their anxiety levels dropped. Jean's feelings of anxiety only rise again when Andrew is symptomatic. Thus, there is a circularity between perception of severity, feelings of anxiety and behaviour. Andrew's asthmatic symptoms

reverberate throughout the system, causing changes and responses in other family members. This supports the finding by Mann et al. (1990) that change induced in one relationship subsystem provokes changes in other subsystems within the family.

The circularity of affecting and being affected by the child's asthma is apparent in a number of other specific aspects of this family's functioning. At a physiological level, Jean described the impact of Andrew's asthma on his sleep and coping patterns and vice versa. One of Andrew's main symptoms is coughing, which means that, when he is symptomatic, he does not sleep well. Lack of sleep makes Andrew tired, irritable and lethargic, and that in turn impacts on the way in which he is able to cope with his asthma. This illustrates circularity as a reciprocal pattern of interaction in which an event (Andrew's lack of sleep) can be both the effect of an earlier event (coughing) and the cause of a later event (poor coping) (Keeney, 1979).

Circularity is also apparent in Andrew's level of involvement in sport. George and Jean said that Andrew was not as active as their other two sons. Rather than play outside, he preferred to play on the computer and pursue other indoor activities. There appears to be a pattern of behaviour and response here. Sport exacerbates Andrew's asthma whereas indoor activities have no effect on his condition. Thus, his preference for indoor rather than outdoor pursuits is reinforced by a reduction in symptoms and his likelihood to pursue outdoor activities is curtailed by an increase in symptoms when he does play outdoors. This illustrates one of the three ways in which the family can respond to the stress of asthma, as described by Stroh Becvar and Becvar (1988), i.e. self-limitation (the other two responses described are denial and reorganisation). Self-limitation involves the choice to avoid the environmental demand by limiting one's activities or potential. Thus, Andrew chooses not to play outdoors because of the potential risk of an attack.

These two observations (the effect of Andrew's coughing and his self-limitation of outdoor activities) illustrate Marteau et al.'s (1987) conclusion that it appears necessary to think of a complex of *mutually interacting* factors, i.e. physiological, psychological and social that contribute to a child's asthma and the way in which the family functions. Further, it supports Campbell's (1993) conclusion that, because of the complexity of childhood chronic illness, a more holistic approach is necessary to help families cope with the stress of asthma.

I have already touched on the notion of feedback in my discussion of Andrew's level of involvement in sport. Understanding *feedback* (Goldenberg & Goldenberg, 1991; O'Connor & Lubin, 1984; Stroh Becvar & Becvar, 1988) is integral to understanding circularity. *Negative feedback* is used to maintain family functioning within acceptable normal limits by countering deviation from normal or expected behaviour. Negative feedback maintains the functional integrity of the system, and always operates within the system's interpretation of what is normal. Further, it is specific to the system under consideration. So, it is not surprising that George will use Andrew's love of the computer as a tool when implementing negative feedback. George said that Andrew's greatest punishment was to deprive him of his computer. This illustrates one of the three basic principles governing family system theory put forward by Stroh Becvar and Becvar (1988), which states that the meaning of a given behaviour is not the true meaning of the behaviour. Rather, the meaning is subjective and is given a particular meaning by the individual. Thus, Andrew's reaction to the restrictions on the amount of time he could spend on the computer would be different to the reaction of one of his brothers.

Negative feedback is also illustrated by the response that Andrew has when he eats or drinks something that the dietician identified as a trigger for his asthma. George said that Andrew would start coughing soon after he drank milk. His symptom can, therefore, be viewed as a negative feedback to his action. Further, once diet had been established, within the family system, as a factor exacerbating Andrew's asthma, it allowed for internal judgements and, therefore, negative feedback. So, if Andrew ate or drank something that had been identified as a trigger of his asthma, his father said that he 'had no sympathy for him.'

Positive feedback allows for flexibility and change in the family system by encouraging new behaviour. It acknowledges that change has occurred and has been accepted by the system. This is essential to the family's ability to adapt to new conditions and situations. The Snyman's response to and acceptance of their son's asthma illustrates positive feedback. Andrew's asthma has been acknowledged, changes in the system have been put into place in terms of medication, diet restriction and attitude, and George and Jean have accepted that it is a life-long condition that Andrew must adjust to.

Positive and negative feedback work together to maintain stability and promote flexibility to changing conditions. Thus, in the Snyman's case both positive and negative feedback work

together to allow for acknowledgement of Andrew's asthma without allowing it to become central to the way in which the family functions.

In their acknowledgement of the existence of a physical disease the Snymans were *open to change*. There would have been no change if they had not acknowledged the condition. However, one of the basic concepts of family systems theory is that you cannot make deterministic predictions about developmental processes. All one can predict is that intervention produces change. In the Snyman's case, one of Jean's responses was to consult a dietician for advice about Andrew's asthma. The dietician introduced a new way of eating, not only to Andrew but to the entire family. Thus, Andrew's asthma produced change throughout the family system. This illustrates one of Keeney's (1979) generalizations for systems theory that change (e.g. asthma) in one part of the system may result in change (e.g new diet) in other parts of the system. Jean's response also illustrates one of the ways in which the family responds to stress (Stroh Becvar & Becvar, 1988), i.e. reorganisation. One of the other responses, self-limitation, has already been discussed in this chapter. Reorganisation means that the family acknowledges the demand and enters into a process of communication and negotiation to reorganise the system and to establish new routines to cope with the new system.. Thus, Jean consulted a dietician and established a new way of eating for the entire family in the hope that it would have a positive effect on Andrew's asthma.

Systems theory emphasises a *developmental* perspective (Goldenberg & Goldenberg, 1991; O'Connor & Lubin, 1984). Families go through different phases, i.e. marriage, arrival of children, school-going years and so on. Each milestone indicates a crisis that must be dealt with within the system. The family must deal with developmental tasks as well as the crises that require mastery at each stage. Both continuity and change characterize the family as it progresses through time. Families that successfully adapt to these changes experience less disruption. Jean and George said that currently their time together was limited but they recognized that this was a period in their lives and they expected to spend more time together when their children were less demanding. Thus, this couple acknowledged the current crisis but dealt with it within the context of understanding that the context would change, bringing with it a new way of interacting. The healthy family is creative and resilient in adapting to changing conditions and crises (Wasilewski et al., 1988), and the Snyman family appears to be healthy. Further, in analysing their reported perceptions and

behaviour, this family appears to have most of the characteristics of healthy families, as described by Stroh Becvar and Becvar (1988) (See pages 33 and 34 for a discussion on these characteristics).

The conclusion that Jean and George's reported attitudes and behaviours are characteristic of a healthy family is supported by the results of their FAD scores. There was agreement between George and Jean on issues related to problem solving, communication, affective involvement and general functioning, and the scores on these dimensions were in the 'healthy' range. In particular, parental agreement as regards communication is crucial to healthy family functioning (Stroh Becvar & Becvar, 1988). A number of studies have shown that pathological parental communication patterns impact negatively on the child's asthma (Gardner, 1982; Hermanns et al., 1989; Wamboldt et al., 1995; Wikran et al., 1978).

4.5 CONCLUSION

George and Jean have three boys, with Andrew, the asthmatic, being the eldest. The Snymans have a very busy household, and both George and Jean said that their children took up a lot of their time. Andrew's asthma has had some impact on the family's functioning. For example, Andrew has been put onto a new restricted diet and smoking has been banned inside the house. Thus, the couple has responded to the stress of Andrew's asthma by re-organising the family system and establishing new routines. Apart from these changes, George and Jean said that because Andrew's asthma was not severe (it has been diagnosed as mild to moderate), it has had little impact on the family's finances, emotional life, social life and allocation of time. The stress and anxiety that Jean experiences are confined to those periods when Andrew is symptomatic and having an asthma attack.

George and Jean did not feel that Andrew was different to his brothers in any significant way. They did not think that he behaved differently or was treated differently because he was asthmatic, and felt that any difference in their treatment of him and in his behaviour was related to his personality, his temperament and to his position in the family rather than to his asthma.

George and Jean portrayed a family unit where there was agreement on the important issues, where individual interests and opinions were encouraged and in which the couple centred

their lives round their family. The Snymans provided an example of a family that functioned in a healthy way, and that had integrated their child's asthma into the family unit in a positive and supportive manner.

CHAPTER 5

THE HOWARDS:

A FAMILY OF INDIVIDUALS

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THE HOWARDS: A FAMILY OF INDIVIDUALS

5.1 FAMILY BACKGROUND

Susan is in her mid forties and Wesley is in his mid fifties. The marriage is his second and her first. Wesley has three children from a previous marriage. The couple have two children, James who is eighteen and Sarah, who is fourteen. Both children are asthmatic but the discussion focussed on Sarah, who the parents perceive to be more severely asthmatic, and who is in the correct age bracket for this dissertation. The paediatric pulmonologist assessed Sarah's asthma as severe, in line with the couple's perception of the severity of her condition.

5.2 THE INTERVIEW

The interview with Susan and Wesley took place one evening. It was 7 pm and Wesley had just returned from work. We sat in easy chairs, around a coffee table, with the sound of children and family activities in the background.

Susan answered most of the questions, often in great detail. She liked to give her opinions on each issue. She often answered for Wesley, getting tacit approval for what she was saying by reading his body language. After the interview she was anxious to tell me that he suffered from Parkinson's syndrome, which had made him more placid and unemotional than he had previously been. Wesley did not talk often and, when he did, he did not go into any detail. Susan is a free-lance journalist and Wesley is involved in a family business, a large art gallery in Rosebank, Johannesburg.

Wesley handles the finances, in that he checks Susan's final bookkeeping and manages the major expenses of the household.

Susan is the primary carer of children, and manages her work around the children. Both children are in high school so caregiving, per se, is minimal. When the children were

younger, Susan's parents gave her a lot of support and, by her own admission, she has always had excellent domestic help and support.

The couple share an interest in art movies, and see them once or twice a month. They attend business functions related to Wesley's work but prefer to spend their 'off-time' at home, watching videos, listening to music and spending time in the garden. Wesley is interested in sport, particularly golf, but this interest is not shared by any of the other family members. Susan remarked that they were busier in terms of their careers now than they were when the children were younger, and they often worked over weekends. She felt that it was "just a stage in our lives" and that she anticipated having more time to spend together at some later stage.

The couple have dinner together every night and would prefer to have it with their children but, due to their and their children's schedules, they seldom manage to do so. The family appears to be made up of individuals who like to spend time on their own and who each have their own unique interests. The only time that they spend together is on holiday – an annual holiday at Knysna and, recently, a holiday overseas. Susan will occasionally take the children on holiday, with Wesley joining them at a late stage. The extended family will sometimes get together for a family occasion. The children from both of Wesley's marriages grew up in the home that the family still lives in and clearly still regard it as 'home'.

Susan admitted to losing her temper very easily. She said that Wesley was very calm and phlegmatic and waited for her to cool down before they talked through issues. So, conflict resolution had a pattern of her losing her temper, time spent cooling down, talking through the problem and her apologising.

Both of the Howard's younger children have asthma but only Sarah (14 years old) has experienced "life-threatening situations, where she has been on a drip and oxygen". Susan gave a long list of factors that negatively affected Sarah's asthma, from teething and puberty to school science experiments and dust. Apart from dancing, which is unaffected by her asthma, Sarah does not take part in any sport. Susan said that both her children are so used to having asthma that they have learned to live with it, "they've had it for so long that they just don't do that run. They just hold themselves back."

Sarah's lack of sporting activity was not perceived to be a major restriction for her, as "she didn't inherit great sports' genes." For Sarah, the major restrictions were social, i.e. sleeping out and school camps. "Sleeping out was definitely a problem for a long time – both she and I were nervous about that. And you arrive at the house and look at the cats, and all those things and your heart sinks...once or twice I was phoned to fetch her in the middle of the night...school camps were a nightmare because you don't know where they are going to. You just know that it will always be a cheap, damp, dusty place – all the stuff that school camps are, which is a worry." At the end of the interview, Susan remarked that Sarah and James had never felt completely carefree, and this saddened her, "I am terribly sad that they have never known what it is like to be totally carefree. They are both sick and tired of medicating. That is an awful burden for them."

Susan has felt and continues to feel very stressed by her daughter's asthma. She feels that she must be close to her daughter all the time and any time spent away from home is stressful to both her and Sarah. "I used to travel quite a lot for business but it was so stressful. I would phone five times a day just to check that all the medicating had been done. And even if nothing was said, it was sensed and I overreacted – I can't tell you the stress it placed on me." Susan also said that after Sarah had been hospitalised she (Susan) experienced "terrible dips". "I usually have a very bad feeling of not having coped, why didn't I notice the signs, very weepy and accusatory. I always felt that Wesley didn't get involved enough and didn't learn the medication so I could never get a break. So I would get upset and angry about it. Every day for the last fourteen years I have had to remember and remind."

Financially, Sarah's asthma has not strained the family. Because of the high claims over the years they have to pay high medical aid premiums but the family is able to cope financially.

Susan said that Sarah's asthma had made Sarah closer to her. She felt that this was both good and bad. When asked, specifically, Susan said that as she grew older, Sarah was becoming more independent and less attached to her. In Susan's opinion, the major positive impact of asthma is that Sarah is more empathetic to people in distress, she is a caring friend and she is stoical with pain.

Wesley said that his attitude towards Sarah was not affected by her asthma. Susan, however, said that she was more protective towards her. Both parents agreed that discipline was not affected by Sarah's asthma but was personality-related. Unlike her brother, Sarah was not perceived to need disciplining.

The couple were asked what their fears and concerns were for Sarah. Susan worried about future overseas travel, and whether she would cope with medication in foreign countries. She was also concerned about Sarah bruising easily and developing osteoporosis because she had been on oral cortisone so often, and she worried about her future choice of marriage partner also being an asthmatic.

Susan did not expect Sarah's asthma to either improve or get worse. Wesley said that his asthma had improved since puberty and he felt more positive than Susan did. Susan felt that people learned to adapt to their asthma and so, as they grew older, they coped better. "I don't think they will ever just grow out of it. It has never got less. They are as medicated now as they ever were. Sadly, I don't think that it will. If it was they would have begun to show signs by now."

Regarding their aspirations for Sarah, Wesley and Susan want her to reach her potential. Susan said that Sarah was artistic and observant but she worried that her self-confidence was low. Neither parent was specific about their aspirations but were keen for Sarah to find her own way, probably in the arts.

Sarah was perceived to develop good interpersonal relationships, particularly with young children. "She has a rare talent where she doesn't speak down to them but communicates so effectively with them." When asked which words best described Sarah, Susan said she was 'gentle', 'empathetic', 'observant', 'needing protection, vulnerable', 'generous, very giving', 'quite shy', and Wesley said she was 'caring'.

In this family, Susan has taken the most strain because of her children's asthma. Over the years she has experienced great stress and curtailed her career, which involved travelling, so that she could be near her daughter. Wesley appears to have left the management to Susan, seldom becoming involved, and this has increased her stress levels.

5.3 THE FAD SCALE

Susan and Wesley were shown a list of statements and asked to rate their level of agreement with each statement on a four-point scale (strongly agree, agree, disagree, strongly disagree). Susan and Wesley completed the FAD questionnaire separately, without discussing it with each other. Figure 5.1 shows the *individual mean score* for Susan and Wesley as well as the FAD norm. The individual scores for Susan and Wesley are to be found in Addendum C. Figure 5.2 shows the *family mean score* (the combination of Susan's and Wesley's scores) and the FAD norm. Scores on the following dimensions were compared: problem solving, communication, roles, affective responsiveness, affective involvement, behaviour control and general functioning. High scores on the FAD scales mean unhealthy functioning.

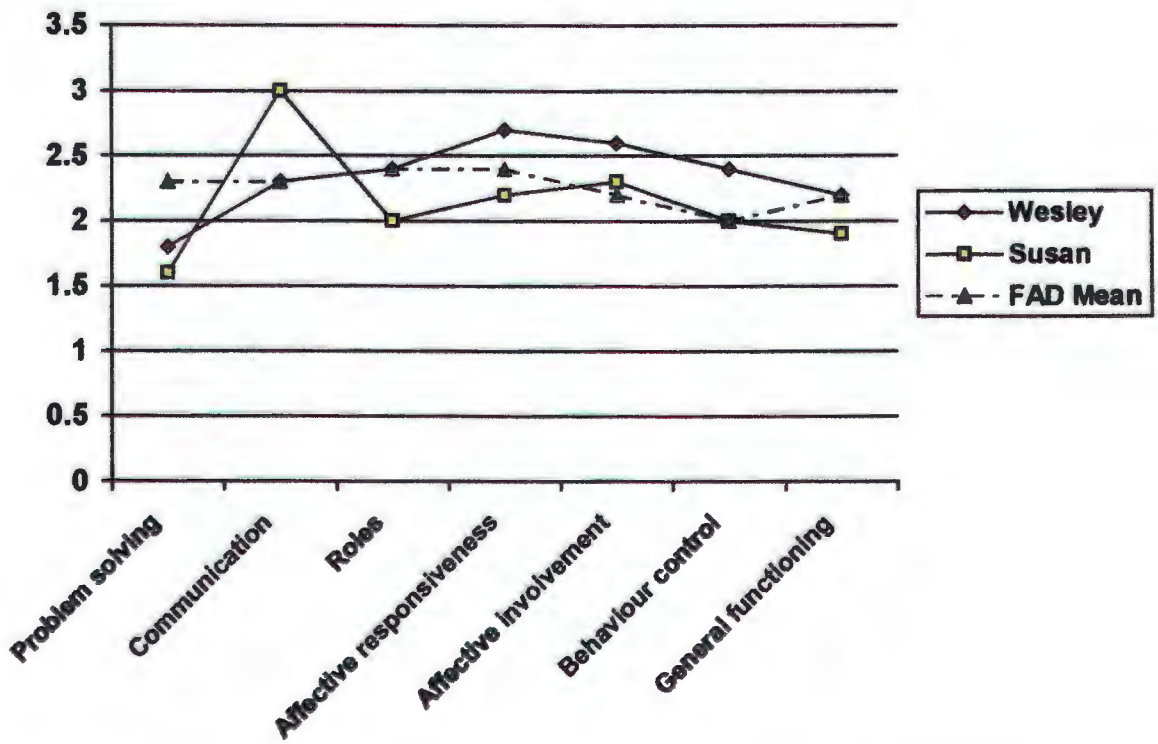

Figure 5.1 Comparative individual mean scores for the different categories in the FAD scale: Wesley and Susan

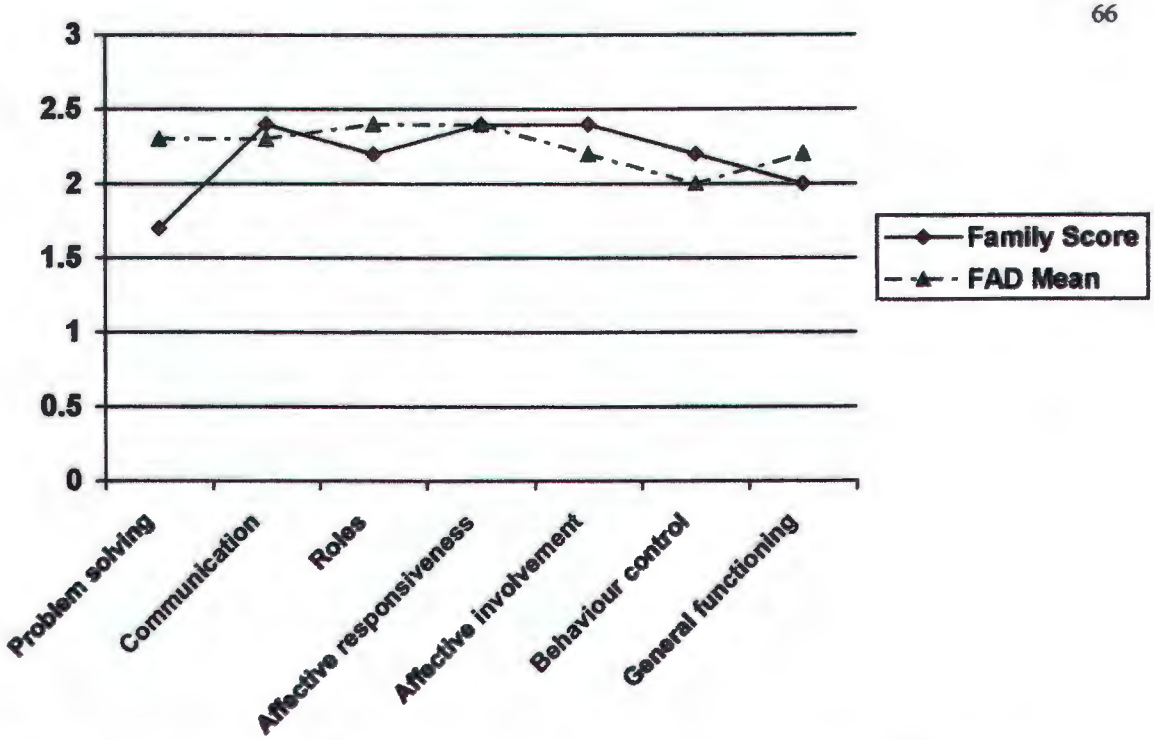

Figure 5.2 Comparative family mean scores for the different categories in the FAD scale: the Howard family

The joint family score (Figure 5.2) as well as the individual scores for Susan and Wesley (Figure 5.1) for *problem solving*, *roles* and *general functioning* were all on or below the FAD norm, indicating healthy functioning on these dimensions.

The joint family score for *communication* (2.4) was slightly above the norm of 2.3 (Figure 5.2). Wesley's individual score was on the norm (Figure 5.1.) but Susan's score (3.0) was particularly high, indicating problems in maintaining clear communication. This finding was supported by her dominance and verbosity in the interview.

The joint family score for *affective responsiveness* was on the norm of 2.4 (Figure 5.2). This score was the mean for a 'healthy' low score for Susan (2.2) and an 'unhealthy' high score of 2.7 for Wesley (Figure 5.1). This means that Wesley does not respond in an appropriate and healthy way to the emotional demands that exist in the family. This finding on the FAD score was also apparent during the interview. For example, Susan expressed her frustration at having to shoulder the physical and emotional burden of Sarah's asthma all the time. Further, there was a large difference between Wesley's (2.7) and Susan's (2.2) scores for affective responsiveness, and their scores were on either side of the norm. Unlike

the Snyman's, who also had a high score on this dimension, the Howard's children are no longer young so this score is not an indicator of the demands of a younger family. It appears that there are other factors, perhaps including the severity of Sarah's asthma, that play a role in the difference in scores.

The joint family score (2.4) for *affective involvement* was in the 'unhealthy' range, above the FAD norm of 2.2 (Figure 5.2). Susan's individual score was 2.3 and Wesley's was 2.6 (Figure 5.1), indicating that both of them are less involved emotionally than is healthy. Indeed, the emotional isolation in this family that was communicated during the interview was so striking that it led to the title given to the Howard family: a family of individuals.

The joint family score (2.2) for *behaviour control* was also in the 'unhealthy' range, above the FAD norm of 2.0 (Figure 5.2). Susan's individual score was on the FAD norm but Wesley's score was 2.4, indicating a lack of involvement in controlling family behaviour on Wesley's part. This, too, was communicated during the interview and Susan made a number of references to Wesley's emotional and physical distance from the family.

The family mean score for *general functioning* was in the 'healthy' range (2.0) below the FAD norm of 2.2 (Figure 5.2). Wesley's individual score was 2.2 and Susan's was 1.9 (Figure 5.1), indicating that although some of the individual factors (i.e. communication, affective involvement and behaviour control) indicated some problems in healthy functioning, the general functioning of the family is healthy.

5.4 DISCUSSION OF THE EFFECT OF SARAH'S ASTHMA ON THE HOWARD FAMILY

Sarah's asthma falls within the severe range, as defined by Barnes and Newhouse (1994), i.e. wheezy episodes occurring at least once a week, hospitalisation or emergency room visits at least four times per year and peak flow meter readings of at least 40% below best achievable value.

One of Keeney's (1979) generalizations relative to system theory is that difficulties in any part of the system may give rise to *symptomatic expression in other parts* of the system.

This seems to be true in Susan's response to Sarah's asthma. Sarah's asthma causes Susan to feel anxious and her anxiety levels are dependent on the severity of Sarah's symptoms.

Susan's description of her anxiety illustrates a fundamental tenet of systems theory, i.e. that individuals are a *part* of events, they both influence events and are influenced by other events (Becvar & Stroh Becvar, 1982; Goldenberg & Goldenberg, 1991; Hetherington & Clingempeel, 1992; O'Connor & Lubin, 1984). One needs to look at the system holistically and multi-directionally within the context of mutual interaction and mutual influence. Thus, Susan may feel that Sarah's asthma causes her to become anxious, and Sarah may feel that her mother's anxiety exacerbates her asthma.

Further, systems theory contends that not only do individuals reciprocally influence each other, but *relationships within families* influence each other (Bardill, 1997; Bowen, 1978; O'Connor & Lubin, 1984). Cox et al. (1989) and Mann et al. (1990) found that one relationship subsystem influences other subsystems within the family. In the Howard household, as Wesley's chronic illness (Parkinson's) progresses, Susan feels that she is carrying a greater burden in terms of caring for her husband as well as for her asthmatic children, and particularly for Sarah. Her changing relationship with her husband is bound to affect her relationship with Sarah.

In looking at the various elements impacting on Sarah's asthma and being impacted on by her asthma, it becomes clear that no element within this family system can be understood in isolation because none of the elements function independently. This confirms Keeney's (1979) portrayal of a 'unitary interactive system'.

Stroh Becvar and Becvar (1988) give three basic principles governing family systems theory, two of which are well illustrated in this family, i.e. *one cannot not behave*, and *one cannot not communicate*. Wesley's passivity illustrates both of these principles, his lack of involvement in understanding and managing Sarah's condition is behaviour in itself, and his non-verbal communication with his wife during the interview as well as his minimal verbal communication has message value. In attempting to understand his behaviour, it is helpful to think of it in terms of circularity and feedback (O'Connor & Lubin, 1984). Sarah develops asthma, Susan gathers as much information as she can about the condition and soon becomes an 'expert' to the point of starting a support group for parents of asthmatic

children. Because Susan is so competent in coping with Sarah's asthma, Wesley may have felt that his involvement was not necessary. Wesley's lack of involvement appears to have increased Susan's level of anxiety, her feelings of responsibility and her need to be in control of the situation, which would further ensure that Wesley retains his passive role.

Susan's feelings of anxiety confirm the *anxious and over-protective* characteristics of mothers of asthmatic children found in research (Block, 1969; Byrne & Murrell, 1977; Hilliard et al., 1985; Williams, 1975). Susan's explanation for her anxiety supports Byrne and Murrell's (1977) interpretation that maternal anxiety is a response to the child's long-continuing illness.

Susan's anxiety also supports the conclusion of two separate studies by McNichol et al. (1973) and Staudenmeyer (1981) that anxiety, over-concern and over-protectiveness is more likely to occur in mothers of children with severe and continuing asthma.

Wesley's lack of involvement and the individual nature of the Howard family, also supports another of McNichol et al.'s (1973) findings, i.e. that families with a severely asthmatic child showed greater *resentment* between parents (as illustrated by Susan's remark that Wesley didn't get involved enough, she never got a break and felt upset and angry about this), fewer fathers taking responsibility and fewer joint family activities taking place (the Howard family were only together when on holiday).

Because Sarah's asthma is severe, with ever-present symptoms, she appears to be stuck with carrying her mother's and possibly her family's anxiety most of the time. It seems that the problem of focussing attention on one individual in a family more than is healthy is more likely to occur in families with a severely asthmatic child (Minuchin, 1974). Wesley's lack of involvement and Susan's resentment at having to shoulder the burden of Sarah's asthma is congruent with one of the findings by Barmettler and Fields (1976), in which they reported on the attitudes and experiences of parents of asthmatic children. Their work highlighted the complexity of feeling that parents of asthmatics have to cope with, particularly if their child has severe asthma.

Wesley's withdrawal could also be indicative of problems in this family relating to *boundaries* and compliance to family *rules* (Becvar & Stroh Becvar, 1982; Bertonaffly,

1968; Minuchin, 1974; Wolf Tatem & DelCampo, 1995). Thus, Wesley's withdrawal could be an indicator that the mother-child subsystem has become overly strong. Possibly, in the Howard family, a family rule could be that "mother is the one who really cares about the child; the child will not cope away from the mother." In compliance with this rule, and to reduce anxiety when separated from the mother, the child would do something to make separation less likely. This would explain why Sarah became symptomatic when her mother went on a business trip. In fact, Susan and Wesley said that Sarah would become symptomatic before her mother left for the trip. In the context of systems theory, however, it is important to interpret this behaviour without apportioning blame. The child, the mother and the family do not 'need' Sarah's asthma in order to function. The child, the parents and the family both affect Sarah's asthma and are affected by it (Auerswald, 1985; Keeney, 1979).

The findings of the FAD Scale confirm the individual personalities expressed by the Howards during the interview, with Susan's responses tending to be more extreme than Wesley's responses. The response for one statement in particular showed a marked difference, indicative of each individual's subjective response, i.e. Wesley agreed with the statement that 'we are reluctant to show our affection for each other', whereas Susan strongly disagreed.

5.5 CONCLUSION

The ways in which this family coped with Sarah's asthma is a metaphor for the way in which the family functioned. The Howard family seldom spend time together, and the boundaries that exist within the family are diffuse. Each member of the family pursues their own interests and the only time the family is together is during their annual holiday. As regards Sarah's asthma, Susan manages it single-handedly, while Wesley and Sarah's brother remain largely uninvolved. Susan has adjusted her life to the demands of Sarah's asthma, moved to a less demanding job and has got involved in a support group for parents of asthmatic children.

Susan made many references to the major impacts of Sarah's asthma on family functioning, which she viewed as largely contingent on the severity of Sarah's condition. For example, Susan felt resentful that Sarah's asthma was an ever-present source of stress and anxiety.

This resentment in turn, has impacted on her relationship with her husband, who Susan felt did not contribute and support her as much as she would have liked him to.

Susan associated the restrictions that Sarah experienced with the severity of Sarah's condition. These included her high absenteeism from school, her inability to take part in sport as well as restrictions with sleeping over at friends and participating in school tours. Susan said that Sarah had learned over the years how to restrict her activities in order to prevent an asthma attack. Thus, the primary way in which this family responded to the stress of Sarah's asthma was to limit her activities and in this way to reduce the potential risk of an attack with its consequent disruption on family functioning.

It was interesting to note that Susan was one of the few parents to describe positive consequences of Sarah's asthma. This finding gives rise to a tentative conclusion that parents with severely affected asthmatic children will actively look for positive aspects of the disease, as a way of coping with the disease.

Stress as described by Dubo et al. (1961) is well illustrated in the Howard household (e.g. long hours of drudgery, many sleepless nights, numerous trips to the doctor and hospitals, as well as feelings of anxiety, frustration, fatigue and anger). Susan's explanation for her anxiety confirms the conclusion by Byrne and Murrell (1977) that maternal stress is a response to a child's chronic illness.

Sarah is the youngest of Wesley's five children and of Susan's two. Susan felt, however, that the focus of attention that was directed at Sarah was related more to the severity of her asthma than it was to her position as the youngest child. As discussed previously, Minuchin (1974) made a connection between asthma in children and being the focus of family attention more than is healthy. This case study indicates that focus of attention correlates with severe asthma rather than with asthma per se.

Thus, Sarah's asthma occurs within a complex interaction of relationships within the family (Sundberg et al., 1983). Asthma, in the Howard family, could be viewed as a symptom of a dysfunctional family (Minuchin, 1974), as reflective of the state of the family (Sundberg et al., 1983), as the source of family stress (Carson & Schauer, 1992), as the reason for maternal anxiety (McNichol et al., 1973; Staudenmeyer, 1981) or as an indication of diffuse

boundaries (Wolf Tatem & DelCampo, 1995). Irrespective of the way in which we analyse this family, the description that Susan and Wesley gave of their lifestyle and functioning was highly indicative of a family of individuals.

CHAPTER 6

THE ROBINSONS:

A SPORTS-ORIENTATED FAMILY

CHAPTER 6
THE ROBINSONS: A SPORTS-ORIENTATED FAMILY

6.1 FAMILY BACKGROUND

Jenny and Peter are in their mid-forties. They have three sons: Wayne is 20, Brett is 18 and Adam is 9. Adam is asthmatic. His parents and paediatric pulmonologist assess his asthma as mild to moderate.

6.2 THE INTERVIEW

The interview with Jenny and Peter took place one evening. I arrived at 7 o'clock to find Peter watching a replay of the previous weekend's test rugby match. Jenny took me through to the dining room and we waited for Peter as he watched a replay of the last try being scored.

Peter was the dominant conversationalist, with strong views on most topics. He claimed to handle the finances and associated his employment in a bank to explain why he did so. Jenny does not work and she remarked that he managed and she spent.

Jenny has the main responsibility for the children. Her domestic worker and her older sons are her support system. Peter helps with the occasional lift.

The couple spend most of their time together with their boys, either socialising with friends or watching their boys play sport. Peter said that they both liked sport and regularly watched test cricket and night cricket together. Jenny said that they enjoyed theatre and movies. Their conversation centred around the children, day-to-day events and, sometimes, his work. They have recently undergone some house renovations, so that continued to be a major point of discussion.

When asked how they handled conflict, Jenny said that she screamed and shouted and Peter said that he sulked but that they eventually talked about it. Jenny said that she eventually

said sorry. "I don't find it easy to say sorry but eventually I do. I have got better at that."

Family activities centred round sport. The two older boys have South African hockey colours for their age groups. The couple have been very involved with the school hockey committee and both watch their boys play hockey as often as possible.

Jenny said that Adam's asthma was mild to moderate. He has never been hospitalised but has recently, after a break of four years, had an increase in severity. This recent exacerbation has put paid to his success in cross-country running. This year he has not performed as well as he had done in the previous year. Other sports, such as soccer, swimming and cricket has not been dramatically affected by his asthma. The couple were keen to portray him as a 'normal' little boy, who had asthma, which was easily controlled. He occasionally got a "tight" chest, "like when his brothers are chasing him around the house – and he can get a bit tight from the excitement."

Adam's asthma is perceived to have had little impact on the family in terms of time, finance and anxiety. In the Robinson's opinion, Adam's asthma is not severe enough to warrant any stress. When asked why he had not learned more about his child's asthma, Peter replied, "I think if it became a real factor when it was affecting all the things that you asked about – emotionally, financially – if there was trauma often then I would want to know more about it. At the moment it is like having a cold or flu or something like that – it is not a big issue."

Peter and Jenny did not think that there were any positive outcomes related to Adam's asthma. His sport, particularly, had been negatively affected, and for a family, who, by their own admission, was sports' mad, this was perceived to be a major blow. However, the couple did not think that he was as talented at sport as his older brothers, so Adams' asthma was not as negative as it would have been if one of the older boys had the condition. "I think that he is different to the other boys because I think he knows that he will never be as good at sport as they were. He knew that before the asthma ever bothered him. I don't think the asthma is a big issue. He is at St John's and he will never go to any of the schools that his brothers went to and I think that that is a good thing. There is a big age difference and they were so outstanding that to compare him with them would not be fair."

Peter said that he was able to spend less time with Adam than he had done with the older boys because he was busier at work now. He was more stressed and pressured now than then, "I think the older ones got more. I may be a bit wiser now but I am not able to give him the quantity of attention that the older ones got."

Jenny and Peter described Adam as a comedian, a good singer and actor, a good but not outstanding sportsman, a well-behaved child and a child who was very comfortable in the company of his older siblings and their friends and of adults. They said that Adam was interested in the same things that his brothers were and he spent a lot of time in their company. Jenny remarked, "I think he has four parents."

Jenny and Peter were concerned about Adams' self-confidence and self-esteem. They felt that, in light of his older brother's achievements, he might feel that he has underachieved. "I think what it basically boils down to is that we need to build up his self-confidence and his self-esteem. I think that is terrifically important." Peter wanted Adam to succeed and to achieve, "I would like him to achieve some sort of recognition...it doesn't have to be in sport, it could be academic." Jenny wanted Adam to participate in as many school activities as possible, "not to be one of those kids that sit on the side and do nothing."

Peter made the point that their focus on specific children shifted, depending on the children's needs, "I think you concentrate on children at different times in their life. During his first year of school, Adam probably got more attention than the others. This year the middle one is writing matric, so this is his year. Last year the older one was writing matric, so the focus was there...So, I think the focus goes in cycles. Perhaps his next big leap will be when Adam goes to high school. He will get the attention then." Thus, focus and aspirations were dependant on the stage that each child was going through. Aspirations for Adam were centred on his school life and not beyond, as was the case with the other boys.

Jenny had thought that Adam had outgrown his asthma. He had not been on medication for four years prior to this year's exacerbation. She now feels that asthma goes in cycles, "it will disappear and it will get worse but we must just control it all the time." So, Jenny does not expect Adam's asthma to either improve or deteriorate but to be part of his life and that they just have to learn to manage it.

Jenny and Peter said that they had a close family, the boys were loving, liked to spend time together and enjoyed their home. When asked which words best described Adam, Peter said 'cheerful', 'happy', 'a character' and 'loveable' and Jenny said 'easy' and 'clever'.

Jenny and Peter spend much of their leisure time on sporting activities, whether it is watching their own sons play hockey or watching international cricket. Because Adam is asthmatic and not as talented as his older brothers in the sporting field, Jenny and Peter have had to adjust their focus away from sport when interacting with their youngest child. Adams' asthma has impacted more on his own activities rather than on the family's lifestyle, and both parents thought that this low impact was related to the mild and well-controlled nature of Adams' condition.

6.3 THE FAD SCALE

Jenny and Peter were shown a list of statements and asked to rate their level of agreement with each statement on a four-point scale (strongly agree, agree, disagree, strongly disagree). Jenny and Peter completed the FAD questionnaire separately, without discussing it with each other. Figure 6.1 shows the *individual mean score* for Jenny and Peter as well as the FAD norm. The individual scores for Jenny and Peter are to be found in Addendum C. Figure 6.2 shows the *family mean score* (the combination of Jenny's and Peter's scores) and the FAD norm. Scores on the following dimensions were compared: problem solving, communication, roles, affective responsiveness, affective involvement, behaviour control and general functioning. High scores on the FAD scales mean unhealthy functioning.

The joint family scores (Figure 6.2) as well as the individual scores (Figure 6.1) for *problem solving*, *roles* and *affective responsiveness* were all below the FAD norm indicating healthy functioning on these dimensions.

The joint score for *communication* (2.8) was in the 'unhealthy' range above the FAD norm of 2.3 (Figure 6.2). Jenny's individual score was 2.7 and Peter's score was 2.8 (Figure 6.1), showing agreement between the couple. Specifically, Jenny and Peter both agreed with the statement, "You can't tell how a person is feeling from what they are saying", and disagreed with the statement, "People come right out and say things instead of hinting at them."

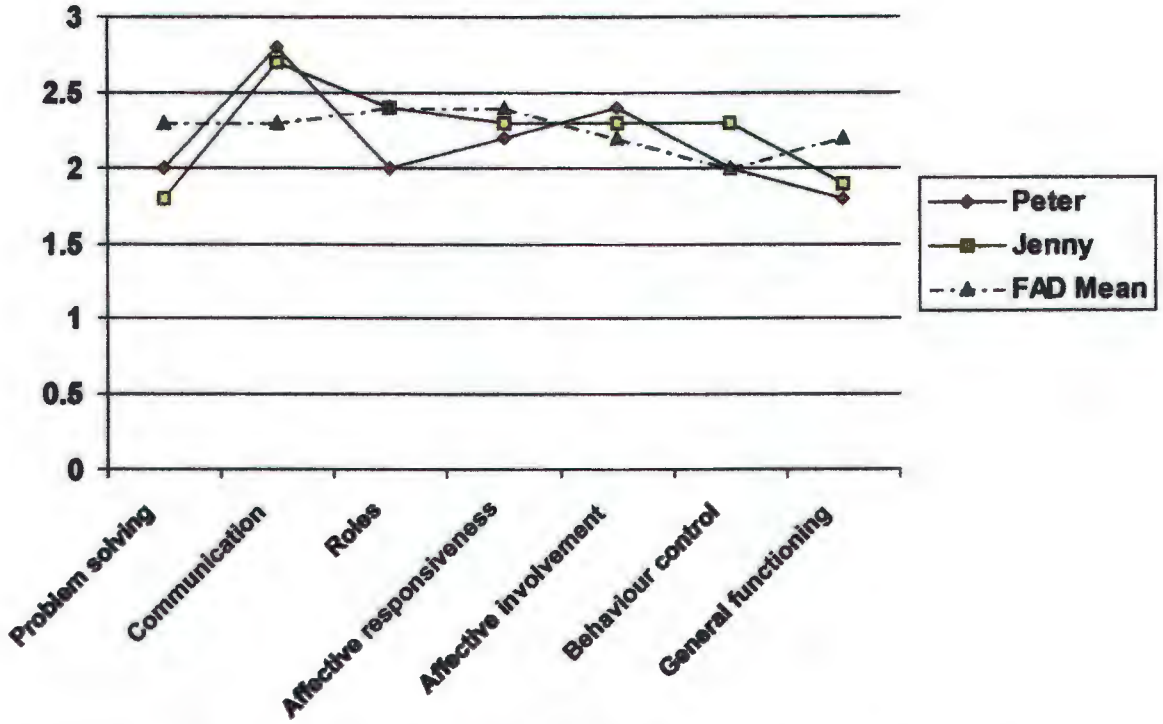

Figure 6.1 Comparative individual mean scores for the different categories in the FAD scale: Peter and Jenny

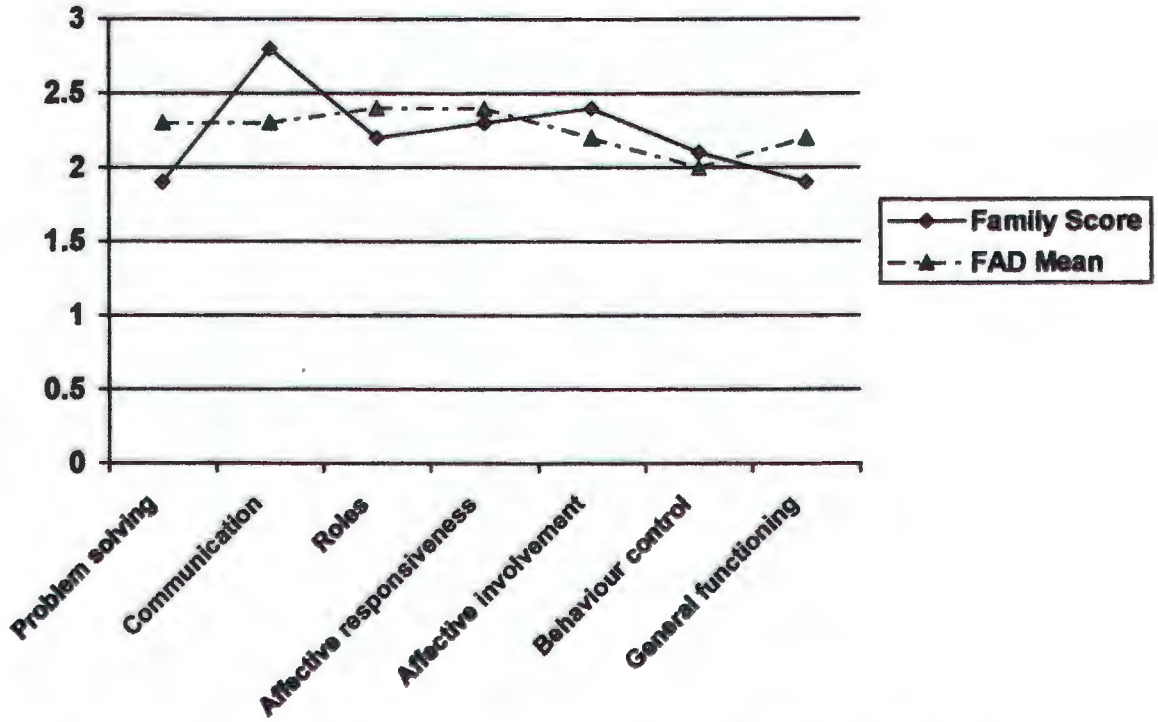

Figure 6.2 Comparative family mean scores for the different categories in the FAD scale: the Robinson family

The joint score for *affective involvement* (2.4) was slightly above the 'healthy' norm of 2.2 (Figure 6.2). Jenny's individual score was 2.3 and Peter's score was 2.4 (Figure 6.1), indicating slightly less emotional involvement between the family members than is healthy. With Adam being much younger than his brothers, this score may be an indicator of parents with older children, who are less demanding than a younger family.

The joint score for *behaviour control* (2.1) was also slightly above the FAD norm of 2.0 (Figure 6.2). Jenny's individual score was 2.3 and Peter's score was 2.0 (Figure 6.1). Again, these scores may well be an indicator of an older family, needing less rigid behaviour controls than a younger family.

The joint score of 1.9 (Figure 6.2) as well as the individual scores of 1.9 for Jenny and 1.8 for Peter (Figure 6.1) were well below the FAD norm (2.2) for *general functioning*, indicating healthy functioning within this family. Peter and Jenny had similar scores on all dimensions, indicating a high level of agreement between the couple regarding the way in which their family functioned, and this was communicated during the interview.

6.4 DISCUSSION OF THE EFFECT OF ADAM'S ASTHMA ON THE ROBINSON FAMILY

Circularity is the reciprocal pattern of interaction (Bardill, 1997; Goldenberg & Goldenberg, 1991, Hetherington & Clingempeel, 1992; Stroh Becvar & Becvar, 1988). The concept of circularity is well illustrated in Peter's assessment of, and response to, the severity of Adam's asthma. He said that, because it was mild, he had never felt the need to become involved in understanding or managing it. He recognised that if Adam's asthma was more severe he may well have become more involved. Thus, there is a circularity between assessment of severity and level of involvement.

Systems theory has provided a useful perspective for looking at relationships within family systems. Systems theory does not ask why something has happened in order to establish a 'billiard ball' model of cause-and-effect. Rather, it focuses on current interactions, where events are studied holistically within the context of mutual interaction and mutual influence (Bertonaffly, 1968; Keeney & Sprenkle, 1982; Walsh, 1993). The relationships and behaviours in the Robinson family give a graphic picture of the behaviour of one individual

being the logical complement of the behaviour of another individual. Jenny and Peter share an interest in sport, their two older sons shows an early talent that Jenny and Peter encouraged. As the boys grew older and became more involved in hockey, so their parents became more involved. Adam has not shown the same sporting promise and his parents have been very careful to avoid comparisons with his older brothers to the extent of sending him to a different school to the one that they attended. The increase in asthmatic symptoms that Adam has experienced has meant further adjustment as regards attitude and coping for Jenny and Peter.

Keeney's concept of *synergism* (1979) is illustrated in this family. Synergism means that the components operating together have a greater total effect than the sum of their individual effects. The components interact so that each influences and is influenced by other components, so that the whole is greater than the sum of the interdependent parts. The combination of the parents' interest in sport and the sporting prowess of the two older boys have resulted in a family whose major focus is sport. Adam's asthma and relative lack of sporting talent came as a major blow to Peter and Jenny. Thus, no element within a system (e.g. Peter's asthma, parents interest in sport) can be understood in isolation because no element functions independently.

Related to the concept of synergism (Keeney, 1979) is the concept that understanding the dynamic relationships causing family members is more illuminating than simply summing up the individual members. Relationships between family members are complex. There is a reciprocal relationship between individuals and between systems in a family. Thus, Adam's asthma is affected by more than one system (Bardill, 1997; Bowen, 1978; Hayden et al., 1998; O'Connor et al., 1998).

The concept of *feedback* is illustrated in this family (Brown & Christensen, 1986; Goldenberg & Goldenberg, 1991), particularly that of positive feedback. Positive feedback allows for flexibility and change in the family system and it encourages new behaviour. Before Adam was born, the family operated in a specific way. The family's positive reaction to the diagnosis of asthma (a potentially negative event) introduced change in the family system and encouraged new behaviour.

Related to the concept of feedback is that of morphostasis, morphogenesis and homeostasis (Bray & Williamson, 1987; Goldenberg & Goldenberg, 1991; Stroh Becvar & Becvar, 1988). *Morphostasis* is the system's tendency towards stability, and it serves to maintain the system in a state of dynamic equilibrium. Peter's limited response to Adam's asthma is an example of morphostatis. *Morphogenesis* is the system's enhancing behaviour and allows for growth, innovation and change. Jenny and Peter's acknowledgement of Adam's condition and the impact that it has had on his sporting ability is an example of morphogenesis. *Homeostasis* refers to the concept of dynamic equilibrium. Feedback allows for the input of information in order to alter and correct the system's functioning. In healthy families, such as the Robinsons, there is a balance, with a dynamic equilibrium around a set point. The system has retained its integrity while acknowledging the need for change.

Peter and Jenny spontaneously talked about the changes that occur within the family as the children develop. Each milestone brings with it a crisis that needs to be dealt with. Families that successfully adapt to these changes experience less disruption (Goldenberg & Goldenberg, 1991; O'Connor & Lubin, 1984; Wasilewski et al., 1988).

Adam's parents and paediatric pulmonologist have assessed his asthma to be mild to moderate. When describing Adam's asthma and the effect that it has had on the family functioning, Jenny and Peter expressed minimal feelings of stress and anxiety. This confirms the findings that stress and anxiety are related to the perception of severity of the child's asthma (Baron et al., 1992; McLean & Ching, 1973; McNichol et al., 1973; Staudenmeyer, 1981).

The FAD scores show a strong cohesion and agreement between Jenny and Peter, with all of their mean scores being close to each other. This finding was reflected in the similar views that the couple communicated during the interview. Adam's asthma has been assessed as being mild and, from the results of the FAD scale and the couple's discussion during the interview, it appears to have had little impact on the way in which this family functions.

6.5 CONCLUSION

Adam is the youngest boy in a family of three. His older brothers have achieved national colours for hockey but Adam, who is much younger than his brothers does not have their sporting talent. Peter and Jenny's shared interest in sport was the focus for their shared activity both as a couple and as a family. Although Peter and Jenny enjoyed going out to movies and theatre, their primary leisure and enjoyment centred round sport.

With the family's focus on sport, the only perceived impact of Adam's asthma on family functioning was the negative effect on his own sporting career. Although not as talented as his older brothers, Adam had been achieving moderate success in cricket and running. Peter and Jenny have noticed a drop in Adam's performance since the diagnosis of his asthma.

Apart from this negative impact on Adam's sporting achievements, his asthma has had little impact on the family's functioning or on Adam himself. None of the family members were perceived to have experienced stress or anxiety because of Adam's asthma, and there has been no need to limit Adam's activities or to re-organise the family system. Peter and Jenny associated this lack of impact with Adam's asthmatic status as being so mild as to be little cause for concern.

Peter and Jenny distinguished between Adam and his brothers but their comparison was based on sporting ability rather than health status or any other factors. Adam was perceived to be less gifted in the area of sport than his brothers but to have other gifts that the family valued. This family offered an interesting analysis of how a family's prime focus (in this case, their sports' orientation) can influence their perceptions of the impact of paediatric asthma on family functioning.

CHAPTER 7

THE WINTERS:

AN ISOLATED FAMILY UNIT

CHAPTER 7
THE WINTERS: AN ISOLATED FAMILY UNIT

7.1 FAMILY BACKGROUND

Bill and Shirley are in their late thirties. Their only child, Warren, aged nine, was asleep in bed by the time I arrived to conduct the interview on a weekday evening. Bill and Shirley said that Warren has moderately severe asthma, and the paediatric pulmonologist said it was moderate to severe.

7.2 THE INTERVIEW

Bill and Shirley claim to decide and do most things together. Financially, they operate a joint account and, although Shirley pays the accounts, they decide how they are going to spend their money together.

Both Bill and Shirley felt that Shirley did most of the child caring. Bill get so much enjoyment out of spending time with his son that even though he spend a lot of time with him, especially over weekends, he doesn't consider it to be caring. He said, "He is my buddy. I am his best playing buddy." Shirley said, "They are lego freaks. They love to play and it is wonderful."

Shirley did not work full-time and therefore said that she did not need any help with caring for Warren. However, if help is needed, Shirley has a sister, parents and a domestic worker as her support system.

Time spent together focussed on the home. Shirley, Bill and Warren preferred to spend leisure time at home. Socially, the couple preferred to be at home rather than go out. They talk about everyday happenings, see the occasional movie and enjoy their garden, their animals and entertaining in their home. Shirley remarked, "We try and find time to do things together. We don't live separate lives from each other. Bill will help me clean the kitchen floor, he will vacuum, we do most things together."

Conflict is handled quickly. Shirley screams and Bill ignores her but the couple is proud of never having gone to bed on an argument. Shirley said, "We have our argument and get over it. We fight like hell and when it is over, it is forgotten."

When asked what they did as a family, Bill and Shirley said that they didn't really do anything but rather spent their time together at home. By their own admission, the Winters' lives were focussed on their only child, Warren. "I think our whole life revolves around him, to be quite honest. He goes peep and we jump."

Sport did not play a major role in this home. Shirley and Bill encourage Warren to play sport but he is not keen and prefers indoor activities such as lego and computer games. Warren is a loner with few friends. He had formed a strong attachment to a neighbour and when the family relocated to Cape Town was deeply distressed, and missed his friend. He has not made any other close friends, either in his neighbourhood or at school.

Warren's asthma is triggered by stress, food allergies (his mother mentioned, peanuts, cows milk, soya) and often begins with cold or flu symptoms. Shirley monitored his illness, checked that he took his medication regularly and worried when he developed asthma symptoms. She said that, when they could not get the asthma under control, she got hysterical. In her words, "I want to kill everybody. Warren is sick and I can't get it right!"

Warren's asthma has always been a financial burden, despite membership of a medical aid. When Warren was first diagnosed, it was particularly difficult because they did not realise that this was a disease that no-one could cure, and he would always have it. Shirley said, "It was hard. It was one of the reasons why we didn't have another child. The first three years were hell. He was sick all the time."

Time spent related to Warren's asthma has never been a major issue. Nebulisation is done while Warren watches TV, and the time taken does not cause any stress.

When asked whether Warren's asthma had had any positive impacts on the family, Bill said that he never smoked inside the house and Shirley said that the family was very close. "I think we have become a bit more close. I think we are closer. We are more of a family unit – bonded."

Bill and Shirley felt that Warren was more spoilt than he would have been had he not had asthma. He is the youngest cousin and grandchild, and Shirley said, "Because he is the youngest of all the grandchildren and a lot of drama took place for everybody they dote on him a little bit more, worry about him more, spoil him that little bit more." However, Bill and Shirley said that their attitude towards their son would have been the same had he not had asthma.

Bill and Shirley both expected Warren's asthma to improve with age, mainly because he was not currently as severely affected as when he was first diagnosed. They fear that he will smoke when he is older and that the asthma will cause him problems in later life.

Shirley and Bill would like Warren to be more involved in sport than he is currently, not only because of its physical benefits but also for its social benefits. Shirley said, "We want him to get deeply involved in a sport. A sport of his choice. Go out there and enjoy it - because then he will get to mix with people. That helps a lot. Get him out of his loneliness in a round about way."

Warren finds it difficult to make friends. He is possessive of his toys and bedroom and gets distressed when other children interfere with and break his things. He lacks self-confidence and backs off when things become too stressful. Bill said, "He did karate for two years and then gave it up because he didn't like being shouted at. He was invited to the national championships and that is when the wheels fell off – far too much pressure."

Bill and Shirley said that Warren had moderately severe asthma and that they were luckier than others because it was not so severe. Warren's major concern was having to take medication every day but, for Shirley and Bill, this was not a major issue.

When asked which words best described Warren, Shirley described him as a very loving little boy and a loner. Bill said that he was his best friend and that he lacked self-confidence.

7.3 THE FAD SCALE

Bill and Shirley were shown a list of statements and asked to rate their level of agreement with each statement on a four-point scale (strongly agree, agree, disagree, strongly disagree). Bill and Shirley completed the FAD questionnaire separately, without discussing it with each other. Figure 7.1 shows the *individual mean score* for Bill and Shirley as well as the FAD norm. The individual scores for Bill and Shirley are to be found in Addendum C. Figure 7.2 shows the *family mean score* (the combination of Bill's and Shirley's scores) and the FAD norm. Scores on the following dimensions were compared: problem solving, communication, roles, affective responsiveness, affective involvement, behaviour control and general functioning. High scores on the FAD scales mean unhealthy functioning.

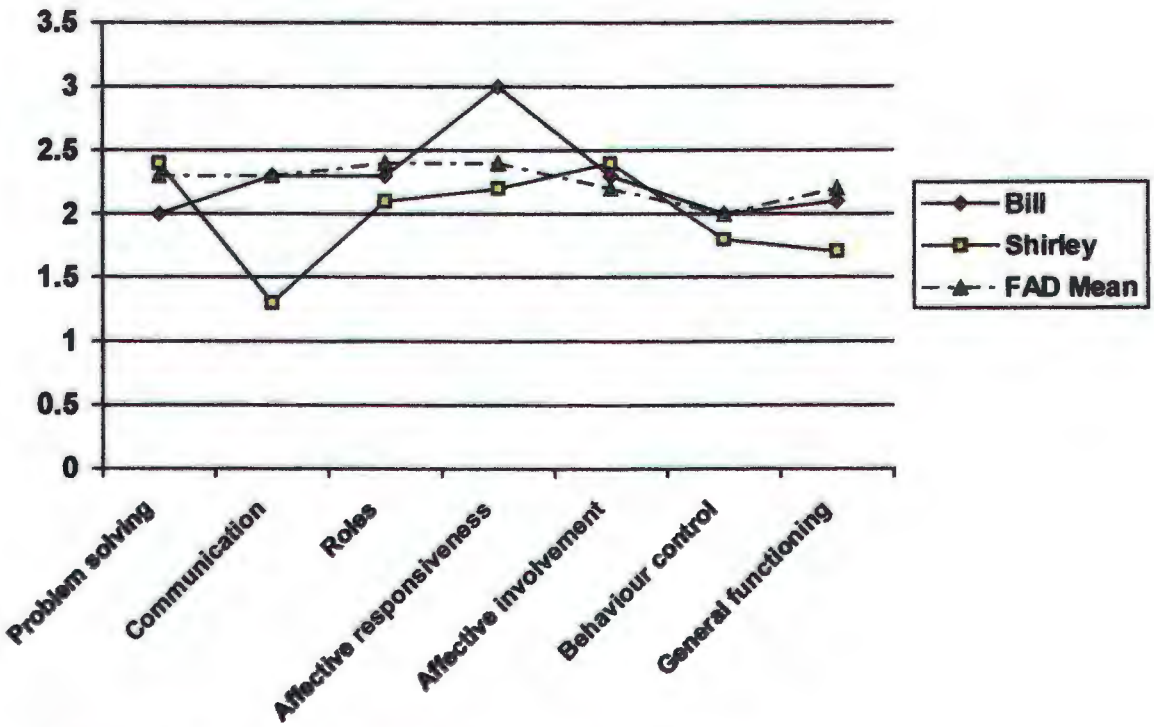

Figure 7.1 Comparative individual mean scores for the different categories in the FAD scale: Bill and Shirley

The joint family scores (Figure 7.2) as well as Bill and Shirley's individual scores (Figure 7.1) for *communication*, *roles* and *behaviour control* were all on or below the FAD norms, indicating healthy functioning on these dimensions.

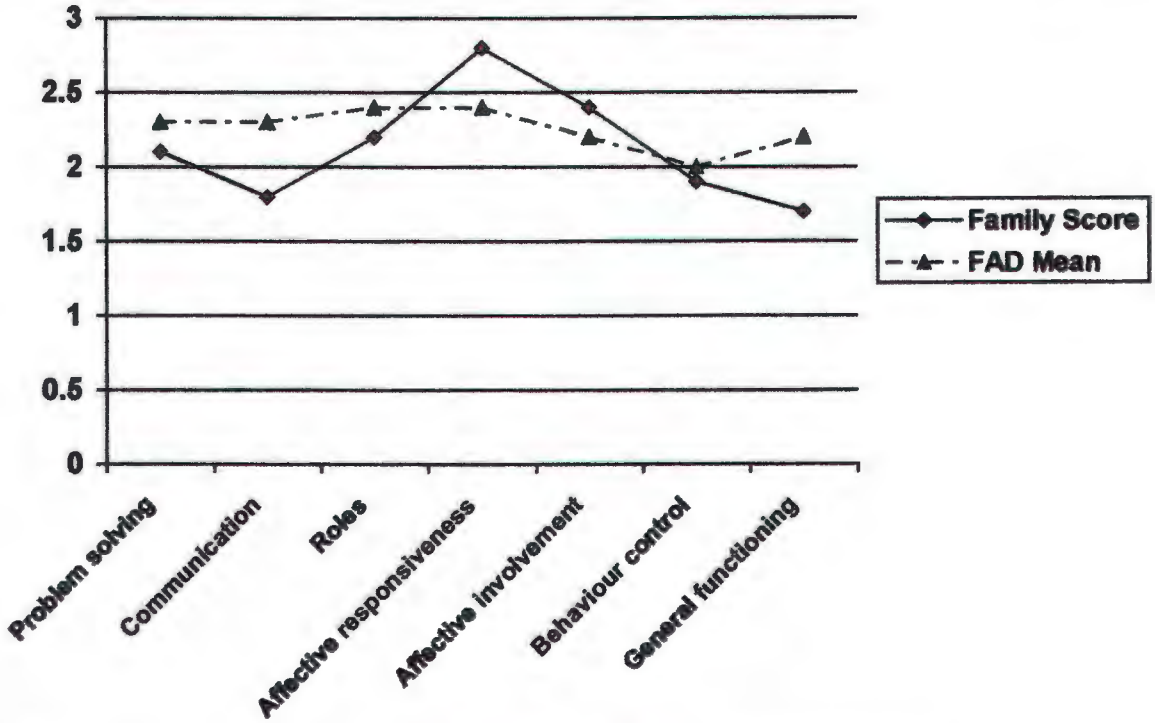

Figure 7.2 Comparative family mean scores for the different categories in the FAD scale: the Winters family

The joint family score for *problem solving* (2.1) was below the FAD norm of 2.3 (Figure 7.2) as was Bill's individual score of 2.0 (Figure 7.1). However, Shirley's individual score (2.4) was slightly above the 'healthy' norm, indicating that she has some difficulties in confronting problems adequately. Specifically, Shirley disagreed with the statement, "After our family tries to solve a problem, we usually discuss whether it worked or not."

The joint score for *affective responsiveness* (2.8) was above the 'healthy' FAD norm of 2.4 (Figure 7.2). Further, Bill (3.0) and Shirley's (2.2) individual scores (Figure 7.1) were relatively far apart from each other and positioned on either side of the FAD norm. Bill's high score indicated that he has problems in experiencing the full range of appropriate feelings. An example of this in the in-depth interview was the couple's description of their handling of conflicts: Bill ignores Shirley when she gets angry. The couple's scores on either side of the norm indicates that Bill's lack of response is a source of conflict for this family. Unlike the Snyman's, this is a one-child family and therefore the emotional and physical demands on the parents must be less than for a family with more children. Thus, this difference in scores indicates factors other than the demands of a young or a large

family. This finding could be related to the severity of Warren's asthma or to Shirley's role as Warren's primary caregiver. Bill may well feel emotionally excluded from this relationship, which may be intensified by the severity of Warren's asthma, and this feeling of exclusion may very well extend to other areas of the couple's and family's functioning.

The joint score for *affective involvement* (2.4) was above the FAD norm of 2.2 (Figure 7.2). Bill's score was 2.3 and Shirley's score was 2.4 (Figure 7.1), indicating some, but not major, problems in Bill and Shirley's degree of emotional involvement.

The joint score of 1.7 (Figure 7.2) as well as the individual scores of Shirley, which was 1.7 and Bill, which was 2.1 (Figure 7.1) were below the FAD norm of 2.2 for *general functioning*, indicating that, although there were differences in individual scores and indications of problems on specific factors, the way in which this family functioned was generally healthy.

7.4 DISCUSSION OF THE EFFECT OF WARREN'S ASTHMA ON THE WINTER FAMILY

Apart from his asthma, the Winter's primary concern for Warren is that he has no friends. Family Systems theory provides the framework to understanding this phenomenon in that it assumes multiple causalities for an event rather than simple cause-and-effect sequences (Anderson et al., 1986; Goldenberg & Goldenberg, 1991; Hetherington & Clingempeel, 1992; Keeney, 1979). Thus, Warren's isolation could be consequent on the severity of his asthma (Richards, 1994), on learned behaviour (parent's preference for being at home, friend moving away) (Skinner, 1974), on being an only child (Minuchin, 1974), on a personality trait (Baron et al., 1992) and/or on over-protection by his parents (Block, 1969; Williams, 1975).

Further, any two or more of these factors could be acting *synergistically* (Keeney, 1979) to ensure a whole that is greater than the sum of its parts. Thus Warren's isolation could be primarily consequent on the synergism between the severity of his condition and that he is an only child. However, we must bear in mind that family systems theory does not make deterministic predictions (O'Connor & Lubin, 1984). The focus is on current interaction and organization and not on the origins of these characteristic patterns and processes. The

important issue to understand when thinking about synergism is that the system (i.e. the Winter family) cannot fully be explained if it is broken down into its component parts. No element can be understood in isolation because it never functions independently (Bardill, 1997; Bowen, 1978; Keeney, 1979).

Of course, in focussing on Warren's asthma, it is equally possible to view the severity of his condition as consequential on his isolation. Thus, a circularity between severity of condition and isolation appears to be in operation (Anderson et al., 1986; Bardill, 1997; Goldenberg & Goldenberg, 1991; Keeney, 1979).

Circularity is a reciprocal concept to be found in the interface between individuals and between systems, and paediatric asthma is affected by more than one system (Meijer, 1976; O'Connor & Lubin, 1984). It is interesting to look at the relationships that exist in a small family unit consisting of three individuals. This family comprises the minimum number of relationships, i.e. three dyads and one triangle (Bardill, 1997; Bowen, 1978; Hinde, 1989). Thus this family unit is relatively simple, and the number of possible interactions is relatively limited. However, when one includes the extended family of grandparents, aunts, uncles and cousins, this series of interlocking triangles becomes very complex. Each relationship triangle will both affect and be affected by Warren and by his asthma.

Feedback processes are self-correcting mechanisms (Brown & Christensen, 1986; Goldenberg & Goldenberg, 1991). They indicate variation in the system and serve to ensure the survival of the system. Negative feedback maintains family function by countering deviation from normal or expected behaviour. Positive feedback allows for change by encouraging new behaviour. In the Winter family asthmatic symptoms provide negative feedback, which must be dealt with to maintain the integrity of the family system. Morphogenesis (Bray & Williamson, 1987; Goldenberg & Goldenberg, 1991; Stroh Becvar & Becvar, 1988), which allows for growth and innovation occurred in this family when, in response to Warren's asthmatic symptoms, a new family rule banning smoking in the house was introduced. A reduction in symptoms would serve as positive feedback to this change.

The Winters appear to have good and efficient *communication*, and thus do not fall into that group of parents of asthmatic children who have poor communication which negatively impacts on and is impacted upon by their child's asthma (Hermanns et al., 1989; Wikran et

al., 1978). This is a particularly interesting finding because there is some evidence to suggest a correlation between poor parental communication and severe paediatric asthma (Wamboldt et al., 1995). The Winters' communication pattern confirms the lack of evidence to support a cause-and-effect pattern between poor parental communication and severe paediatric asthma.

Bill and Shirley said that Warren was a loner and dependant on them. This gives support to the finding by Khampalikit (1983) that children who perceived their asthma to be moderate or severe were more likely to be dependant than were children who perceived their asthma to be mild.

Shirley's description of her reaction when Warren has an asthma attack is typical of that described by Barmettler and Fields (1976), particularly her feelings of panic, helplessness and fear for the survival of her child. However, Shirley's stress is confined to the periods when Warren is having an attack. Her general lack of stress appears to be related to the close involvement that Bill has with Warren. This supports the finding by Wasilewski et al. (1988) that families in which the mother was not the sole caregiver experienced less stress. Certainly, Shirley did not complain about having to shoulder the burden of responsibility in caring for her son.

Further, Shirley's feelings of anxiety have diminished as Warren's asthma has become less severe. This supports the finding by Staudenmeyer (1981) that the degree of parental anxiety is related to the severity of the child's asthma. Possibly it is not the severity of the child's asthma per se but rather the parent's perception of severity that is crucial.

In a *healthy family* no one member is stuck with carrying all of the family's anxiety all of the time (Goldenberg & Goldenberg, 1991; Minuchin, 1974; Stroh Becvar & Becvar, 1988). This is a potential problem for a family with an asthmatic child, and the potential problem increases when the child has no siblings. Bill and Shirley talked about Warren being the focus of their own attention as well as receiving more attention from the extended family members than other members received. However, being the focus of attention is not necessarily entirely negative. Warren being the focus of attention has resulted in a strong family cohesion which may well be a positive coping mechanism. This was the conclusion of Meijer and Oppenheimer (1995) that cohesion in families with a child suffering from

asthma must be seen as a coping mechanism employed by the family in the interests of their sick child and should not be interpreted negatively.

Warren's preference for indoor activities, such as lego and computer games may be viewed as *self-limitation*, a response to the stress of asthma as described by Stroh Becvar and Becvar (1988). Self-limitation involves the choice to avoid the environmental demand by limiting one's activities. So, Warren may choose to avoid outdoor activities because of the potential of an attack or, as his parents interpreted it, he may avoid competitive sport because it makes him feel anxious. Again, it is possible that more than one factor is impacting on, and being impacted on by Warren's behaviour (Goldenberg & Goldenberg, 1991; Keeney, 1979).

That paediatric asthma affects and is affected by the family in which it occurs is further confirmed by the reported impact of Warren's asthma in the areas of financial burden, social and familial isolation and personal strain, and this is confirmation of the findings by Mailick et al. (1994).

The FAD scores confirm the findings in the qualitative interview that this was a couple that holds similar views but who have different needs and abilities regarding the expression of emotions and feelings.

7.5 CONCLUSION

The Winter family are a small isolated family unit, whose major focus is their only child, Warren. Bill and Shirley share most activities, including housework and child-care. Leisure time is primarily spent at home, with limited contact with the outside world.

Bill and Shirley felt that Warren's asthma has had less of an impact on the family's functioning than it has had on his personality and temperament. They felt that Warren's asthma had isolated him, that he is a loner with few friends and that he lacks self-confidence. Warren's preference for being alone may have influenced the way in which he coped with the stress of asthma, which was to limit his outdoor activities and social life.

Bill and Shirley were concerned that Warren preferred to be alone and found it difficult to make friends. He is an only child and the youngest grandchild, and is the focus of his parents' and grandparents' attention. Bill and Shirley felt that his position in the family as well as his asthma ensured that he continued to be the centre of attention.

Shirley expressed more feelings of stress and anxiety in relation to Warren's asthma than Bill did. However, these feelings are confined to those periods when Warren has an asthma attack. Possibly this couple's sharing of responsibilities is the reasons why, even though Warren has moderately severe asthma, Shirley expressed less feelings of stress than other mothers with moderate to severely asthmatic children did.

This family offered an interesting study on the mutual interaction between paediatric asthma and asthmatic children that are loners. Bill and Shirley's description of the ways in which the family functions and the circularity of impacts on Warren's asthma provides insights into the complexity of factors that are associated with paediatric asthma.

CHAPTER 8

THE MURRAYS:

A COMPETITIVE FAMILY

CHAPTER 8
THE MURRAYS: A COMPETITIVE FAMILY

8.1 FAMILY BACKGROUND

Anne and Walter are in their late thirties. They have three children: Ryan, who is asthmatic is nine, Brett is seven and Catherine is six. Anne and Walter said that Ryan had severe asthma, and their paediatrician agreed with this assessment.

8.2 THE INTERVIEW

During the week Anne bears the responsibility for the children. She does not work outside of the home and is very involved in her children's lives, both at school and in their after-school activities. Anne said that Walter had always been involved with the children. "My husband is the most wonderful father a child could want. He does everything for the children. When he is here he gives 100%". Walter said that he made a point of attending important sports events that his children were taking part in during the week. Apart from Walter, Anne did not have a support system. Her mother used to help but was now too old. However, Anne did not express the need for more help.

Over the weekends, Anne and Walter said that they focussed on the children. Walter, particularly felt that this was the quality time that he could spend with his children and show an interest in their sporting activities.

Anne said that she worried about her children, particularly about Ryan, who has asthma. She said that Walter always asked why she got worried before an event had even happened.

Time spent together as a couple was limited. Anne was resentful of the fact that Walter put her needs after the children. Anne said, "At the moment that is the biggest bone of contention in our lives. We don't spend enough time together. The kids are so demanding. Walter is not here that much and when he is they demand 100%, and I am the one who is left out. We never go out – just the two of us." Walter's business life is busy and Anne is

never able to join her husband at conferences because she has no-one to leave the children with.

Anne said that they didn't talk much because Walter was either busy with the children or too tired to communicate with her. She said, "I try but it is quite difficult to talk to Walter because there are the kids and then he is so tired or he is watching the news or reading the newspaper. And he can't do two things at once – he can't watch news on TV and listen to me."

Anne said that the major issue surrounding conflict had to do with disciplining the children. She was the disciplinarian whereas Walter was more easy-going. She felt that he did not back her decisions. She said, "Often when I say they have to do this because they have done x, y, and z wrong he is quite happy to let them go, and it is not right. He does not back me in those situations." Arguments, however, did not last long. "We may argue a bit and moan but it does not last long."

Walter claimed to be in charge of the finances. Anne said that she was very involved and said that Walter did what she asked him to do.

The family does a lot of things together, most revolving around the children - involvement in the children's sports, motor biking for Walter and the children, and holidays. Most of these 'fun' times occur at holiday time or over weekends. Weeks are taken up with work, school and sports. Friends have children the same age as the Murrays and socialisation takes place over weekends.

Ryan is nine years old and has had asthma for most of his life. Anne said that she took a long time to accept that he had asthma. Initially she was sceptical and resentful, mainly because she did not understand the nature of the condition. When Ryan was younger, Anne said that she sometimes restricted his social activities because she was embarrassed by the reaction of other mothers, who felt Ryan was too sick to be out and about. Until they met their current paediatrician, she had restricted some events when she felt he was too sick to attend. Their current paediatrician has advised them not to restrict any of his activities and to rather deal with exacerbations if and when they occur. Anne is very dependent on her doctor and complies strictly with what he says, "He was cross with me for taking Ryan to

other doctors. But now we are the best of friends. He loves Ryan and I trust him absolutely. Whatever he says I do, and I do it religiously."

Anne and Walter said that Ryan was very competitive, both at school and on the sports field, and that his asthma had never restricted him. Playing sport will often make him cough but this has never stopped him from participating. Walter said, "he is an incredibly strong person, strong-willed, highly competitive. And, he sets very high standards for himself – in sport and in the classroom. He is a very high achiever and he loves sport."

Anne said that Ryan's illness made her very stressed, particularly when he had an exacerbation. She said, "I start shouting at the other children because I am so stressed. I have even shouted at Ryan when it happens." Walter said that he got worried because he hates to see any of his children sick. However, his main reaction is to ignore it until he no longer can. He firmly believes that Ryan will grow out of his asthma. He says he leaves it up to Anne because there is no need for both of them to get involved in managing Ryan's asthma. Both said that Ryan was very responsible about taking his medication and had no problems if he slept over at a friend's house.

Time spent in the doctor's waiting room was a problem, particularly seeing as they had more than one child. Ryan resented the time spent being nebulised, especially if he had to be nebulised before school. Finances, as well, were problematic, with medical aid limits running out five months into the year.

Walter could not see any positive impacts from Ryan's asthma. After some thought, Anne said that she was more comfortable dealing with sickness, and had been of help to friends with asthmatic children.

Anne said that her attitude towards Ryan was different to her attitude towards their other two children. She said, "I don't know if it is a first-born thing or if it is because we have been through so much together. There have been times when I have thought he was not going to make it. So, I have a special place in my heart for Ryan." Walter and Anne said that Ryan was more competitive and more talented than their other two children. They also said that he was more sensitive and took life's knocks harder than the other two did.

Anne and Walter said that they did not differ in the disciplining of their children. However, when Ryan was taking oral corticosteroids he underwent a personality change. Anne said, "I have to warn everyone. Then, I can't discipline him. I have learned that. You are fighting a brick wall. The more you try and discipline him the more violently he reacts, and then it is just a vicious circle."

Anne and Walter's fears for their son related more to his personality than to his asthma. They said that his perfectionist nature meant that he often missed out on things that he did not want to even try. Both said that they were sure that he would outgrow his asthma. Anne even said that their paediatrician held a similar view, "The doctor had told me that Ryan would not grow out of it and that he is very bad but I think, even he, is starting to change his mind. I really believe in my heart that Ryan will grow out of it."

Anne and Walter said that, apart from happiness, enjoyment and trying hard, they had no aspirations for Ryan. Both were obviously very proud of their son's sporting and academic talent but said that they played it down because of Ryan's less talented siblings. "He is exceptionally bright and good at sport. He is just one of those boys that has been blessed. You don't want teachers to expect Brett to be like his brother, Ryan. He is a completely different child." Anne said that Ryan was different to children of his own age. She said, "He is on a different wavelength to other children. He is nine years old, going on 58. That is just him. He sits with adults and he has adult conversations with them, not kid conversations." Ryan's parents said that he had a wide circle of friends and a busy social life. He is a big brother to his siblings and looks after them.

When asked which words best described Ryan, Anne said 'competitive', 'sensitive', 'perfectionist', 'sporty' and 'talented'. Walter said 'resilient', 'go-getter' and 'tough'.

8.3 THE FAD SCALE

Anne and Walter were shown a list of statements and asked to rate their level of agreement with each statement on a four-point scale (strongly agree, agree, disagree, strongly disagree). Anne and Walter completed the FAD questionnaire separately, without discussing it with each other. Figure 8.1 shows the *individual mean score* for Anne and Walter as well as the FAD norm. The individual scores for Anne and Walter are to be found

in Addendum C. Figure 8.2 shows the *family mean score* (the combination of Anne's and Walter's scores) and the FAD norm. Scores on the following dimensions were compared: problem solving, communication, roles, affective responsiveness, affective involvement, behaviour control and general functioning. High scores on the FAD scales mean unhealthy functioning.

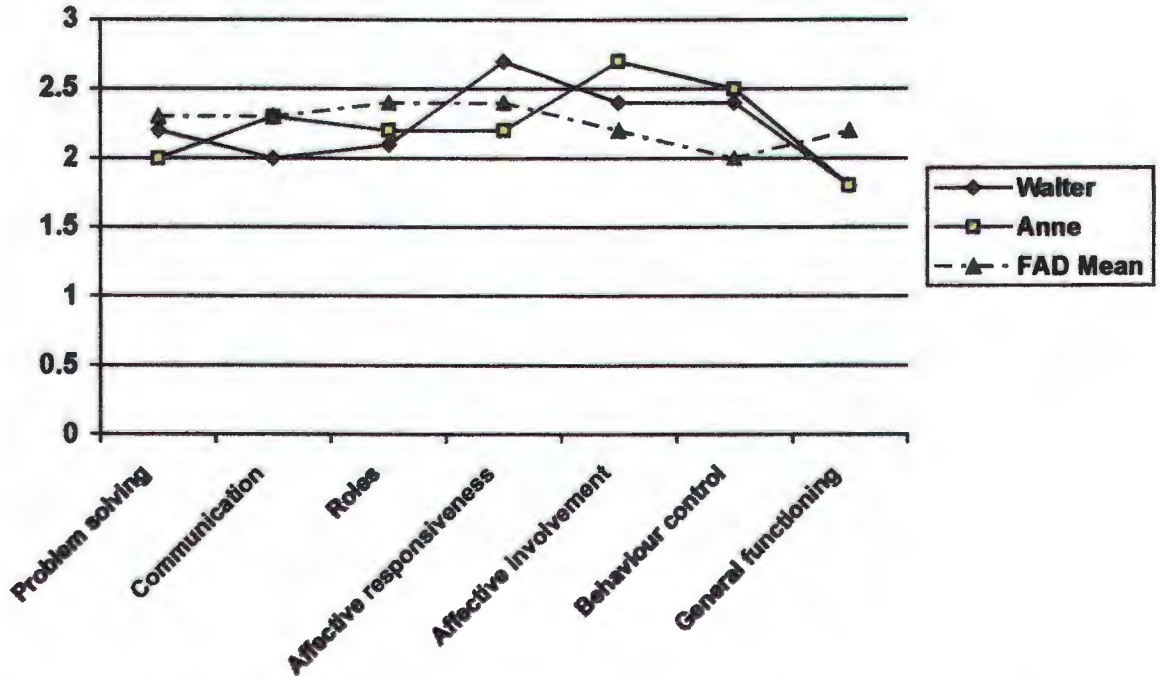

Figure 8.1 Comparative individual mean scores for the different categories in the FAD scale: Walter and Anne

The joint family scores (Figure 8.2) as well as the individual scores for Walter and Anne (Figure 8.1) for *problem solving*, *communication* and *roles* were all on or below the FAD norms, indicating healthy functioning on these dimensions.

The joint score for *affective responsiveness* (2.4) was the same as the FAD norm (Figure 8.2). However, Anne (2.2) and Walter's (2.8) individual scores (Figure 8.1) were very different and their scores were on either side of the norm. This difference in score indicates that Walter is less accepting than his wife of the emotional demands existing in the family.

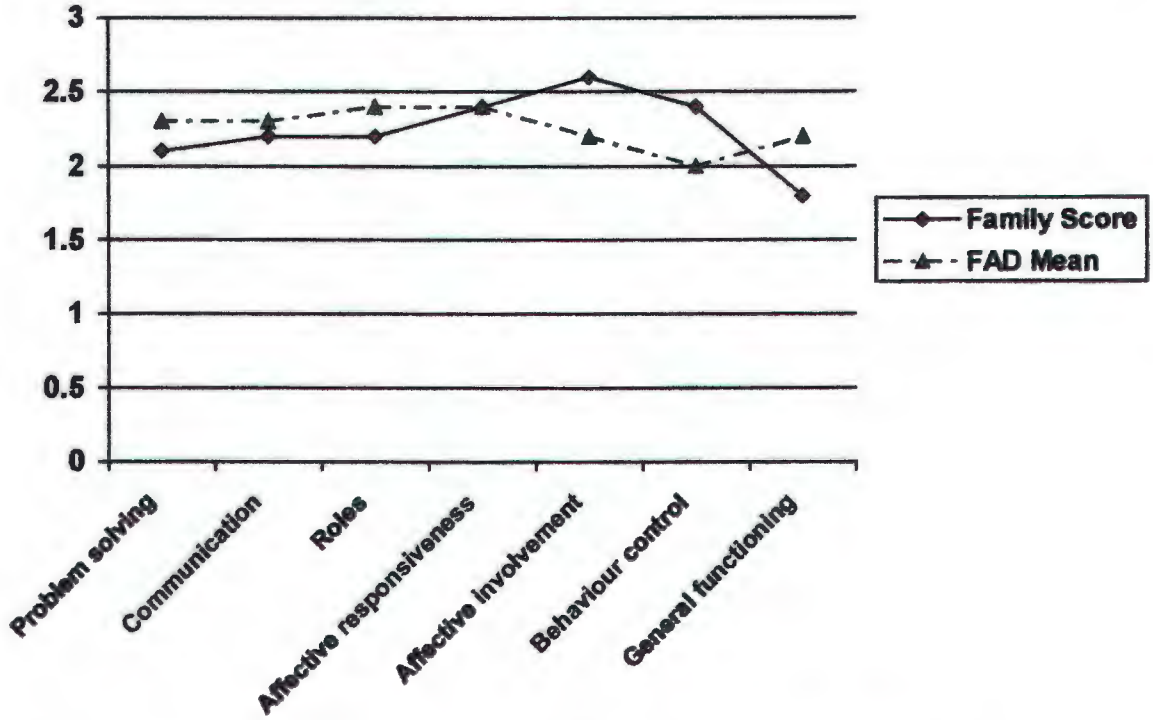

Figure 8.2 Comparative family mean scores for the different categories in the FAD scale: the Murray family

This finding supports the views expressed by Anne during the interview, when she said that Walter did not talk to her and that she had to compete with the children for his attention.

The joint score for *affective involvement* (2.6) was higher than the FAD norm of 2.2 (Figure 8.2), and both Anne's (2.7) and Walter's (2.4) individual scores (Figure 8.1) were in the 'unhealthy' range. This finding indicates problems in the degree of emotional involvement for both Anne and Walter. On the individual statements, Anne strongly agreed with "We are too self-centred" and agreed with "You only get the interest of others when something is important to them" and "Even though we mean well we intrude too much into each others' lives", whereas Walter disagreed with these statements.

The joint score for *behaviour control* (2.4) was higher than the FAD norm of 2.0 (Figure 8.2) and, again, Anne's (2.5) and Walter's (2.4) individual scores (Figure 8.1) were in the 'unhealthy' range. This finding indicates problems in the maintenance of family standards for both parents in this family, which is an unusual finding considering that the children were all in primary school. It does, however, give support to the feelings that Anne

communicated during the interview about her frustration at the lack of support she got from Walter when disciplining the children.

The joint score (Figure 8.2) as well as each of the individual scores (Figure 8.1) for *general functioning* was 1.8, which is well within the 'healthy' range (the FAD norm was 2.2). This means that, although there are differences in scores on a number of the factors measured, the general functioning of this family is healthy.

8.4 DISCUSSION OF THE EFFECT OF RYAN'S ASTHMA ON THE MURRAY FAMILY

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). There are a number of interactions in the Murray family that illustrate circularity. Firstly, the communication patterns between Anne and Walter: Walter works hard and has limited time to spend with the family, when he is at home, he focuses his attention on the children rather than Anne, she is resentful of Walter's lack of attention and this creates conflict, making it more likely that Walter will chose to spend his off-work time with his children, where he experiences little conflict. Family systems theory recognises that Anne's resentment is both the cause and result of Walter's poor communication with her.

A further example of circularity is Anne's feelings of stress when Ryan is symptomatic. The question of whether Anne's stress impacts on Ryan's asthma and vice versa is answered in the concept of circularity: Anne's stress both impacts on, and is impacted upon by Ryan's asthma.

It is interesting to note Anne's description of Ryan's behaviour when he is on oral corticosteroids, "Then I can't discipline him. I have learned that. You are fighting a brick wall. The more you try and discipline him the more violently he reacts, and then it is just a vicious circle." Her use of the words "vicious circle" illustrates the circularity of behaviour in this interaction.

This discussion about interactions in this family also illustrates a further aspect of systems theory – the focus is on the process of relationships between people, on the *interactions*

occurring here and now (Goldenberg & Goldenberg, 1991; Keeney, 1979). This means that rather than looking for reasons as to why events occur and for antecedent causes, people and events are studied holistically within the context of mutual interaction and influence (Keeney & Sprenkle, 1982). The interaction as described in the Murray household illustrates how the behaviour of one individual is the logical complement of the behaviour of another individual and vice versa.

This means that *change* within one relationship subsystem provokes change in other subsystems within the family (Mann et al., 1990). Anne described how she restricted Ryan's social activities because she was aware of criticism (negative feedback) from other mothers if she allowed Ryan to go out when he was symptomatic. The paediatrician's permission to allow Ryan unrestricted activity provoked a change in Ryan's social life. The positive feedback given by the paediatrician allowed for change in the family system by encouraging new behaviour (Brown & Christensen, 1986).

Anne's description of the *stress* she experiences associated with Ryan's asthma confirms the findings of Richards (1994), who described parental anxiety, over-protection, attention deprivation of siblings and fatigue caused by sleep disturbance. This pattern is particularly prevalent among parents of children with severe asthma. It is interesting to note that Ryan's asthma is defined by both his parents and paediatrician as severe.

Of further interest is the poor *communication* pattern between Anne and Walter, as described by Anne. Poor communication has been the focus of a number of studies in families with an asthmatic child (Hermanns et al., 1989; Wamboldt et al., 1995; Wikran et al., 1978). These studies established a relationship between poor parental communication and asthma. Again, this pattern is particularly prevalent among parents of children with severe asthma.

Families of *severely* affected asthmatic children have also been found to show evidence of more stress than other families. One of the findings of McNichol et al. (1973) was the greater resentment between these parents compared to a control group. They interpreted this symptom as a metaphor for the ecology of the relationship system. Thus, within the context of family systems theory, no one individual or fact is to blame, i.e. neither Ryan,

Walter, Anne, the siblings or the asthma is to blame. Rather, the symptom is an expression of the family system.

There was congruence between the mean scores for Anne and Walter (on the FAD scale) for 'problem solving', 'affective involvement', 'behaviour control' and 'general functioning'. The only extreme difference in individual scores was under 'affective involvement', where Anne strongly agreed and Walter disagreed with the statement; "We are too self-controlled" – again, reflecting the dissatisfaction and lack of fulfilment that Anne currently feels.

The mean scores for 'affective responsiveness' were positioned on either side of the FAD mean, reflecting Anne's expression of, and Walter's lack of expression of, emotion and tenderness. The difference in scores on this dimension reflects the isolation that Anne feels in this family, a feeling that she communicated during the interview. Anne has formed a strong alliance with her asthmatic son, Ryan, and feels that they have learned to cope with his asthma together.

8.5 CONCLUSION

Ryan is the oldest child in a family of three children. His mother described a close bond with him, formed during the early days when his asthma was first diagnosed. This bond was strengthened by Ryan's position in the family as well as Ryan and Anne's shared experiences when he suffers because of his asthma.

This family appears to be structured around a number of separate units: father and children; mother and eldest son; occasionally, parents and children. Although the family spends a lot of time together, Anne constantly referred to her frustration in not getting enough of her husband's attention. Even when there was the opportunity to communicate at the end of the day, she said that he was too tired to talk to her.

Ryan's asthma has impacted on this family, and particularly on the stress experienced by Anne, which is not shared by other members in the family, and specifically not by Walter. He says that he ignores it until he no longer can and Anne is left holding the load of practical management as well as emotional anxiety on her own.

The Murrays are a competitive family and the children are encouraged to achieve. Anne and Walter described Ryan as capable and talented. As the oldest child, he was perceived to be a responsible person who took care of his younger siblings. He is a high achiever and has set the standard for his siblings to follow. He has severe asthma but unlike the other child with severe asthma (i.e. Sarah) included in this study, Ryan's asthma has not restricted or limited his achievements. Rather, this family has responded by reorganising the family system and encouraging new behaviour, i.e. by closely monitoring his maintenance medication and allowing him unrestricted sporting and social activities.

The complexity of issues involved when investigating the interaction between paediatric asthma and family functioning is well illustrated in this family. What has the major impact? Is it Ryan's asthma, the severity of his condition, his chronological position in the family or the competitiveness inherent in this family? Instinctively, and within the context of family systems theory, we have to acknowledge the circularity of factors impacting within this and other families.

CHAPTER 9

THE STONES:

A MOTHER AND HER BOYS

CHAPTER 9
THE STONES: A MOTHER AND HER BOYS

9.1 FAMILY BACKGROUND

I interviewed Roger and Cheryl on a Saturday morning. Roger had just returned from a baseball practice with their son, Dale, aged ten, who is an only child. The house smelled of animals and, when I asked them what pets they had, they said they had five dogs, a couple of birds and a hamster. Throughout the interview, Cheryl fondled a Maltese poodle in her lap. Both parents said that Dale's asthma was mild to moderate. His paediatrician said that it was mild.

9.2 THE INTERVIEW

Cheryl is a teacher and comes home with her son every afternoon. She supervises all of his homework except the reading, which Roger does when he comes home. Cheryl said that Dale and Roger play at night and that Roger takes Dale to all his sporting activities.

Both Cheryl and Roger's parents live close by and they are able to call on them to help with childcare if necessary. Because they only have one child, this does not often happen.

Their house takes up a lot of their energy. They have recently undertaken renovations. As Roger said, "we are always doing some project or other, here at home." Time spent together is usually at home although they each have their own particular interest, Cheryl making miniature bears and Roger surfing the internet. They have a TV room, where they spend most of their time together. Roger said, "we don't go out to movies or anything like that really. We like to be at home. We would rather hire a video than go out to watch a movie." By their own admission, conversation is limited to mundane, everyday issues.

Cheryl and Roger like to go away for weekends with their son, Dale. Cheryl said that they chose places where 'the boys' would be occupied while she could do something quiet on her own, "I send them off to play."

The family also spent a lot of their weekend time with the extended family. They have few friends and prefer to spend their social time alone or with family. Neither is involved in the school Parent Teachers' Association (PTA), mainly because Cheryl is a teacher at another school and her work involves her with school activities.

In conflict situations, Roger loses his temper, and Cheryl sulks until Roger apologises. Conflict does not last as long as it used to, usually a couple of hours and then they start talking again. Cheryl makes teddy bears for a hobby, and she said that her trips overseas to sell her bears work as a breather for her.

In terms of the family's finances, Roger said he organised the stop orders but Cheryl paid the bills.

Dale was diagnosed as an asthmatic when he was four. He had always had 'chest problems' and these were only resolved when he was diagnosed and treated correctly. Cheryl said that dust, seeds and pollen made Dale's asthma worse. He never has a full-blown attack, but rather gets a tight chest which is relieved with medication. Cheryl was adamant that Dale was not allergic to pets. He said that they had had him tested specifically for this allergy and she was relieved to find out that he was not allergic because she would not have been able to get rid of her pets. Interestingly, I had an allergy attack while interviewing Cheryl and Roger, and was convinced it was triggered by the pets.

Cheryl and Roger said that they had not placed any restrictions on Dale, particularly since their paediatrician had told them that the more he did the better for him. Roger said that he played a lot of sport with Dale, and that sport had never made Dale's asthma worse. Both Roger and Cheryl said that Dale occasionally used his asthma as an excuse to get out of something he did not want to do. Cheryl said she could usually tell when to take him seriously.

Cheryl and Roger said that Dale's asthma does not have a major impact on family functioning. When he was first diagnosed they were concerned but he is currently well-controlled and neither expressed major concerns. Cheryl, talking about the early days, said, "When he was much smaller, I remember seeing him running down the road, and having to

stop halfway to catch his breath and cough. That is when I felt bad. When he couldn't just be a boy."

Cheryl said that Dale had developed a tic, which she felt was related to asthma, "He has developed a nervous tic, which comes from Roger's side of the family. It is involved with his asthma – he will sniff constantly so that it becomes a habit. We don't make too much of a big deal of it or it would become even more of a problem. I think the asthma gives him ways of verbalising it – because he has asthma he can cough or clear his throat consistently."

Dale's asthma has not impacted on the family's finances. They belong to a medical aid and do not have to pay in any extra towards his treatment. Time is more of an issue, mainly because their doctor's rooms were so far away from where they lived. Cheryl said that she "sent Roger."

Cheryl and Roger could not think of any way in which asthma had impacted positively on the family or on Dale.

I asked Cheryl and Roger why they had only had one child. Cheryl responded, "I have two children (points to husband). I don't know why but we just made a decision to have one child. I have two kids. Dale turned out to be the quiet one." Roger reacted to his wife's comments by smiling at her and then looking out of the window.

Cheryl said that she was "quite hard on Dale." She is a teacher and said that she expected more from Dale than she does from other children. She said she has always found him to be difficult and strong-willed. Roger said that he is intelligent and found school work easy.

Cheryl and Roger's fears and concerns about Dale were related to the South African environment and to their high expectations for him and not to his asthma. "It is always in the back of your mind, what is going to happen here in South Africa. I just want him to be happy and I sometimes wonder whether we just don't expect so much of him that he always feels that he has to live up to almost impossible expectations."

Cheryl and Roger expect Dale to grow out of his asthma, mainly because he is much better now than he used to be. "They have suggested that, because he has childhood asthma, that he has a good chance of outgrowing it." Both parents said that they would classify Dale's asthma as mild to moderate. "Once or twice a year he will need extra medication."

Apart from getting a good education, Cheryl and Roger do not have any aspirations for Dale. "I think as long as he is happy in himself, that is fine. We have told him that he doesn't have any choice – he has to go to university. From there, we will give him free reign. After that, he can follow his heart. I just feel he must have an education."

Dale has a good relationship with his peers at school. He has a lot of friends but no close friends. "I see at cricket, he is accepted by the other boys. He is accepted as one of the guys. He is not the best but he will always be a part of the team so he is accepted there. He doesn't like to be the centre of attraction but he is accepted as part of it."

Dale has a close relationship with his father, more of a friendship than a father-son relationship. Cheryl said she did most of the disciplining, "I tend to be the one who does the punishing or whatever. They play like kids. They argue and perform and carry on."

When asked which words best described Dale, Cheryl said 'difficult', 'strong-willed', 'a tough exterior but inside just a teddy bear', and 'balanced'. Roger said, 'he doesn't like to be the centre of the crowd'.

9.3 THE FAD SCALE

Cheryl and Roger were shown a list of statements and asked to rate their level of agreement with each statement on a four-point scale (strongly agree, agree, disagree, strongly disagree). Cheryl and Roger completed the FAD questionnaire separately, without discussing it with each other. Figure 9.1 shows the *individual mean score* for Cheryl and Roger as well as the FAD norm. The individual scores for Cheryl and Roger are to be found in Addendum C. Figure 9.2 shows the *family mean score* (the combination of Cheryl's and Roger's scores) and the FAD norm. Scores on the following dimensions were compared: problem solving, communication, roles, affective responsiveness, affective involvement,

behaviour control and general functioning. High scores on the FAD scales mean unhealthy functioning.

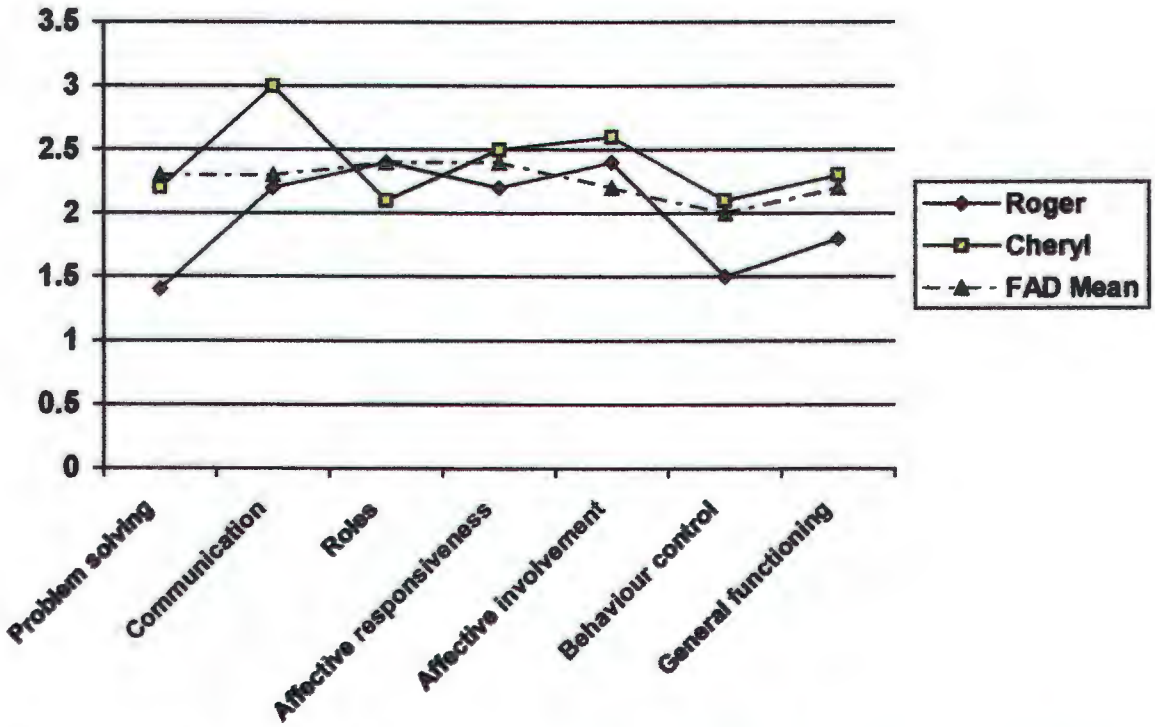

Figure 9.1 Comparative individual mean scores for the different categories in the FAD scale: Roger and Cheryl

The joint family scores (Figure 9.2) as well as the individual scores (Figure 9.1) for *problem solving* and *roles* were below the FAD norms, indicating healthy functioning on these dimensions.

The joint score for *communication* (Figure 9.2) was 2.6, above the FAD norm of 2.3. Cheryl's (3.0) and Roger's (2.2) individual scores (Figure 9.1) were far apart and on either side of the FAD norm, indicating problems with communication in this family and, specifically, Cheryl's problems in maintaining clear communication. Her responses indicated her inability to interpret what other family members were thinking based on what they said. Two examples in the in-depth interview that support this finding are: Cheryl's referral to and treatment of Roger as a 'second son' and her choice to ignore Ryan's tic rather than take action on it.

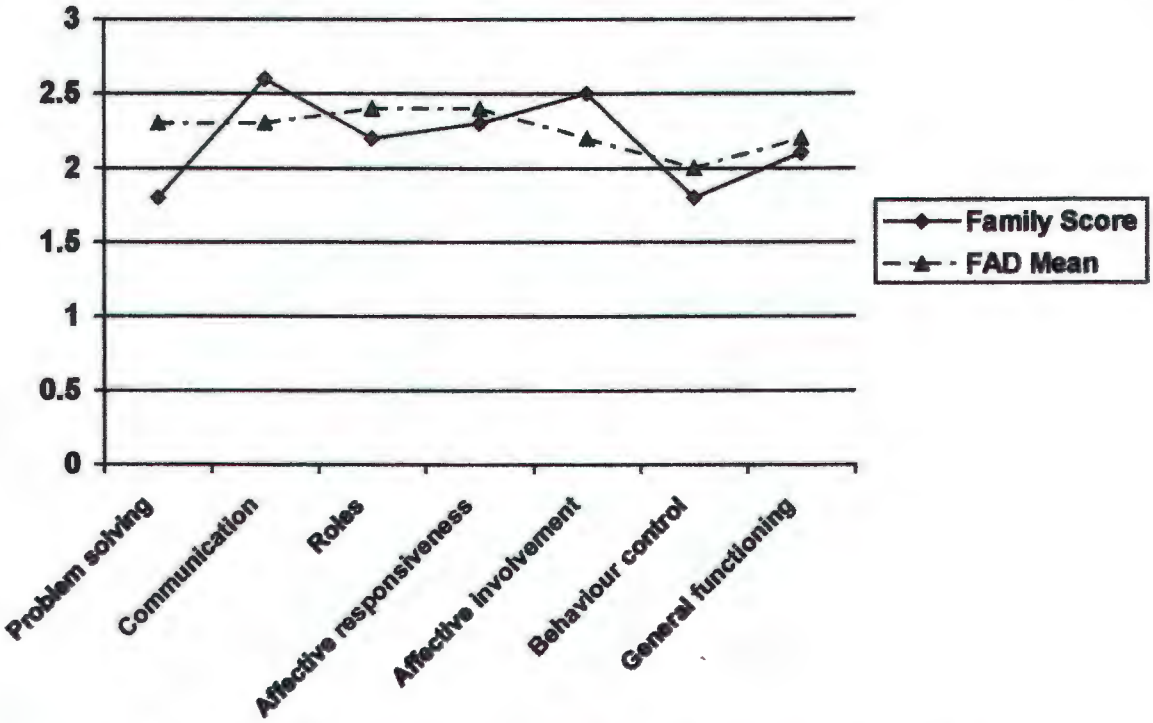

Figure 9.2 Comparative family mean scores for the different categories in the FAD scale: the Stone family

The joint score for *affective responsiveness* (2.3) was below the FAD norm of 2.4 (Figure 9.2). However, Cheryl's (2.5) individual score (Figure 9.1) was in the 'unhealthy' range, whereas Roger's (2.2) was in the 'healthy' range, indicating a conflict in this area and specific problems as regards Cheryl's ability to cope with the emotional demands of the family. This is something that she corroborated during the interview, saying that she enjoyed her overseas trips because they gave her a break from the family.

The joint score for *affective involvement* (2.5) was above the FAD norm of 2.2 (Figure 9.2), as were both Cheryl's (2.6) and Roger's (2.4) individual scores (Figure 9.1). This finding confirms the finding during the in-depth interview that Cheryl and Roger have problems regarding their degree of emotional involvement in the family. Cheryl, particularly, agreed with statements, "We are too self-centred" and "We get involved with each other only when something interests us."

The joint score for *behaviour control* (1.8) was below the FAD norm of 2.0 (Figure 9.2). However, Cheryl's individual score of 2.1 (Figure 9.1) was in the 'unhealthy' range,

whereas Roger's (1.5) was in the 'healthy' range. This difference indicates a conflict area for this couple, and specific problems regarding Cheryl's ability to maintain family standards. In particular, she agreed with the statement, "You can easily get away with breaking the rules." She illustrated this attitude graphically in her insistence on keeping so many animals in the home even though she knew that animal hair is highly likely to cause asthmatic symptoms. Further, during the interview, Cheryl's attitude towards Roger and Dale was that of 'two naughty boys having fun'. She said that she disciplined Dale and was "hard on him". The qualitative and quantitative findings therefore reflect a person who needs to be in control and who dominates this family. Her feeling that family members can get away with breaking the rules could reflect dissatisfaction with the amount of support that she gets from Roger but could also reflect her belief that neither Roger nor Dale meet the high standards that she sets.

Thus, there was a difference in Roger and Cheryl's scores on three of the seven dimensions. The problems that these differences indicate is reflected in their different scores for *general functioning*, with Roger scoring 1.8 and Cheryl scoring 2.3 around an FAD norm of 2.2 (Figure 9.1). This dimension is used as an independent indicator of the health of a family (Stevenson-Hinde & Akister, 1995). The differences in scores on three dimensions as well as the relatively high number of individual scores falling in the 'unhealthy' range confirms that the general functioning dimension does indeed measure the general health in the functioning of families and that the categories highlight specific problems in functioning. The interview, the discussion of which follows, indicated many problems and the differences in the FAD scores for Cheryl and Roger confirms that this family is less healthy than the normative population.

9.4 DISCUSSION OF THE EFFECT OF DALE'S ASTHMA ON THE STONE FAMILY

Cheryl's instinct to mother is expressed in many ways within the family system, from her relationship with her husband, to her son, to her pets and even in her choice of hobby, i.e. making teddy bears, and career, i.e. a teacher. Within the context of family systems theory the *circularity* that exists between each of these aspects of her life both reinforces her 'mothering' instinct and allows expression of it. This family is a particularly good example of the value of viewing the individuals and events within a family as being integral parts of

the system rather than within the cause–and-effect logic of linear thinking. Individuals influence the drift of events and are influenced by other events (Becvar & Stroh Becvar, 1982). Thus Cheryl's mothering instinct influences the events and people close to her and is, in turn, influenced by their behaviour and response to her. It is this holistic study of people and events (Bertonaffly, 1968; Keeney & Sprenkle, 1982) that adds richness to our understanding of the context of mutual interaction and mutual influence.

Within the context of the Stone family, it is interesting to note the *positive connection* between the affective quality of the marital and the parent-child relationships (Cox et al., 1989), and specifically the 'mother-child' relationship that Cheryl has with both Roger and Dale, which is reinforced by the friendship between father and son. Thus, not only do individuals within the Stone family influence each other but the triad relationships (parent-parent, father-son, mother-son) within the family influence each other.

The uniqueness of the Stone family structure is further understood by the concept of *synergism* (Keeney, 1979), which proposes that the components operating together have a greater total effect than the sum of their individual effects. Synergism occurs because of the interaction between the component parts and produces a whole that is greater than one could have anticipated by focussing on the individual parts. The unique structure of a 'mother and her two boys' is enhanced by the other dynamics and relationships within the family system. The corollary to this concept is that each element cannot be fully understood in isolation, as it never function independently. In other words, the relationship between Cheryl and her son, and between Cheryl and her husband, can never be fully understood in isolation from an understanding of the whole family structure.

The concept of *circularity* is well illustrated in this family (Goldenberg & Goldenberg, 1991). Circularity describes the reciprocal, multi-directional relationship that occurs between individuals and systems. Cheryl's assertion that she has two boys is reinforced and illustrated in a number of ways: Cheryl's description of evenings when Dale and Roger play while she prepares dinner; her description of their choice of holiday destinations as places where the boys can play while she does something quiet on her own; and her claim to 'send' Roger with Dale when a doctor's visit is required. There is a circularity of interaction between Cheryl's assertion that she has two boys and Roger's tacit acceptance of this claim. Further, Cheryl's description of her relationship with Dale appears to give some

support to Meijer's (1976) finding that mothers have a dominating over-involved relationship with their asthmatic sons.

The three basic principles governing family systems theory developed by Stroh Becvar and Becvar (1988) are well illustrated in this family. The first two: *one cannot not behave* and *one cannot not communicate* are illustrated by Roger's passive acceptance of Cheryl's interpretation of their relationship. By neither doing or saying anything, he is behaving and communicating a message that is congruent with Cheryl's. The third principle is 'the meaning of a given behaviour is not the true meaning of the behaviour; it is the personal truth for the person who has given it a particular meaning.' This family structure could well be interpreted in other ways but the Stone family has constructed its own unique perception and has given meaning and order to the family structure.

This family portrays a unit that is internally organised and stable but with little adaptation and *change* (Bertonaffly, 1968; Goldenberg & Goldenberg, 1991). The family tends to operate in isolation, preferring to spend time at home and seldom socialising. Patterns of functioning (she makes teddy bears, he surfs the internet) are established and the status quo is maintained (negative feedback). However, positive feedback, which allows for flexibility and change, and encourages new behaviour, is largely ignored. Roger and Cheryl have accepted the diagnosis of Dale's asthma but have not internalised it to the extent of bringing about change within the system. Although they had tested Dale for allergy to dog's hair, this was done with little commitment as Cheryl said she would not have given up her dogs if the tests had been positive.

Related to the concept of feedback is *homeostasis* (Stroh Becvar and Becvar, 1988). In healthy systems, there is a dynamic equilibrium between stability (morphostasis) and change (morphogenesis). Healthy families are creative and resilient in adapting to changing conditions, and families that successfully adapt to change experience less disruption (Wasilewski et al., 1988). Symptoms within a family system may be indicative of difficulties in coping with changes. One of the generalisations relative to systems theory as postulated by Keeney (1979) is that difficulties in any part of the relationship system may give rise to symptomatic expression in other parts of the system. This perception of the dynamics within the Stone family may give greater insight into Dale's symptoms of asthma and the more recent development of a further symptom, i.e. a 'nervous tic'. Neither of these

symptoms has resulted in change within the system, with Cheryl expressing the view that they "don't make too much of a big deal of it (the tic) as it would become even more of a problem". This interpretation of these two symptoms is described by Sundberg et al. (1983) who said that symptomatic or irrational patterns of behaviour may be employed by members of a dysfunctional family in an attempt to maintain the marginal stability of the unbalanced system. Dale's behaviour is not disturbed but rather the result of the complex interactions between him and the family in which it is occurring.

Cheryl and Roger's lack of acknowledgment of these symptoms illustrates one of three ways in which a family can respond to the stress of asthma: self-limitation, denial and recognition (Stroh Becvar & Becvar, 1988). This family *denies* the existence of the demand and, in doing so, establishes a consensus of unreality, convincing Dale that there is no problem and that no change is necessary.

Cheryl's FAD scores on a number of the dimensions were different from, and were less 'healthy' than, Roger's scores or the FAD norms. The FAD findings support the findings in the in-depth interview, i.e. Cheryl has a strong need to control, she is reluctant to express affection, she finds it difficult to interpret what others in the family are communicating to her and she has problems communicating clearly. The FAD scores confirm the conclusion made during the analysis and discussion of the interview, that this family does not function optimally.

9.5 CONCLUSION

Dale is an only child who lives in a family with strong boundaries and limited contact with the outside world. Leisure time is spent at home or with the extended family and the family seldom leaves the home outside of working and school hours. Cheryl's portrayal of herself as the mother figure, with her husband and son dependent on her is the dominant theme in this tightly knit family unit.

Dale's asthma has had little impact on the way in which this family functions. Indeed, apart from giving Dale his medication, Cheryl and Roger prefer to ignore the symptoms in the belief that the more attention they give to Dale's asthma, the more of a problem it will become. The development of another 'symptom', a tic, has been dealt with in the same

way, with minimal attention given to it in the belief that this will limit its effects. Thus, this couple has responded to the stress of Dale's asthma by denying its existence, and there have been few adjustments in family functioning and lifestyle. Rather, the reverse appears to be the case, with the way in which the family functions appearing to have an impact on maintaining Dale's asthma.

Cheryl is the dominant personality in this household: she dominated the conversation and her reference to Roger as 'one of her children', was not challenged by him. Roger and Dale are close but the couple described their relationship as friends rather than as father and son. Cheryl claimed to do the disciplining, whilst Roger "played" with his son. The triad that this family forms is indeed one of a mother and her two boys.

Dale has mild asthma and has experienced few asthma attacks. The fact that it is so mild probably impacts on the couple's lack of attention to Dale's asthma. There were strong indications of a circular relationship between the couple's denial, the mild nature of Dale's condition and the development of a further symptom, a tic.

This family offered a valuable insight into the functioning of some families who have a child with asthma. It appears that denying the existence of asthma is related to the type of family functioning as described by Minuchin (1974), where asthma is viewed as a symptom of a dysfunctional family.

CHAPTER 10

THE PERRYS:

A FATHER, A SON AND A FAMILY

CHAPTER 10
THE PERRYS: A FATHER, A SON AND A FAMILY

10.1 FAMILY BACKGROUND

Lynn and Darren are in their mid-forties, and have three children. Lauren is 18, Jennifer is 13 and Dean, their only son and the asthmatic in the family, is 10. Lynn runs a play group from home, and proudly showed me her work space before we started the interview. Darren thought Dean's asthma was mild and Lynn, in agreement with the paediatrician, thought it was moderately severe.

10.2 THE INTERVIEW

Lynn bears the main responsibility of looking after the children. During the week, she makes sure homework is done and takes care of after-school activities. Over the weekends, the family spends time together. Darren said, "She is here. I am at work. She does all the schoolwork. I help out over weekends. Over weekends, it depends on what we are doing. We do most things as a family."

Their work and family take up most of their time. Lynn said, "There is not much time left after the children. Our interests are quite diverse. I am a bookworm and Darren is a TV addict. I will sit here and read and Darren will watch TV."

Darren and Lynn said that they seldom fought. If a conflict arose they discussed it until they resolved it and neither held a grudge. "We made a pact a long time ago not to go to sleep before we had sorted it out. We discuss things and they do come to a head."

Lynn and Darren also discuss their budget together, never making any major purchases on their own. Darren said, "It is always a joint thing. I will never buy anything without first discussing it with Lynn. As far as monthly finances go, I make sure it goes in the bank and she makes sure it gets paid."

The family spends a lot of time involved in sport. The children play sport at school and club sport, together with their father, over the weekends. Lynn does not participate but enjoys being a spectator. Dean is a good sportsman, and plays soccer, baseball and cricket. Darren is involved with the club, as a coach and player in the older league. Darren said that he noticed that Dean occasionally played below his potential and wondered whether it was laziness or Dean's asthma.

Lynn classified Dean as an allergic asthmatic. The dust in winter and the pollens in spring and summer cause allergic rhinitis as well as asthma. Dean's medication and dairy-free diet keeps him well-controlled.

The one area that Lynn has placed restrictions on is swimming. She said that if Dean gets cold after swimming, he gets sick. "I have to restrict him from swimming parties. Some people seem to have swimming parties towards the end of summer or the beginning of winter. The water is just too cold. He can swim and he is very active but at soon as he gets out and that cold air hits his chest, that night he is sick. Recently I had to say no to Dean because the children were in the pool in the rain. Dean was upset because he was getting singled out, he was different. He complies but sulks."

Other negative effects of Dean's asthma are an increase in Dean's weight, his restricted diet, which impacts on the entire family and finance. Lynn said that Dean's medication had caused weight gain, "The medication has certainly blown him up like a balloon. It has increased his appetite horrendously. Last night I was looking at old photographs of him and his face is not even the same shape any more. It has got quite round. It worries me because there must be an effect long-term." Lynn also commented on the resentment that other family members have because they too have to comply with Dean's diet, "We will be driving past McDonalds and we will see their ice-cream for 99c. My husband will say, "let's stop...no we can't". So the rest of us suffer because of Dean. I don't really resent it but the other child (younger sister) does." A further negative effect was the cost of Dean's medication, "For some reason we have never managed to get Dean on to chronic medication. We didn't know we could claim on chronic until recently. Our medical aid is up by March and then we pay this heavy 20% levy. It does take its toll. Dean's script alone is huge and then when we do visit the doctor we always pay up front and get the money back later."

Lynn said that she was more protective of Dean than she was of her other children. "You have to watch him constantly. You have to watch that he is not overdoing things. He is not allowed to run riot."

Lynn and Darren have different concerns for their son. Lynn was worried that Dean would never have any relief from his asthma and that it would be a life-long condition. "Just where it is going to end? I don't want him to have to take medication for life." Darren was concerned that Dean's sport would be limited. "My concerns are that he is very sporty. We thought he was just getting lazy but, now that he is taking his asthma medication, we realise that that is what the problem was. I saw it from a different perspective because I was his coach. So, that is my concern, that it might jeopardise his sport."

Darren and Lynn said that Dean's relationship with his father was 'special'. "I have an excellent relationship with him – he is my son. We play sport together. He loves the fact that I get involved with coaching, and I like that sort of thing." Lynn said that Dean was loving towards her, "He shows more emotion than his sisters. He will come and put his arms around me. I have to beg his sisters to do that." Darren and Lynn described Dean's relationship with his sisters as 'close' and 'argumentative'.

Darren thought that Dean's asthma was mild and Lynn thought it was moderately severe. Darren based his assessment on Dean's ability to breathe. "When I think of asthma I think of not being able to breath at all, and Dean does not have that. I think of someone that battles to breathe, that has to have their pump with them all the time. So, if you ask me how he is affected I would have to say 'mild'". Lynn based her assessment on the lung function tests that Dean has at the doctor's rooms. "He is only using 66% of his lungs – I think that is moderate." Both Lynn and Darren expect Dean's asthma to improve, mainly because of his age and that he is better than when first diagnosed. "I expect him to grow out of it because he is so young. That is something I hear – that children with asthma grow out of it."

When asked which words best described Dean, Lynn said 'soft', 'sensitive', 'athletic' and 'even-tempered.' Darren said 'gets on with everybody, including adults.'

10.3 THE FAD SCALE

Lynn and Darren were shown a list of statements and asked to rate their level of agreement with each statement on a four-point scale (strongly agree, agree, disagree, strongly disagree). Lynn and Darren completed the FAD questionnaire separately, without discussing it with each other. Figure 10.1 shows the *individual mean score* for Lynn and Darren as well as the FAD norm. The individual scores for Lynn and Darren are to be found in Addendum C. Figure 10.2 shows the *family mean score* (the combination of Lynn's and Darren's scores) and the FAD norm. Scores on the following dimensions were compared: problem solving, communication, roles, affective responsiveness, affective involvement, behaviour control and general functioning. High scores on the FAD scales mean unhealthy functioning.

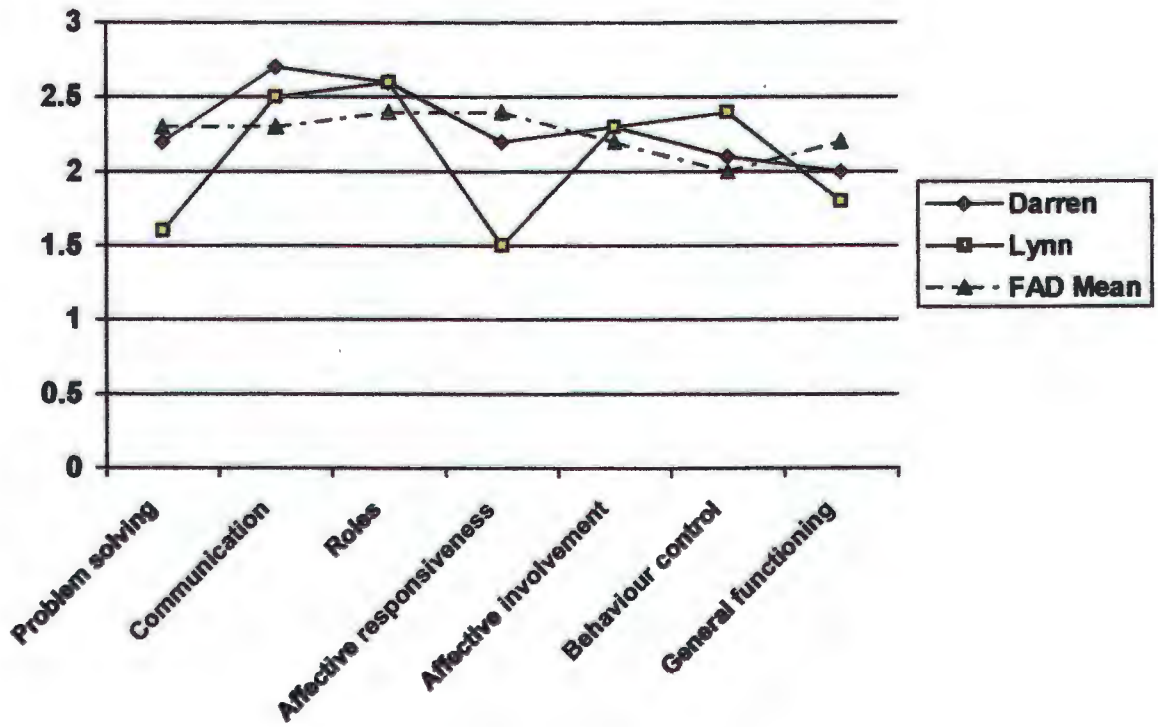

Figure 10.1 Comparative individual mean scores for the different categories in The FAD scale: Darren and Lynn

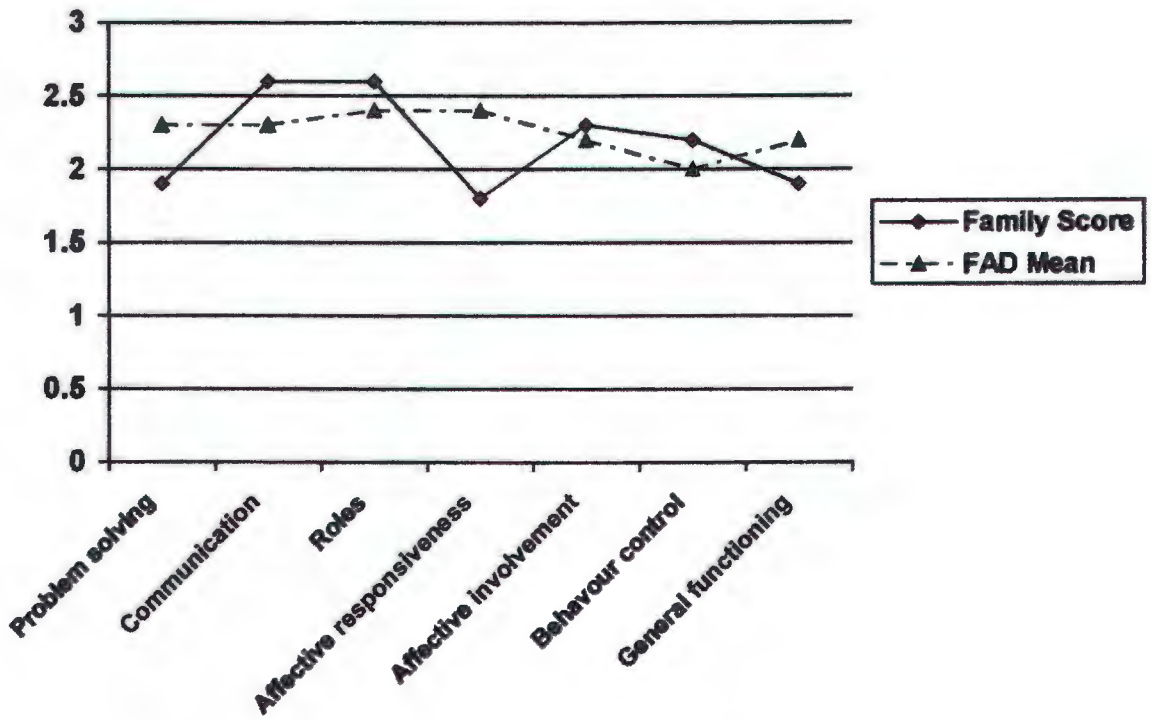

Figure 10.2 Comparative family mean scores for the different categories in the FAD scale: the Perry family

The joint family scores (Figure 10.2) as well as the individual scores for Darren and Lynn (Figure 10.1) for *problem solving* and *affective responsiveness* were below the FAD norms, indicating healthy functioning on these dimensions.

The joint score for *communication* (2.6) was above the FAD norm of 2.3 (Figure 10.2), as were both Lynn's (2.5) and Darren's (2.7) individual scores (Figure 10.1), indicating that this couple have problems in maintaining clear communication. Specifically, Lynn and Darren both disagreed with the statement, "When we don't like what someone has done, we tell them" (i.e., they don't communicate their displeasure to other family members).

The joint score for *roles* (2.6) was above the FAD norm of 2.4 (Figure 10.2), as were both Lynn's (2.6) and Darren's (2.6) individual scores (Figure 10.1), indicating that this couple have problems in establishing responsibility for family tasks. In particular, Lynn strongly agreed and Darren agreed with the statement, "Family tasks don't get spread around

enough." Like the Snymans, this couple has a young family and their scores on this dimension could reflect the burden of responsibility they feel because of their young family.

The joint score for *affective involvement* (2.3) was just above the FAD norm of 2.2 (Figure 10.2), and Lynn and Darren had the same individual scores of 2.3 (Figure 10.1), indicating that this couple have problems in their degree of emotional involvement in this family. Specifically, both agreed with the statement, "If someone is in trouble, the others become too involved." This couple did not communicate any problems in this area during the interview and this slightly raised score should be interpreted circumspectly.

The joint score for *behaviour control* (2.2) was above the FAD norm of 2.0 (Figure 10.2). Lynn's individual score was 2.4 and Darren's score was 2.1 (Figure 10.1), which means that the scores were on either side of the FAD norm, indicating parental disagreement on the maintenance of family standards. Again, Darren and Lynn did not communicate any problems in this area during the interview. On the FAD scale, Darren agreed and Lynn disagreed with the statement, "You can easily get away with breaking the rules." So Darren, but not Lynn, felt that rules could easily be broken. Specifically, Lynn felt that the family did not know what to do in an emergency and didn't have rules about dangerous situations. Darren disagreed with her on both issues. From the FAD scores, we can infer that Darren likes to have and appears to have tighter control on the family than Lynn does.

Darren and Lynn's individual scores (Figure 10.1) for the dimensions of *communication*, *roles* and *affective involvement* were close, indicating parental agreement on these issues. This close parental agreement is reflected in the scores for *general functioning*. The joint score was 1.9 (Figure 10.2), Lynn's individual score was 1.8 (Figure 10.1) and Darren's individual score was 2.0, all well within the 'healthy' range below the FAD score of 2.2.

10.4 DISCUSSION OF THE EFFECT OF DEAN'S ASTHMA ON THE PERRY FAMILY

In family systems theory the individual is not examined in isolation. Rather, relationships are studied, and particularly how individuals interact and influence each other. Each person's behaviour becomes reinforcing feedback for the behaviour of the other. The relationship between Darren and Dean is interesting in that they appear to have found a

unique dyad within this family. Most of Darren's out-of-work activities are focussed on shared sporting activities with his son. They attend the same club, with Darren being involved as both a player and a coach for his son's soccer team. Of course, this interview was focussed specifically on the asthmatic child - Dean, and there is no way to compare Darren's reported relationship with his son to his relationship with each of his two daughters, but certainly the shared activity between father and son appeared to form a focus for the social activity of the entire family.

Dean's asthma has affected his parent's perception of him. There has been a *circular* reaction (Goldenberg & Goldenberg, 1991) in terms of their high expectations of his sport prowess being limited by the physical restrictions caused by his asthma. Darren and Lynn have attributed Dean's weight gain and underperformance on the soccer field to the treatment for his condition as well as to the asthma itself. The parents' shift in perception can be viewed as a logical complement to Dean's behaviour. Equally, his behaviour could be viewed as complementary to their perception.

Dean's asthma has had further impacts on the family, illustrating the interrelationship that exists between individuals within a person-event system (Keeney, 1979). Thus, the entire Perry family feels the effect of Dean's restricted diet (e.g. no McDonald's ice-cream), causing some resentment with Dean's younger sister which, in turn affects their relationship. Financially, the family is affected by bills for Dean's medication and treatment.

The notion of feedback (Keeney, 1979) is well illustrated in the family. *Negative feedback*, which is used to maintain family functioning with acceptable normal limits by countering deviation is illustrated by Lynn's restriction on Dean's swimming. She has noticed that Dean gets sick if he gets cold while swimming, she does not allow him to swim, he gets angry at being singled out and their relationship suffers.

Positive feedback, which allows for flexibility and changes in the family by encouraging new behaviour, is illustrated by the Perry's acceptance of Dean's diagnosis of asthma. By restricting his diet and expressing their understanding of his lapses in performance they communicated their acknowledgment of the condition. Thus, the family has adapted to this

situation, reorganised the system, and established new ways of behaviour (Stroh Becvar and Becvar, 1988).

Although during the interview Darren and Lynn communicated strong parental agreement, both of their mean scores for communication on the FAD scale were above the healthy norm, with their scores for the specific factors under this dimension indicating a lack of openness when dealing with problems. This finding may be associated with the strong alliance that Darren has formed with his son, Dean. The family appears to function around this very important relationship. Other relationships and other issues appear to be less important to this central dyad.

10.5 CONCLUSION

Dean is the youngest child and the only son in a family of three children. Darren's relationship with his son, Dean, is central to the way in which this family functions and indeed to its lifestyle, with much of the family's leisure activities focussing on Dean and Darren's sports, particularly soccer. The Perry family may be a complex unit, comprising five persons, ten dyads and twenty-seven triangles, making up a total of forty-two units, but the father and son relationship was so important that it lead me to describe this family as "a father, a son and a family."

Lynn is far more aware of the impact that Dean's asthma has had on Dean's life and the family's lifestyle and functioning than Darren is. She talked about the negative effect that his medication has had on him physically ("blown him up like a balloon"), about his diet restrictions frustrating other family members and about the drain on the family's finances due to Dean's visits to the doctor and his medication. Generally, Lynn has coped with the stress of Dean's asthma by limiting his swimming activities when it is cold and restricting his diet in order to limit the effects of his asthma on both Dean and the family.

Darren and Lynn disagreed on how severe they thought their son's asthma was, and this difference in perception appears to have affected the ways in which they interact with him individually. Lynn said that Dean's asthma was moderately severe and she has placed restrictions on him with regard diet, which is dairy-free, and to swimming, which she forbids if it is cold or when he is not well. Darren, on the other hand said that Dean's

asthma was mild and he was only concerned that Dean's sporting achievements are going to be curtailed because of his asthma. He invests a lot of time and energy in promoting Dean's sporting career and refuses to accept that Dean's asthma will restrict him in any way. Thus, Dean and Darren have formed a significant relationship that appears to govern the family and the way in which the family functions.

CHAPTER 11

THE VAN JAARSVELDS:

A PRECIOUS ONLY CHILD

CHAPTER 11
THE VAN JAARSVELDS: A PRECIOUS ONLY CHILD

11.1 FAMILY BACKGROUND

Johan and Renee are in their mid thirties and have one child, a son, called Neil. Neil is eight years old and was diagnosed with asthma when he was a baby. Johan, Renee and the paediatrician agree that his asthma is mild.

11.2 THE INTERVIEW

I interviewed Johan and Renee one Saturday afternoon. Their son, Neil, aged eight, was sent to his room to watch TV while the interview was being conducted.

Renee said that she had always handled the finances, and was primarily responsible for looking after Neil. She worked as a bookkeeper at Neil's school, so they kept the same hours. If she needs help with Neil, she asks friends.

The couple play sport together, tennis and golf, and have recently included Neil in both sports. They both enjoy watching sport on TV, and prefer this to going out to watch a movie. Renee and Johan talk about everyday things, and will often talk during the day.

In terms of coping with conflict, Renee said that she 'bottled' things up and then exploded and that Johan became quiet, sulky and withdrawn. Conflict situations could take a few days to resolve but "eventually we get over it. We never get to the point of me kicking him out of the house or anything like that. We just get on with life again."

Family activities centred round tennis, golf, the occasional game of ten pin bowling and weekend fishing and hiking trips. The family made a point of doing things together, "We don't like to do too many things that we can't do together. My husband does not go fishing all on his own. If we can't go together then he doesn't go." Because she is on the staff at

Neil's school, Renee is not involved as a parent, for example on the Parent Teachers' Association (PTA).

Neil is a loner. His mother said he had 'only-child syndrome'. His 'aloneness' is exacerbated by the fact that Neil's school is far away and so playing with friends is difficult to arrange. Johan said that Neil didn't understand adult-child boundaries and they were having to teach him that there were times when he could not be part of adult conversation, and should be on his own or with his friends.

Johan said that he also has asthma so, when Neil developed chest problems, diagnosis of asthma was easy to accept. Neil is on maintenance inhaled steroids and seldom needs medication for a tight chest. Renee is more involved in the day-to-day treatment of Neil's asthma but said that her husband was better at recognising the symptoms quickly.

Grass, dust, dogs and cats make Neil's asthma worse. The family has recently been given a cat and, even though they are aware of Neil's allergic response, they have decided to keep the cat. "When I see how he loves the cat and what it has done for him, I think there are more positives than negatives. The odd allergies are fine. Neil is aware of his allergies. If he has been playing with the cat he will go and wash his hands."

Renee and Johan do not restrict their child from playing sport. "His asthma has never stopped him from playing soccer. He will be coughing his lungs out but he will keep on running. I feel so sorry for my child. If he wanted to get out of anything he could use it as an excuse but he never does." Renee said that when Neil is sick she may try to keep him quiet. "If he is coughing and when he is sick, I will try and not let him run around too much. You can't do that with a child too much. I would never say that I have placed restrictions on him. I just don't let him get too excited and run around."

Renee and Johan are on a good medical aid, so Neil's asthma has not placed a financial burden on them. They complained that they had to pay doctor's fees up-front and then claim back from the medical aid. When asked about time, they said that they had not needed to visit the doctor that often for it to be a problem.

Renee and Johan both said that there were no positive outcomes associated with having an asthmatic child. "I can't say that I have noticed anything positive but there is nothing that negative either. You just live with it."

Renee said that she 'babied' Neil, "maybe because he is an only child." She put his clothes out for him and saw to all his needs. She worried about Neil having an asthma attack when she or her husband was not close by. She did not think that schoolteachers had enough knowledge about asthma. Other concerns that this couple had for their child related to "the usual things like drugs, sex and corruption."

Renee and Johan want Neil to make a success of his life and to know that he is well loved and cared for. They want him to understand the value of money, of life and to be well-mannered.

Johan and Neil have a close and loving relationship, and will often go camping together. Neil is the centre of this home, "If he is not in the home, if he goes to a party, we look at each other and wonder what to do. He is the centre, with us loving him, playing with him, he is there." Renee related a frightening experience that had occurred a few years previously, during a camping trip. Johan and Neil were fishing on a dam when their boat capsized and, for a few moments of panic, Johan was unable to find Neil. This event has had a profound effect on Johan and Renee, and has increased the value-driven perception of him as a 'precious' only child.

Johan and Renee both expect Neil's asthma to improve as he gets older – mainly because Johan's asthma improved with age.

When asked which words best described Neil, Renee said 'he is the most precious thing in my life", lovable', 'a very big heart', 'he shares his possessions – someone will come here that he doesn't know and he will look for something to give them.' Johan said 'he is very open – he knows that we won't tolerate lies.'

11.3 THE FAD SCALE

Johan and Renee were shown a list of statements and asked to rate their level of agreement with each statement on a four-point scale (strongly agree, agree, disagree, strongly disagree). Johan and Renee completed the FAD questionnaire separately, without discussing it with each other. Figure 11.1 shows the *individual mean score* for Johan and Renee as well as the FAD norm. The individual scores for Johan and Renee are to be found in Addendum C. Figure 11.2 shows the *family mean score* (the combination of Johan's and Renee's scores) and the FAD norm. Scores on the following dimensions were compared: problem solving, communication, roles, affective responsiveness, affective involvement, behaviour control and general functioning. High scores on the FAD scales mean unhealthy functioning.

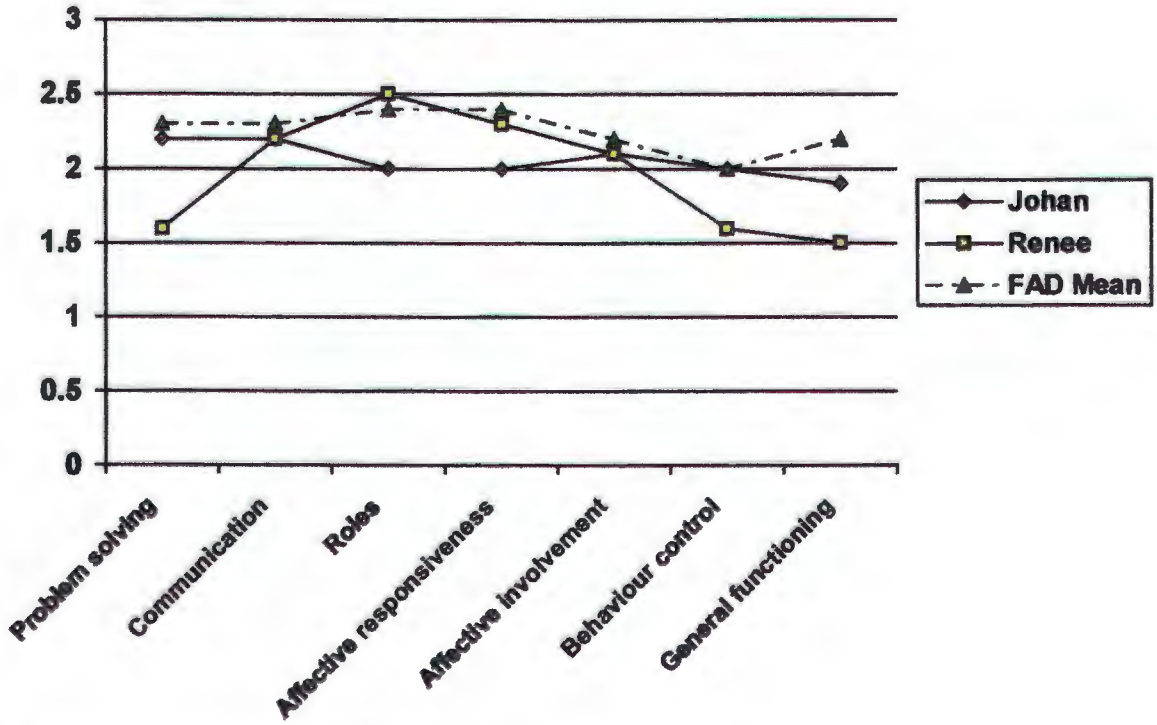

Figure 11.1 Comparative individual mean scores for the different categories in the FAD scale: Johan and Renee

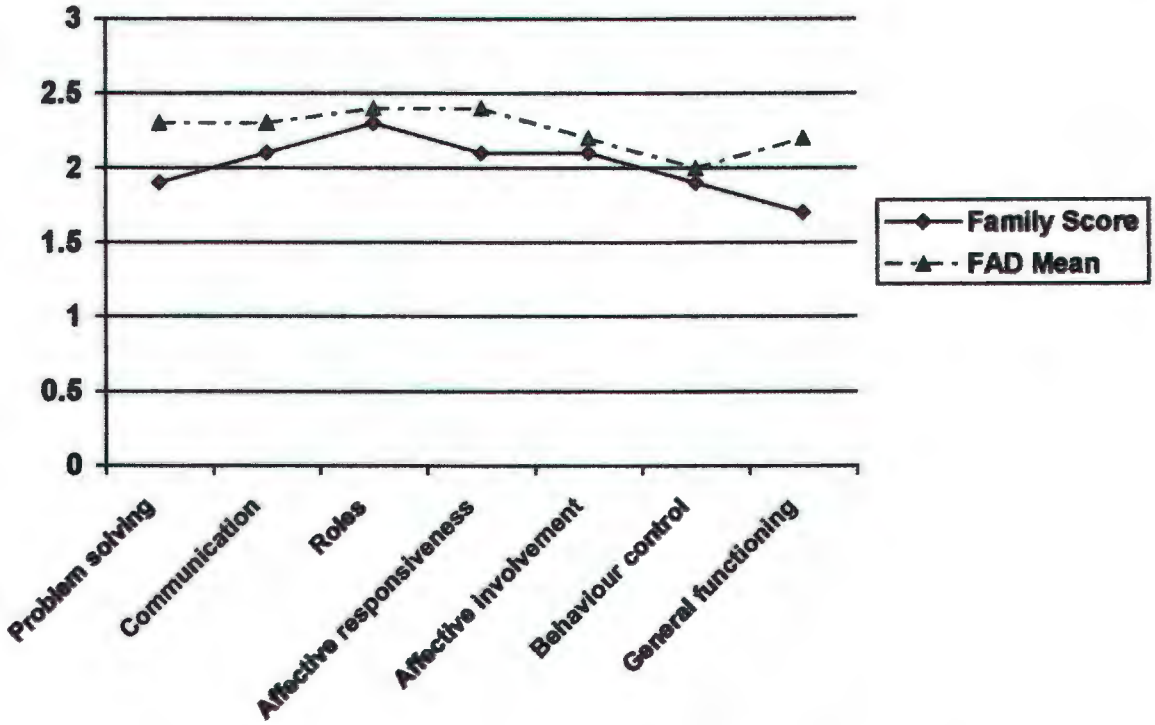

Figure 11.2 Comparitive family mean scores for the different categories in the FAD scale: the Van Jaarsveld family

The joint family scores (Figure 11.2) as well as the individual scores for Johan and Renee (Figure 11.1) for *problem solving, communication, affective responsiveness, affective involvement* and *behaviour control* were all on or below the FAD norms, indicating healthy functioning on these dimensions.

On one dimension - *roles* - there was a significant difference between Johan and Renee's scores, with Johan scoring 2.0 and Renee scoring 2.5 (Figure 11.1), around an FAD norm of 2.4 and a joint family score of 2.3 (Figure 11.2), indicating that Renee is less comfortable with the division of responsibility for family tasks than Johan is. This score confirms the feeling that Renee expressed during the interview, that she is dissatisfied with the tasks assigned to her, which leave her little time for her own interests.

The healthy functioning indicated on the individual dimensions is reflected in the *general functioning* score: The FAD norm was 2.2, the joint score was 1.7 (Figure 11.2), Renee's individual score was 1.5 and Johan's score was 1.9 (Figure 11.1).

11.4 DISCUSSION OF THE EFFECT OF NEIL'S ASTHMA ON THE VAN JAARSVELD FAMILY

Renee's description of more than one factor impacting on her child's 'aloneness' is congruent with family system's theory's focus on the *interaction* between individuals and events. There is a mutual interaction between Neil's 'aloneness', his position in the family as an only child, and his lack of friends because his school is far away and because his cousins have recently moved away. Thus, more than one individual and event is perceived to impact on and be impacted upon by this aspect of Neil.

Neil's '*aloneness*' and *dependence* on his parents for emotional support gives an alternative interpretation to the conclusion that Khampalikit (1983) came to in his study of children's perception of their illness. He concluded that those children who perceived their asthma to be moderate or severe were more dependent on their parents for emotional support than were children who perceived their asthma to be mild. Neil and his parents perceived his asthma to be mild. Indeed, apart from allergic exacerbations, their experience has not been otherwise. This finding highlights the danger in forming cause-and-effect relationship between two events. Although two events may indeed by related in some way, the researcher must be wary of excluding other events and behaviours, which at face value, do not seem to be related. Family systems theory makes an attempt to achieve a more *holistic* and inclusive vision of situations and events (Bertonaffly, 1968; Keeney & Sprenkle, 1982). Systemic thinking allows us to escape linear-type logic, which assumes that we can objectively identify discrete events with set beginnings and endings. Systems thinking recognises that we are a part of events. Neil's aloneness and dependence are influenced by the drift of events (opening up the possibility that there could be more than one event) and influences other events (Stroh Becvar & Becvar, 1988). Further, Neil's dependence on his parents is reflected by their dependence on him. Renee described how Neil was the focus for the family and they were 'lost' if he was not there.

Renee described an interesting dynamic in their decision to keep a cat. Renee and Johan recognised that the cat caused Neil's asthma to get worse (*negative feedback*) but also recognised that Neil's emotional reaction towards the cat had been beneficial (*positive feedback*). In a healthy family, positive and negative feedback loops work together to

maintain stability and promote change (Stroh Becvar & Becvar, 1988). Thus, Renee and Johan made a decision, based on the balance between Neil's physical and emotional needs, and put in place new behaviour (Neil washes his hands after playing with the cat) to help keep the negative feedback (allergic reaction) to a minimum.

Renee and Johan referred to Neil as their "precious' child. This attitude is part of a *circularity* of events and perceptions. Circularity 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). Thus, Neil's position as an only child, his asthmatic symptoms and the near-drowning experience would reinforce his uniqueness within the family, and the couple's perception of him as 'precious' would add an intensity to his position in the family, to their reaction to his asthmatic symptoms and to the near-drowning experience.

Further, Renee and Johan's explanations for why Neil is so precious illustrates one of the principles of family systems theory, as given by Stroh Becvar & Becvar (1988). This principle states that the meaning of a given behaviour is not the *true meaning* of the behaviour. It is the personal truth for the person who has given it a particular meaning. Thus, reality is not external to Renee and Johan but constructed by them as they bring their own personal perceptions to bear on it, and to give meaning to it.

Neil's position as the focus of the family is related to strong parental agreement and family cohesion. This could be viewed as positive in that *parental agreement* is crucial to healthy family functioning (Gardner, 1982). It could also be viewed as negative, and as an indicator of *enmeshment* (Minuchin, 1974), where family members are over-concerned and over-involved in each other's lives. The boundaries which differentiate subsystems and separate sub-units of the overall system are diffuse, and may indicate a more extreme form of proximity and intensity in this family interaction than is healthy. This view is supported by the conclusion of Wolf Tatem and DelCampo (1995), who found that symptomatic behaviour in a child (e.g. mutism, asthma) could be an indicator of a family problem, and that the family structure, role distribution and modelled behaviour contributed to its occurrence and maintenance. It is interesting that the mutual dependence that appears to exist in this family (as discussed on page 124) has been associated with the development of

a symptom (e.g. asthma) within the family (Prest & Protinsky, 1993). The symptom may be seen as a manifestation of the family emotional process.

Neil's asthma can be viewed in a number of ways: as functional within the family system (Gerson, 1993; Sundberg et al., 1983); as reflective of the state of the family; or as part of the complex interaction within the family system in which it occurs. Whichever way we choose to interpret Neil's asthma within this family system, it appears certain that there is a relationship between family and illness and that Neil's asthma will both affect and be affected by the family context (Marteau et al., 1987). Indeed, the attitudes of concern and protection that Renee expressed could well be a response to Neil's long-continuing illness (Hillard et al., 1985). Further, the cohesion within this family gives support to the finding by Baron et al. (1992), who found that children with high levels of dependence were more likely to live in a highly cohesive family, regardless of the severity of their asthma.

The cohesion and agreement between the couple is reflected in their FAD scores. With the exception of their scores for 'roles', their responses are very close to each other. The difference in the 'roles' score reflects a difference in satisfaction with the way family roles are structured. Johan was more satisfied with his involvement in family tasks and duties, and the time given for him to pursue his own interests than was Renee (whose mean score was slightly above the healthy norm). Apart from this one area, the cohesion in their responses was significantly close. The FAD results confirm the close structure and functioning of this family.

11.5 CONCLUSION

Neil is an only child and is the focus of Renee and Johan's attention. The couple include him in their preferred leisure activities; playing tennis and golf and fishing. The individuals in this family enjoy being with each other, they spend time together and support each other. Renee and Johan truly enjoy being with their precious only child.

Neil's asthma, which is mild, appears to have had little effect on the way in which the family functions, and the family has not had to find ways of coping with the minimal stress it has introduced. Renee said that she could not think of anything either positive or negative associated with Neil's asthma, "You just live with it." This confirms the experience of other

parents of children with mild asthma included in this study. Together with the very different experiences of parents of children with severe asthma, this finding indicates that there is a strong relationship between the severity of the child's asthma and its impact on family functioning.

Neil's parents describe him as a loner and attribute this to his status as an only child. It is interesting to note that Renee and Johan spontaneously talked about at least one other factor, which they perceived to continue to impact on him being a loner; they live far away from school and so find it difficult to arrange for Neil to play with friends outside of school. This is interesting because it appears that people instinctively know one of the basic assumptions of family systems theory: that there may be more than one factor impacting on behaviour.

Thus, this family has a close structure and functions in a healthy way. It was the only family that showed no signs of emotional disengagement by any of the family members, and the analysis of this family offered a view of a close family that enjoyed spending time together.

CHAPTER 12

CONCLUSION:

THE INTERACTION BETWEEN PAEDIATRIC ASTHMA AND FAMILY FUNCTIONING

CHAPTER 12
CONCLUSION: THE INTERACTION BETWEEN PAEDIATRIC ASTHMA AND FAMILY FUNCTIONING

12.1 INTRODUCTION

In chapters 4 to 11, the interaction between paediatric asthma and family functioning were discussed in the context of each individual family. In this chapter, I will draw together the findings from the case studies as well as the FAD scales, and discuss them as they relate to family systems theory. Conclusions on the aims of this study as set out in chapter 1 will also be given, with specific reference to:

- Family structure and functioning (e.g. the number of family members, boundaries and rules).
- Impact of the child's asthma on family functioning (e.g. stress, coping, restrictions, positive impacts and impacts on finance, time, emotional life and social activities).
- The impact of the severity of the child's asthma on family functioning and lifestyle
- Parental attitudes towards the child (e.g. perceived similarities and differences between children in the family, and perceived behavioural disturbances in the asthmatic child).

Although there are many similarities between and connections that one can make about the families included in this study, it is clear that each is a *unique unit*. The ways in which each family unit operates, the processes each unit employs to function, the ways in which the parents of each unit describe the family and indeed the words they use to describe their families are unique. The individual responses during the in-depth interview as well as the scores on the FAD scale showed a remarkable uniqueness about each family even though they were drawn from an homogenous strata of society (i.e. white, middle to upper class and all resident in Gauteng). For example, the Robinsons interpreted Adam's asthma from their point of view as a sports-oriented family, whereas the Van Jaarsvelds' focus was on their precious only child. Society, the more inclusive system level in which these families

function, has determined the broad outlines for the structure and functioning of the families but each family has developed its own unique form and style. In the same way, each family has set broad outlines for structure and functioning, yet the individuals within each family are unique. For some families, this meant that the individuals had their own interests and seldom met together as a family (e.g. the Howards). For other families, the structure was much closer and they did most things together (e.g. the Winters). This uniqueness will also be evident in the following discussion on family functioning, including sharing of responsibility, roles, resolution of conflict, communication, problem solving, behaviour control and general functioning.

12.2 FAMILY STRUCTURE AND FUNCTIONING

The interviews as well as the FAD scores indicated that each couple established its own way of dealing with issues related to structure and functioning. For example, in some families there was shared responsibility for finance (e.g. the Winters) and in other families, one partner managed it exclusively (e.g. the Robinsons). In some families, there was shared responsibility for child care (e.g. the Winters) and in others the wife had no help from her husband (e.g. the Howards). According to the FAD scale, the sharing of responsibility is related to the *roles* that parents play in the family. Two of the families, the Snymans and the Perrys, had difficulty in establishing responsibility for family tasks. The wives, in both cases, felt that they did not have sufficient time to pursue their own interests. These feelings could be an indicator of the age of their children, with both sets of parents feeling burdened by the responsibilities of a young family. In the in-depth interviews both couples indicated that they put the needs of their children ahead of their own but expected that there would be a shift in focus as their children grew older. Renee Van Jaarsveld also felt burdened by her role in the family. Both her FAD responses and her views expressed during the interview indicated that, even though the Van Jaarsvelds have only one child, care giving and housework is her full responsibility and she feels burdened by the roles assigned to her which leave little time for her to pursue her own interests.

The FAD scores for *communication* indicated that half of the couples interviewed had problems with communication. Responses on the individual statements showed that communication in these families was not honest and open. The two couples whose FAD scores indicated significant problems with communication, i.e. the Howards and the Stones,

also had clear unresolved conflicts. For example, Susan expressed her feelings of isolation and resentment caused by years of coping with Sarah's asthma on her own with neither emotional nor practical support from her husband. This was a role that she had absorbed over the years, it was something that the couple has never really talked about, and it had created conflict that has never been resolved. More recently, Wesley's diagnosis of Parkinsons has further impacted on communication between the couple. His condition was not discussed during the interview but was confided by Susan outside of his hearing. It has added to Susan's burden of responsibility in the family, and has decreased the likelihood of more honest and open communication between the couple.

The communication problems in the Stone family were different from the Howards' problems. In the mistaken belief that by ignoring Dale's asthmatic and tic symptoms, they would reduce its impact on the family, Cheryl and Roger do not allow open and honest communication in their family. Further evidence of poor communication patterns in this family were Cheryl's demeaning references to her husband as 'one of her children' and his apparent acceptance of her dominance.

Most of the parents included in the study did not have any difficulties with *problem solving*. This means that most parents were able to confront their problems, discuss them and act as a family on decisions regarding problems.

Half of the couples participating in this study had FAD scores indicating problems with *controlling behaviour* appropriately. This means that in general they had problems with dealing with emergencies, in maintaining cleanliness in the home and with the appropriate expression of anger and discipline. However, in interpreting these findings, the unique structure of each family must be taken into account. Thus, the high scores for the Howard and Robinson families may well be an indicator of a family with older children needing less rigid behaviour controls than a family with younger children. The other two couples, the Perrys and Murrays, indicated parental disagreement on the maintenance of family standards. Lynn and Darren did not communicate any specific problems during their interview but Anne felt that she did not get enough support from Walter when disciplining the children.

Parents' experience of asthma outside of the current family unit influenced their relationships and behaviour within the current family unit. Those parents who had previous personal experience of asthma accepted their child's diagnosis of asthma more readily and experienced less stress during an exacerbation than did those parents who had no previous experience of asthma. For example, Wesley Howard said that he expected Sarah's asthma to improve as she grew older because his asthma had, whereas Susan was more pessimistic, "I don't think she will ever grow out of it. It has never got less." Renee Van Jaarsveld said that her husband, an asthmatic, was better at recognizing the symptoms quickly than she was. Thus, viewing the family system vertically gives further insights into the impact of paediatric asthma on family functioning (Bardill, 1997; Bowen, 1978; Hinde, 1989).

Within each family, the *number of people* that comprised the family unit impacted on the complexity and functioning of the family unit, as with the birth of each child the family system becomes an ever-increasing series of interlocking triangles. Thus a family of five, such as the Snyman family, is a very complex system, comprising five persons, ten relationships (dyads) and twenty-seven triangles, making up a total of forty-two units. Other families, for example the Winters family, are less complex with three persons, three dyads and one triangle making up a total of only seven units.

One-child parents were more likely to describe their family as doing most things together. The triangle of three appears to be an exclusive relationship with much stronger links than the individual triangles within a more complex system. The Winters, Stones and Van Jaarsvelds all claimed to spend most of their leisure hours together. Renee said, "We don't like to do too many things that we can't do together. My husband does not go fishing all on his own. If we can't go together then he doesn't go." Bill and Shirley even claimed to share the housework, "We don't live separate lives from each other. Bill will help me clean the kitchen floor, he will vacuum, we do most things together."

One-child parents were also more likely to describe their child as a loner that did not understand adult-child boundaries (Goldenberg & Goldenberg, 1991). Shirley Winters described Warren as a loner, with few friends and her husband described him as, "my buddy. I am his best playing buddy." Johan Van Jaarsveld said that they were having to teach Neil that there were times when he could not be part of adult conversation.

The concept of *boundaries* has been well described by Minuchin (1974) and most families fell somewhere along the continuum between enmeshment (rigid boundaries) and disengagement (diffuse boundaries). It is interesting to note that the parents who described more extreme forms of proximity and intensity in family interactions belonged to one-child families. So, it appears that the fewer sub-units there are in the family system, the greater the likelihood that family members will be over-involved in each others' lives.

The Howard family is the only family that offered support for Wolf Tatem and DelCampo's (1995) conclusion that the child's symptom (asthma) is an indication of compliance to *family rules*. WolfTatem and DelCampo described a family rule that fits very well with Susan's description of events. This family rule is that "mother is the one who really cares about the child, and the child will not cope away from her mother". If this rule applies, the child will do something to make separation less likely. Indeed, the Howards described Sarah becoming symptomatic even before Susan went away. This behaviour would reinforce the family rule. Again, it is impossible to establish a cause-and-effect relationship between these behaviours. The problem with apportioning blame is that one can easily misinterpret behaviours. For example, this study gives no support for the conclusion of James and Arnold (in Stern, 1981) that the asthmatic child is unable to express hostility towards the mother and turns this hostility inwards. Rather than apportioning blame we need to recognize that parents of children with asthma are a part of events. They are influenced by, and their behaviour influences their child's asthma. Our understanding of the impact that asthma has on family functioning and lifestyle is enriched as we move away from linear logic, and keep changing our perspective as we try to come to a more holistic understanding of the issues impacting on and being impacted upon by the child's asthma.

12.3 THE INTERACTION BETWEEN THE CHILD'S ASTHMA AND FAMILY FUNCTIONING

The parents' description of their families and the impact that their child's asthma has had on family functioning highlighted the *complexity* of the interactions that occur within families. Descriptions moved from one aspect to another as parents attempted to give a complete picture. Because we were focusing primarily on one aspect, the asthmatic child, and there was a time constraint, the complexity of each family could not be fully explored. However, because of these constraints, the *holistic* nature of families was highlighted, illustrating how

family systems form a whole that transcends the sum of its separate parts. Parents did not simply describe each individual within the family as an isolated unit but rather described the dynamic and often complex relationships that exist between family members. For example, Lynn Perry described the impact of Dean's restricted diet on the whole family. "We will be driving past McDonalds and we will see their ice-cream for 99c, and my husband will say, "let's stop...no we can't." So the rest of us suffer because of Dean. I don't really resent it but the other child (younger sister) does." So, parents recognize that their child's asthma impacts in a myriad of ways on the family's lifestyle and functioning.

In terms of family systems theory, individuals within a family are not seen in isolation but rather as *interacting* and *influential* members within a family context (Goldenberg & Goldenberg, 1991; Hetherington & Clingempeel, 1992; Keeney, 1979). This *circular* model postulates that the symptomatic child and family are involved in a transaction of mutual accommodation. There is an interactional relationship between the physiological aspects of asthma, the interrelationships in the asthmatic child's family and in the child's physical environment. Susan Howard's description of the impact that Sarah's asthma has had on the way in which the family functions and on the impact of the environment on Sarah's asthma illustrates this circularity well. Susan described the impact of teething, puberty, school science experiments and dust on Sarah's asthma as well as the stress it has generated for her and the restrictions that it has placed on her own professional life, where she is no longer able to be away from the home for any extended period.

The circularity between *anxious, over-protective maternal behaviour* as a response to the child's asthma and a reinforcement of these behaviors in prolonging the occurrence of the asthmatic symptoms in the child is more apparent in families with a severely asthmatic child than in families with a mildly asthmatic child (Hilliard et al., 1985; McNichol et al., 1973; Staudenmeyer, 1981). Susan Howard's description of the stress she feels, the need to be close to her daughter all the time, being protective and limiting her own career fits into this profile. In contrast to this, parents with a mildly asthmatic child were anxious to portray their child as 'normal'. George and Jean Snyman said that Andrew was "a normal little boy, who happens to have a condition that is treatable, and that we have under control." They said his asthma had a minimal impact on their lives as a couple and as a family. The comparison between Susan's description of the impacts of Sarah's asthma on the family's

life, and particularly on the quality of her own (Susan) life, is in sharp contrast to the minimal impacts described by Jean and George.

It is only those parents with *severely asthmatic* children that expressed feelings of ongoing anxiety. As Susan said, "I can't tell you the stress it has placed on me...every day for the last fourteen years I have had to remember and remind." This finding supports Staudenmeyer's (1981) conclusion that the amount of debilitation experienced by the child and the more severe the child's asthma, the greater the degree of parental anxiety and the worse the parents' quality of life. It also supports the research conducted by McNichol et al. (1973) who found that over-concern and over-protective mothers were found only among mothers of children with severe and continuing asthma. Further, research by Barmettler and Fields (1976) highlighted the complexity of feeling that parents of asthmatic children have to deal with as they live on a day-to-day basis with a severe and potentially life-threatening disease. They reported parental feelings of duty, resentment, feeling controlled by the child and resentful of the manipulation, feelings of panic and fear with each asthma attack, feelings of regret and guilt about their inability to help their child. Fathers felt hurt at being left out but powerless to improve the situation. Mothers felt resentful toward the father for having left them to shoulder the burden alone. Interestingly, only Susan Howard, expressed these feelings and from her account, their child appeared to be the most severely asthmatic of all the children studied.

Susan Howard's description of the stress her family has experienced gives support for McNichol et al.'s (1973) other finding that the families of severely affected groups of children showed evidence of more stress than other families. In support of McNichol et al. (1973), Susan reported greater resentment, minimal involvement of the father and fewer joint activities than parents in other families did. All the evidence points to a mutual interaction between the severity of the child's asthma and the stress that the family experiences. However, it would be simplistic to conclude that severity of asthma is the only or the major factor associated with family stress. McLean & Ching (1973) concluded that the emotional status of the child and family was a more important factor than the child's asthma. It is feasible that the minimal number of joint family activities in the Howard family is an indicator of poor inter-relationships. Again, the evidence points to a mutual interaction between the family situation and the child's adjustment, with the recognition that the child's asthma may add a new dimension. It is clear that limiting a study of the

aetiology of paediatric asthma to one or two factors limits one's understanding of the disease and its mutual interaction with family functioning.

Thus, there appears to be a link between the *severity* of the child's asthma, the degree of *anxiety* experienced by the parents and the parents' *quality* of life. Further, the findings from this study point to a link between high maternal anxiety and one-child families. All of the mothers in a one-child family described their anxiety when their child had an asthma attack. For example, Shirley Winter said that when they could not get Warren's asthma under control she got hysterical. "I want to kill everybody. Warren is sick and I can't get it right." Families are complex units and to isolate one or two factors as the most crucial 'causes and sustainers' of paediatric asthma is pointless. In terms of family systems theory, there is no value in proving which comes first, the asthma, the child's position in the family, the mother's anxiety or her protectiveness. The debate about whether the mother's behaviour is a response to a long-continuing illness or in some way causes the child's asthma is of little concern. Systems theory recognizes the current context where there is circularity between the child's asthma and behaviour and the mother's attitudes and behaviour. Thus, as the child's asthma gets worse, so the mother becomes more anxious, she communicates her anxiety to her child and the child's asthma deteriorates. There is mutual interaction through a series of feedback loops.

The *restrictions* that couples put into place in response to their child's asthma can be interpreted in the context of *feedback* (Bertonaffly, 1968; Goldenberg & Goldenberg, 1991). Negative feedback maintains the functional stability and integrity of the system and positive feedback allows for flexibility and change. All of the families that were interviewed described feedback loops to illustrate both processes. For example, George and Jean Snyman restrict Andrew's time spent on the computer if they feel he needs to be disciplined (negative feedback). They have introduced a new diet for Andrew and for the entire family in response to Andrew's asthma with positive results for all concerned (positive feedback). Anne Walters described how she restricted Ryan's social activities because of criticism from other mothers (negative feedback) and then encouraged him to go out when their paediatrician gave permission to allow Ryan unrestricted activity (positive feedback).

Again, it was only the family with a severely asthmatic child (i.e. the Howards), that found the restrictions onerous. Susan's description of the restrictions that she has had to put into

place because of Sarah's asthma as well as the restrictions that Sarah's asthma has had on her personally have already been discussed in detail.

The notion of homeostasis and the openness/closedness of the system all relate to feedback (Becvar & Becvar, 1988; Bertonaffly, 1968; Goldenberg & Goldenberg, 1991). Feedback is the regulating mechanism by which a system maintains homeostasis. Openness and closedness refers to the ways in which systems react to feedback by either incorporating new information into a system and introducing change (openness) or sealing themselves off from all but necessary exchanges with the outside world in an attempt to establish maximum order (closedness). In healthy families, there is a balance between openness and closedness and between morphostasis (stability) and morphogenesis (growth/change). Families that successfully adapt to change experience less disruption (Wasilewski et al., 1988).

Healthy families are creative and resilient in adapting to changing conditions, crises or periods of stress. All of the parents interviewed gave example of ways in which they adapted to change. For example, Renee and Johan Van Jaarsveld made a decision regarding their son's cat, based on the balance between Neil's emotional and physical needs. The cat causes Neil's asthma to get worse (negative feedback) but his emotional response to the cat has been beneficial (positive feedback). So, Renee and Johan now make Neil wash his hands after playing with the cat (new behaviour) to limit the negative effects of the allergic reaction.

Stroh Becvar and Becvar (1988) described three ways in which the family system may *cope* with the stress of asthma: self-limitation, denial or reorganization. Each one of these responses was described by at least one parent in this study. The first, *self-limitation* involves the choice to avoid the environmental demand by limiting one's activities or potential. The Perrys described a diet that they had introduced to limit the effects of an allergic reaction in Dean. This restriction in diet cause resentment among other family members because, even though they were not asthmatic, they also had to comply to a dairy-free diet. Lynn has also restricted Dean's swimming because she believes that he gets sick if he gets cold, "Recently I had to say no to Dean because the children were in the pool in the rain. Dean was upset because he was getting singled out - he was different. He complies but he sulks." So, the restrictions that parents place on members of the family almost inevitably lead to resentment and conflict.

The second reaction to stress is the *denial* of the existence of the demand. Cheryl and Roger Stone, who belong to one of the more dysfunctional families that were interviewed, said that neither Dales' asthma nor a more recent symptom, a nervous tic, had resulted in change within the system. Cheryl said that they "don't make too much of a big deal of it (the tic) as it would become even more of a problem." This gives support to the conclusion of Sundberg et al. (1983) that symptomatic behaviour may be employed by members of a dysfunctional family in an attempt to maintain the marginal stability of the unbalanced system. Thus, Dale's behaviour is not disturbed but rather the result of complex interactions between him and his family. Interestingly, this is a one-child family so the triad relationship may well be more intense than with larger, more complex systems.

The *general functioning* score on the FAD scale confirmed the finding from the interview that the Stones did not function optimally, particularly in the areas of communication, affective responsiveness and affective involvement. Specifically, the Stones do not have open and honest communication, they do not show appropriate affection, they are too self-centred and do not become involved enough in the problems of other members. In the context of family systems theory, it is important to realize that unhealthy functioning does not reside exclusively with either the individual or with the family. The symptomatic child and family are involved in a circular transaction of mutual accommodation. There is a complex of mutually interacting factors that contribute to the child's asthma and the way in which the family functions.

The third reaction to stress is one of *reorganization*, where the family 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. Jenny and Peter Robinson have acknowledged the impact of asthma on their son's sporting activities and have limited Adam's feelings of inadequacy by sending him to a different school from his high 'sport-achieving' brothers. As Peter said, "I think he knows that he will never be as good at sports as his brothers were. He is at St Johns and he will never go to any of the schools that his brothers went to. There is a big age difference and they were so outstanding that to compare him with them would not be fair."

A further example of reorganization is the banning of smoking in the Snyman's home. The Snymans perceived this to be one of the positive consequences of Andrew's asthma on the

family's lifestyle. This reorganization in the family could have been perceived as self-limitation (the first reaction described by Stroh Becvar & Becvar, 1988) but the Snymans felt that this change enhanced their lifestyle rather than limited it and it, therefore, becomes a more positive reaction to Andrew's asthma.

Of interest is that it is only those parents with *severely* asthmatic children that were able to name any *positive impacts* of their child's asthma. Parents of children with mild to moderate asthma were incredulous that one could ask about positive impacts. For example, Renee and Johan Van Jaarsveld said, "I can't say that I have noticed anything positive but there is nothing that negative either. You just live with it." For the parents of children with severe asthma, the reaction was different. Susan Howard said that Sarah was more empathetic to people in distress, she was a caring friend and was stoical with pain. Bill and Shirley Winters said that the family was closer because of Warren's asthma and that they no longer smoked in the house. Anne Murray said that she was more comfortable dealing with sickness. It appears that there is a connection between the perceived severity of the child's asthma and the need to find meaning in the situation. There is a circularity between severe asthma and the factors that impact on the asthma, the ways in which the asthma impacts on the family and the parents' attitude towards the illness. Thus, parents with a child with severe asthma experience all the aspects related to their child's asthma in a more extreme way than do parents of children with mild to moderate asthma.

12.4 PARENTAL ATTITUDES ABOUT THEIR ASTHMATIC CHILD

In describing their families, those parents with more than one child found it impossible to discuss their asthmatic child in isolation. For each of these parents, there were constant references to the way in which the asthmatic child related to his or her siblings. For example, Jean Snyman described Andrew as "different to his younger brothers. He likes to be inside and prefers playing computer games to playing outside and participating in sport." In contrast, those parents with only one child, focused exclusively on that child. For example, Shirley Winters remarked, "I think our whole life revolves around him, to be quite honest. He gives a peep and we jump."

This exclusive focus may be a problem for the healthy functioning of the family. In healthy families, no one member is consistently symptomatic carrying all the family's anxiety all of

the time (Minuchin, 1974). This appears to be a problem in those families with an only child as well as those with a severely asthmatic child. Shirley Winters' remark is just one of the descriptions given by those parents that had only one child indicating that single children can become the focus of family attention more than is healthy. Susan's description of the family's focus on Sarah was equally indicative of unhealthy functioning. She said that Sarah had never felt completely carefree and that coping with asthma was an awful burden for Sarah. Talking about herself, Susan said, "Every day for the last fourteen years I have had to remember and remind." So, severe asthma by its very nature focuses attention on the sufferer more than is healthy.

The Stone family was the only family in this study that offered support for those studies that have established a relationship between paediatric asthma and *behaviour disturbances* in the child (Carson & Schauer, 1992; McNichol et al., 1973; Stern, 1981; Sundberg et al., 1983). As already discussed, the Stone family was the most dysfunctional of all the families included in this study, and there are clearly factors other than Dale's asthma involved in the development of behavioural disturbances such as his tic. A simplistic view that attempts to establish a one-on-one relationship between the child's asthma and behavioural disturbance clearly does not explain the complexity of interactions that occur within a family situation.

The *position* of the asthmatic child in a family of siblings played a role in family functioning and parental attitudes. This was particularly apparent in those families where the asthmatic child was the oldest in the family. George and Jean claimed to treat Andrew differently, and particularly to give him more privileges, because he was older than his brothers and not because he was asthmatic. Walter and Anne said that Ryan's sense of responsibility had developed from his position as the oldest child, and that he had set high academic and sporting standards for his siblings to follow. All of the couples, however, insisted that any differences in their attitude towards their children was not because of their child's asthma but rather because of their child's personality and/or position in the family.

The attitudes that parents have towards each other and towards their children are reflected in their emotional responsiveness and involvement. Four of the husbands, George, Wesley, Bill and Walter, and one of the wives, Cheryl, had problems with *affective responsiveness* on the FAD scale, and specifically with showing appropriate affection and expressing emotions of love tenderness and sadness. These individuals are less accepting than their

partners of the emotional demands existing in the family. The finding that more than half of the sample had problems in this area may be significant. Problems with expressing appropriate emotion may well be a factor that is common in parents of asthmatic children.

Further, in five of the six cases, husbands were found to be generally less accepting of the emotional demands existing in the family than wives were. Of note is that the two couples who did not have problems in this area each had a child with mild asthma. This finding could be significant, and problems with appropriate expression of emotion and affection could indicate either the response of fathers to an ever-present stress of asthma and/or could be a factor related to the severity of the child's asthma. Further research needs to be undertaken in order to quantify this finding to find out whether it is prevalent in a significant number of fathers of children with asthma.

Most of the families who participated in this study were either too intrusive or too self-centred when showing interest in the problems of other family members. Thus, the scores on the dimension of *affective involvement* were even more indicative of a problem in most families with an asthmatic child. The Van Jaarsvelds were the only couple that demonstrated the appropriate level of involvement and truly had the best interests of other family members at heart. So, for this sample, most families have problems in showing appropriate and selfless interest in the problems of other family members. The scores on the specific factors showed that most of these families are too intrusive and become too involved when other family members have problems. For two of the couples, Walter and Anne Murray and Roger and Cheryl Stone, the opposite was true – they felt that family members were too self-centred and did not become involved enough in the problems of other members. The inappropriate affective involvement of most families included in this study is an intriguing finding and indicates further research to find out whether this finding can be generalized to other families with an asthmatic child.

12.5 CONCLUSION

Family systems theory acknowledges the complexity of issues confronting a family with an asthmatic child. In families where the stress of asthma is severe and ever-present, this complexity is particularly apparent. To limit the study of paediatric asthma to one or two factors limits the potential of discovery and deeper understanding of this fascinating and

complex disease. Because it is chronic and therefore an ever-present stressor over which the families have little control, asthma is not merely a physical disease. It is a disease that occurs within a family system and both affects the way in which the family functions and is affected by the processes in the family in a circularity of mutual interaction.

In this study, there was a synergy between the findings of the interviews and the FAD measurement scale, in terms of assessment of the family's healthy functioning. The findings reiterated the complexity of influence of paediatric asthma: the child's asthma effects the functioning of the family, and this effect appears to be influenced by other factors such as the severity of the condition, the size of the family and the ways in which the family copes with the stress of asthma. The child's asthma also appears to be effected by factors that influence family functioning such as the communication patterns between the parents, adherence to family rules and boundaries and the affective involvement and responsiveness of family members.

12.6 LIMITATIONS OF THE STUDY

The methodology chosen for this study was in-depth interviews on a small sample of respondents. This choice of methodology sacrificed the ability to observe and measure a large sample of respondents in exchange for the ability to pursue the attitudes and experiences of a small group of respondents in greater detail. Further, this study included an homogenous group of respondents. All of the families were caucasian, lived in Gauteng (South Africa) and were middle to upper class. This means that, although the information gathered was fascinating and informative, it cannot be extrapolated to the universe of families that have children with asthma. One must be cautious in generalising the findings even to those families that meet the same criteria as the respondents in this study. Other factors, for example, individual and family characteristics and the strength of religious belief, which were not included in this study, may well be more influential than the factors measured in this study.

The author recognises that, in attempting to give a more holistic view of paediatric asthma, there will always be factors and influencers that are not included in a study. Taking an holistic view of any area of study is necessarily complex and it is impossible to include the complexity of issues in one study.

Apart from the paediatric pulmonologist's measurement of the severity of the child's asthma, the instruments used in the study (interview and FAD measurement) were of a self-report nature. Thus, any findings are limited by the parent's own insights into their functioning, and what they are prepared to disclose. On the other hand, a strong point of qualitative exploratory research is that the interviewer allows the respondent to tell his or her personal story.

The small sample size and the in-depth interviewing methodology also means that interviewer bias may be problematic. A genuine attempt was made, however, to be as open as is possible in the face of the obvious subjectivity inherent in using one interviewer to conduct eight in-depth interviews.

12.7 SUGGESTIONS FOR FURTHER RESEARCH

Geographic location, socio-economic status, gender, family size and race may all be factors that impact on parents' experience of their child's asthma. Because of the small sample size included in this study, none of these factors were explored. The author recognises their potential importance, and further exploratory research, using the findings from this and other studies and focussing on differences and similarities on these factors, would be of interest.

As already discussed, this study included only a small sample size, and further research to test the validity of the findings on a larger and more heterogeneous sample would be of value. The FAD findings, particularly on the dimensions of 'affective responsiveness' and 'affective involvement' were especially intriguing, and further research to test whether these findings are common in a larger, less homogenous sample, are indicated. The relationship between the child being the focus of attention, the severity of the child's asthma and the child's status as an only child is another finding that deserves more attention, and research that incorporated larger samples to increase statistical power would be of value.

Research that included observational measures as well as completion of the FAD questionnaire by the asthmatic child and siblings would extend our understanding and gain different perspectives on family functioning. It would also be useful to isolate those factors

that are associated with healthy family functioning within families that have a member with a chronic condition.

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ADDENDUM A:

DISCUSSION GUIDE

ADDENDUM A: DISCUSSION GUIDE
JOINT INTERVIEW WITH THE PARENTS OF AN ASTHMATIC CHILD

I am going to be discussing the impact that your child's asthma has had on the family. Firstly, I would like to discuss your roles in the family.
(Throughout the discussion, the researcher must take note of who dominates the discussion, and in which areas domination occurs).

1. Family Structure and Functioning

1.1 How many people are there in your family unit?
1.2 Who are they? Names and ages.
1.3 What position is your asthmatic child in the family?
probe: first, second, third, out of how many children?
1.4 Who is responsible for looking after the children?
probe : during the week
: over the weekend
1.5 If the mother: Who gives you/your wife the most support? What are her support group/s?
1.6 Who handles the finances?
1.7 If you have a conflict, how do you handle it?
1.8 How do you resolve it?
1.9 When do you, as a couple, spend time together?
1.10 What do you talk about when you are together?
1.11 What activities do you do together?
1.12 What activities do you do as a family?
Spontaneous
Probe : school
: exercise/sport
: play
: social activities

2. Impact of the child's asthma on family functioning and lifestyle

2.1 Looking back at these activities, what restrictions has your child's asthma placed on each one?

Probe : school

: exercise/sport

: play

: social activities

2.2 In which other areas of family life has your child's asthma had a negative effect?

Spontaneous

Probe : time

: finances

: emotional life

2.3 Have there been any areas where asthma has impacted on you family positively?

2.4 In what ways has your family (family members) had a positive impact on your child's asthma?

2.5 And a negative impact?

3. Severity of the child's asthma

3.1 How serious is your child's asthma, according to you personally?

3.2 On what do you base your perception that your child's asthma is mild/moderate/severe?

3.3 In what ways has the severity of your child's asthma affected the way in which your family functions?

4. Parental attitudes about the asthmatic child

4.1 What is your attitude towards your asthmatic child?

Spontaneous

4.2 And compared to your other children?

Probe : similarities and differences in attitude

: similarities and differences in behaviour

: similarities and differences in disciplining

4.3 Does your child have any problems other than their asthma?

4.4 What are your fears/concerns about this child?

4.5 Do you expect that your child's asthma with get better, worse or stay the same?

4.6 What are your aspirations for this child?

4.7 Apart from their asthma, does this child behave differently to your other children?

Spontaneous

Probe : relationships with parents

: relationships with siblings

: relationships with peers

4.8 Please give me five words that best describe your child.

ADDENDUM B:

THE FAMILY ASSESSMENT DEVICE (FAD)

ADDENDUM B: THE FAMILY ASSESSMENT DEVICE (FAD)

	Strongly Agree	Agree	Disagree	Strongly Disagree
PROBLEM SOLVING We usually act on our decisions regarding problems				
After our family tries to solve a problem, we usually discuss whether it worked or not				
We resolve most emotional upsets that come up				
We confront problems involving feelings				
We try to think of different ways to solve problems				
COMMUNICATION When someone is upset the others know why				
You can't tell how a person is feeling from what they are saying				
People come right out and say things instead of hinting at them				
We are frank with each other				
We don't talk to each other when we are angry				
When we don't like what someone has done, we tell them				
ROLES When you ask someone to do something, you have to check that they did it				
We make sure members meet their family responsibilities				
Family tasks don't get spread around enough				
We have trouble meeting our bills				
There's little time to explore personal interests				
We discuss who is to do household jobs				
If people are asked to do something, they need reminding				
We are generally dissatisfied with the family duties assigned to us				
AFFECTIVE RESPONSIVENESS We are reluctant to show our affection for each other				
Some of us just don't respond emotionally				
We do not show our love for each other				
Tenderness takes second place to other things in our family				
We express tenderness				
We cry openly				

	Strongly Agree	Agree	Disagree	Strongly Disagree
AFFECTIVE INVOLVEMENT If someone is in trouble, the others become too involved				
You only get the interest of others when something is important to them				
We are too self-centered				
We get involved with each other only when something interests us				
We show interest in each other when we can get something out of it personally				
Our family shows interest in each other only when they can get something out of it				
Even though we mean well, we intrude too much into each other's lives				
BEHAVIOUR CONTROL We don't know what to do when an emergency come up				
You can easily get away with breaking the rules				
We know what to do in an emergency				
We have no clear expectations about toilet habits				
We have rules about hitting people				
We don't hold to any rules or standards				
Anything goes in our family				
There are rules about dangerous situations				
GENERAL FUNCTIONING Planning family activities is difficult because we misunderstand each other				
In times of crisis we can turn to each other for support				
We cannot talk to each other about the sadness we feel				
Individuals are accepted for what they are				
We avoid discussing our fears and concerns				
We can express feelings to each other				
There are lots of bad feelings in the family				
We feel accepted for what we are				
Making decisions is a problem for our family				
We are able to make decisions about how to solve problems				
We don't get along well together				
We confide in each other				

ADDENDUM C:

RESPONDENTS' INDIVIDUAL FAD RATINGS

ADDENDUM C: RESPONDENTS' INDIVIDUAL FAD RATINGS

FAD scores for the Snyman couple:
George's response = M
Jean's response = F

	Strongly Agree	Agree	Disagree	Strongly Disagree
PROBLEM SOLVING We usually act on our decisions regarding problems	F	M		
After our family tries to solve a problem, we usually discuss whether it worked or not		M	F	
We resolve most emotional upsets that come up		F	M	
We confront problems involving feelings		M	F	
We try to think of different ways to solve problems		MF		
COMMUNICATION When someone is upset the others know why		MF		
You can't tell how a person is feeling from what they are saying		MF		
People come right out and say things instead of hinting at them		MF		
We are frank with each other	F	M		
We don't talk to each other when we are angry		MF		
When we don't like what someone has done, we tell them	F	M		
ROLES When you ask someone to do something, you have to check that they did it	M			F
We make sure members meet their family responsibilities		MF		
Family tasks don't get spread around enough	M		F	
We have trouble meeting our bills			MF	
There's little time to explore personal interests	F	M		
We discuss who is to do household jobs		F		M
If people are asked to do something, they need reminding		M		F
We are generally dissatisfied with the family duties assigned to us		M	F	
AFFECTIVE RESPONSIVENESS We are reluctant to show our affection for each other			M	F
Some of us just don't respond emotionally		M		F
We do not show our love for each other		M	F	
Tenderness takes second place to other things in our family			MF	
We express tenderness			MF	
We cry openly		MF		

	Strongly Agree	Agree	Disagree	Strongly Disagree
AFFECTIVE INVOLVEMENT If someone is in trouble, the others become too involved		MF		
You only get the interest of others when something is important to them		M	F	
We are too self-centered			MF	
We get involved with each other only when something interests us			MF	
We show interest in each other when we can get something out of it personally			MF	
Our family shows interest in each other only when they can get something out of it			MF	
Even though we mean well, we intrude too much into each other's lives		M	F	
BEHAVIOUR CONTROL We don't know what to do when an emergency come up			M	F
You can easily get away with breaking the rules		M		F
We know what to do in an emergency	F	M		
We have no clear expectations about toilet habits			M	F
We have rules about hitting people	MF			
We don't hold to any rules or standards			F	M
Anything goes in our family				MF
There are rules about dangerous situations	MF			
GENERAL FUNCTIONING Planning family activities is difficult because we misunderstand each other			MF	
In times of crisis we can turn to each other for support		MF		
We cannot talk to each other about the sadness we feel			F	M
Individuals are accepted for what they are	F	M		
We avoid discussing our fears and concerns		F	M	
We can express feelings to each other	F	M		
There are lots of bad feelings in the family				MF
We feel accepted for what we are	F	M		
Making decisions is a problem for our family			F	M
We are able to make decisions about how to solve problems	M	F		
We don't get along well together			F	M
We confide in each other	M	F		

FAD scores for the Howard couple:
Wesley's response = M
Susan's response = F

	Strongly Agree	Agree	Disagree	Strongly Disagree
PROBLEM SOLVING We usually act on our decisions regarding problems	F	M		
After our family tries to solve a problem, we usually discuss whether it worked or not	F	M		
We resolve most emotional upsets that come up		MF		
We confront problems involving feelings		MF		
We try to think of different ways to solve problems	M	F		
COMMUNICATION When someone is upset the others know why		MF		
You can't tell how a person is feeling from what they are saying			MF	
People come right out and say things instead of hinting at them		M	F	
We are frank with each other		M	F	
We don't talk to each other when we are angry		MF		
When we don't like what someone has done, we tell them		M	F	
ROLES When you ask someone to do something, you have to check that they did it		MF		
We make sure members meet their family responsibilities	F	M		
Family tasks don't get spread around enough		MF		
We have trouble meeting our bills			M	F
There's little time to explore personal interests		MF		
We discuss who is to do household jobs		F	M	
If people are asked to do something, they need reminding		MF		
We are generally dissatisfied with the family duties assigned to us			MF	
AFFECTIVE RESPONSIVENESS We are reluctant to show our affection for each other		M		F
Some of us just don't respond emotionally	F	M		
We do not show our love for each other			M	F
Tenderness takes second place to other things in our family			MF	
We express tenderness		MF		
We cry openly		F	M	

	Strongly Agree	Agree	Disagree	Strongly Disagree
AFFECTIVE INVOLVEMENT If someone is in trouble, the others become too involved		F	M	
You only get the interest of others when something is important to them		F	M	
We are too self-centered			MF	
We get involved with each other only when something interests us		M	F	
We show interest in each other when we can get something out of it personally			MF	
Our family shows interest in each other only when they can get something out of it			MF	
Even though we mean well, we intrude too much into each other's lives		F	M	
BEHAVIOUR CONTROL We don't know what to do when an emergency come up			MF	
You can easily get away with breaking the rules		M	F	
We know what to do in an emergency		MF		
We have no clear expectations about toilet habits			MF	
We have rules about hitting people		MF		
We don't hold to any rules or standards			MF	
Anything goes in our family		M	F	
There are rules about dangerous situations	F	M		
GENERAL FUNCTIONING Planning family activities is difficult because we misunderstand each other			MF	
In times of crisis we can turn to each other for support		MF		
We cannot talk to each other about the sadness we feel			MF	
Individuals are accepted for what they are		MF		
We avoid discussing our fears and concerns		M		F
We can express feelings to each other	F	M		
There are lots of bad feelings in the family		M	F	
We feel accepted for what we are		M	F	
Making decisions is a problem for our family			MF	
We are able to make decisions about how to solve problems		MF		
We don't get along well together			MF	
We confide in each other		MF		

FAD scores for the Robinson couple:
Peter's response = M
Jenny's response = F

	Strongly Agree	Agree	Disagree	Strongly Disagree
PROBLEM SOLVING We usually act on our decisions regarding problems	F	M		
After our family tries to solve a problem, we usually discuss whether it worked or not		MF		
We resolve most emotional upsets that come up	M	F		
We confront problems involving feelings		MF		
We try to think of different ways to solve problems		F	M	
COMMUNICATION When someone is upset the others know why	F	M		
You can't tell how a person is feeling from what they are saying		MF		
People come right out and say things instead of hinting at them			MF	
We are frank with each other		MF		
We don't talk to each other when we are angry	MF			
When we don't like what someone has done, we tell them		MF		
ROLES When you ask someone to do something, you have to check that they did it		F	M	
We make sure members meet their family responsibilities	M	F		
Family tasks don't get spread around enough		M	F	
We have trouble meeting our bills		F		M
There's little time to explore personal interests		F	M	
We discuss who is to do household jobs		M	F	
If people are asked to do something, they need reminding		F	M	
We are generally dissatisfied with the family duties assigned to us			F	M
AFFECTIVE RESPONSIVENESS We are reluctant to show our affection for each other		F		M
Some of us just don't respond emotionally			MF	
We do not show our love for each other			M	F
Tenderness takes second place to other things in our family			MF	
We express tenderness		M	F	
We cry openly		F	M	

	Strongly Agree	Agree	Disagree	Strongly Disagree
AFFECTIVE INVOLVEMENT If someone is in trouble, the others become too involved		F	M	
You only get the interest of others when something is important to them			MF	
We are too self-centered		M	F	
We get involved with each other only when something interests us			M	F
We show interest in each other when we can get something out of it personally			M	F
Our family shows interest in each other only when they can get something out of it			F	M
Even though we mean well, we intrude too much into each other's lives			MF	
BEHAVIOUR CONTROL We don't know what to do when an emergency come up			MF	
You can easily get away with breaking the rules			MF	
We know what to do in an emergency		MF		
We have no clear expectations about toilet habits			F	M
We have rules about hitting people		MF		
We don't hold to any rules or standards	F			M
Anything goes in our family				MF
There are rules about dangerous situations		MF		
GENERAL FUNCTIONING Planning family activities is difficult because we misunderstand each other			MF	
In times of crisis we can turn to each other for support		MF		
We cannot talk to each other about the sadness we feel		F	M	
Individuals are accepted for what they are	F		M	
We avoid discussing our fears and concerns			MF	
We can express feelings to each other		MF		
There are lots of bad feelings in the family	F			M
We feel accepted for what we are	F	M		
Making decisions is a problem for our family				MF
We are able to make decisions about how to solve problems		MF		
We don't get along well together				MF
We confide in each other		MF		

FAD scores for the Winters couple:
Bill's response = M
Shirley's response = F

	Strongly Agree	Agree	Disagree	Strongly Disagree
PROBLEM SOLVING We usually act on our decisions regarding problems		MF		
After our family tries to solve a problem, we usually discuss whether it worked or not		M	F	
We resolve most emotional upsets that come up	M	F		
We confront problems involving feelings		MF		
We try to think of different ways to solve problems		F	M	
COMMUNICATION When someone is upset the others know why	F		M	
You can't tell how a person is feeling from what they are saying		M	F	
People come right out and say things instead of hinting at them	F	M		
We are frank with each other	F	M		
We don't talk to each other when we are angry			M	F
When we don't like what someone has done, we tell them		MF		
ROLES When you ask someone to do something, you have to check that they did it		F	M	
We make sure members meet their family responsibilities		MF		
Family tasks don't get spread around enough			MF	
We have trouble meeting our bills		MF		
There's little time to explore personal interests		M	F	
We discuss who is to do household jobs		MF		
If people are asked to do something, they need reminding		MF		
We are generally dissatisfied with the family duties assigned to us			MF	
AFFECTIVE RESPONSIVENESS We are reluctant to show our affection for each other		M	F	
Some of us just don't respond emotionally		M	F	
We do not show our love for each other		M	F	
Tenderness takes second place to other things in our family		MF		
We express tenderness			MF	
We cry openly		MF		

	Strongly Agree	Agree	Disagree	Strongly Disagree
AFFECTIVE INVOLVEMENT If someone is in trouble, the others become too involved	F	M		
You only get the interest of others when something is important to them			MF	
We are too self-centered			MF	
We get involved with each other only when something interests us			MF	
We show interest in each other when we can get something out of it personally			M	F
Our family shows interest in each other only when they can get something out of it			MF	
Even though we mean well, we intrude too much into each other's lives		F	M	
BEHAVIOUR CONTROL We don't know what to do when an emergency come up			MF	
You can easily get away with breaking the rules			MF	
We know what to do in an emergency		MF		
We have no clear expectations about toilet habits		M	F	
We have rules about hitting people	F	M		
We don't hold to any rules or standards			M	F
Anything goes in our family			M	F
There are rules about dangerous situations		MF		
GENERAL FUNCTIONING Planning family activities is difficult because we misunderstand each other		M	F	
In times of crisis we can turn to each other for support	F	M		
We cannot talk to each other about the sadness we feel			M	F
Individuals are accepted for what they are		MF		
We avoid discussing our fears and concerns			MF	
We can express feelings to each other		F	M	
There are lots of bad feelings in the family			M	F
We feel accepted for what we are	F	M		
Making decisions is a problem for our family		F	M	
We are able to make decisions about how to solve problems		MF		
We don't get along well together				MF
We confide in each other		MF		

FAD scores for the Murray couple:
Walter's response = M
Anne's response = F

	Strongly Agree	Agree	Disagree	Strongly Disagree
PROBLEM SOLVING We usually act on our decisions regarding problems		FM		
After our family tries to solve a problem, we usually discuss whether it worked or not		F	M	
We resolve most emotional upsets that come up	M	F		
We confront problems involving feelings		FM		
We try to think of different ways to solve problems		F	M	
COMMUNICATION When someone is upset the others know why		F	M	
You can't tell how a person is feeling from what they are saying		F	M	
People come right out and say things instead of hinting at them	M	F		
We are frank with each other	M	F		
We don't talk to each other when we are angry		F	M	
When we don't like what someone has done, we tell them		F	M	
ROLES When you ask someone to do something, you have to check that they did it	F		M	
We make sure members meet their family responsibilities		FM		
Family tasks don't get spread around enough		F	M	
We have trouble meeting our bills		F	M	
There's little time to explore personal interests		F		M
We discuss who is to do household jobs		F	M	
If people are asked to do something, they need reminding		FM		
We are generally dissatisfied with the family duties assigned to us			FM	
AFFECTIVE RESPONSIVENESS We are reluctant to show our affection for each other			FM	
Some of us just don't respond emotionally		M	F	
We do not show our love for each other			FM	
Tenderness takes second place to other things in our family		M	F	
We express tenderness		F	M	
We cry openly		F		M

	Strongly Agree	Agree	Disagree	Strongly Disagree
AFFECTIVE INVOLVEMENT If someone is in trouble, the others become too involved			FM	
You only get the interest of others when something is important to them		F	M	
We are too self-centered	F		M	
We get involved with each other only when something interests us			FM	
We show interest in each other when we can get something out of it personally			FM	
Our family shows interest in each other only when they can get something out of it			FM	
Even though we mean well, we intrude too much into each other's lives		F	M	
BEHAVIOUR CONTROL We don't know what to do when an emergency come up			FM	
You can easily get away with breaking the rules			FM	
We know what to do in an emergency		M	F	
We have no clear expectations about toilet habits			F	M
We have rules about hitting people			MF	
We don't hold to any rules or standards			FM	
Anything goes in our family			FM	
There are rules about dangerous situations		M	F	
GENERAL FUNCTIONING Planning family activities is difficult because we misunderstand each other		F	M	
In times of crisis we can turn to each other for support	FM			
We cannot talk to each other about the sadness we feel		M	F	
Individuals are accepted for what they are		FM		
We avoid discussing our fears and concerns			FM	
We can express feelings to each other	F	M		
There are lots of bad feelings in the family			F	M
We feel accepted for what we are		FM		
Making decisions is a problem for our family			FM	
We are able to make decisions about how to solve problems	M	F		
We don't get along well together				FM
We confide in each other	F	M		

FAD scores for the Stone couple:
Roger's response = M
Cheryl's response = F

	Strongly Agree	Agree	Disagree	Strongly Disagree
PROBLEM SOLVING We usually act on our decisions regarding problems	M	F		
After our family tries to solve a problem, we usually discuss whether it worked or not		MF		
We resolve most emotional upsets that come up	M	F		
We confront problems involving feelings	M		F	
We try to think of different ways to solve problems		MF		
COMMUNICATION When someone is upset the others know why	M		F	
You can't tell how a person is feeling from what they are saying	F	M		
People come right out and say things instead of hinting at them		M	F	
We are frank with each other		M	F	
We don't talk to each other when we are angry		MF		
When we don't like what someone has done, we tell them		MF		
ROLES When you ask someone to do something, you have to check that they did it		F	M	
We make sure members meet their family responsibilities		MF		
Family tasks don't get spread around enough			MF	
We have trouble meeting our bills		MF		
There's little time to explore personal interests			MF	
We discuss who is to do household jobs		MF		
If people are asked to do something, they need reminding		F	M	
We are generally dissatisfied with the family duties assigned to us			MF	
AFFECTIVE RESPONSIVENESS We are reluctant to show our affection for each other		F	M	
Some of us just don't respond emotionally		F	M	
We do not show our love for each other			MF	
Tenderness takes second place to other things in our family			MF	
We express tenderness		MF		
We cry openly		MF		

	Strongly Agree	Agree	Disagree	Strongly Disagree
AFFECTIVE INVOLVEMENT If someone is in trouble, the others become too involved			MF	
You only get the interest of others when something is important to them		F	M	
We are too self-centered		F	M	
We get involved with each other only when something interests us		F	M	
We show interest in each other when we can get something out of it personally			MF	
Our family shows interest in each other only when they can get something out of it			MF	
Even though we mean well, we intrude too much into each other's lives			MF	
BEHAVIOUR CONTROL We don't know what to do when an emergency come up			F	M
You can easily get away with breaking the rules		F	M	
We know what to do in an emergency	M	F		
We have no clear expectations about toilet habits			M	F
We have rules about hitting people	MF			
We don't hold to any rules or standards			F	M
Anything goes in our family			F	M
There are rules about dangerous situations	F	M		
GENERAL FUNCTIONING Planning family activities is difficult because we misunderstand each other			F	M
In times of crisis we can turn to each other for support	M	F		
We cannot talk to each other about the sadness we feel		MF		
Individuals are accepted for what they are		MF		
We avoid discussing our fears and concerns		F	M	
We can express feelings to each other		M	F	
There are lots of bad feelings in the family			MF	
We feel accepted for what we are		MF		
Making decisions is a problem for our family			MF	
We are able to make decisions about how to solve problems		MF		
We don't get along well together			MF	
We confide in each other		M	F	

FAD scores for the Perry couple:
Darren's response = M
Lynn's response = F

	Strongly Agree	Agree	Disagree	Strongly Disagree
PROBLEM SOLVING We usually act on our decisions regarding problems	F	M		
After our family tries to solve a problem, we usually discuss whether it worked or not		F	M	
We resolve most emotional upsets that come up		FM		
We confront problems involving feelings	F	M		
We try to think of different ways to solve problems		FM		
COMMUNICATION When someone is upset the others know why		FM		
You can't tell how a person is feeling from what they are saying		M	F	
People come right out and say things instead of hinting at them			FM	
We are frank with each other		FM		
We don't talk to each other when we are angry			FM	
When we don't like what someone has done, we tell them			FM	
ROLES When you ask someone to do something, you have to check that they did it			FM	
We make sure members meet their family responsibilities		FM		
Family tasks don't get spread around enough	F	M		
We have trouble meeting our bills		M	F	
There's little time to explore personal interests			FM	
We discuss who is to do household jobs		M	F	
If people are asked to do something, they need reminding		FM		
We are generally dissatisfied with the family duties assigned to us		FM		
AFFECTIVE RESPONSIVENESS We are reluctant to show our affection for each other			M	F
Some of us just don't respond emotionally			M	F
We do not show our love for each other			M	F
Tenderness takes second place to other things in our family			M	F
We express tenderness	F	M		
We cry openly	F	M		

	Strongly Agree	Agree	Disagree	Strongly Disagree
AFFECTIVE INVOLVEMENT If someone is in trouble, the others become too involved		FM		
You only get the interest of others when something is important to them			FM	
We are too self-centered			FM	
We get involved with each other only when something interests us			FM	
We show interest in each other when we can get something out of it personally			FM	
Our family shows interest in each other only when they can get something out of it			FM	
Even though we mean well, we intrude too much into each other's lives			FM	
BEHAVIOUR CONTROL We don't know what to do when an emergency come up		F	M	
You can easily get away with breaking the rules		M	F	
We know what to do in an emergency		FM		
We have no clear expectations about toilet habits			M	F
We have rules about hitting people		FM		
We don't hold to any rules or standards			M	F
Anything goes in our family				FM
There are rules about dangerous situations		M		F
GENERAL FUNCTIONING Planning family activities is difficult because we misunderstand each other			M	F
In times of crisis we can turn to each other for support	FM			
We cannot talk to each other about the sadness we feel	F		M	
Individuals are accepted for what they are		FM		
We avoid discussing our fears and concerns			M	F
We can express feelings to each other	F	M		
There are lots of bad feelings in the family		M	F	
We feel accepted for what we are		M	F	
Making decisions is a problem for our family			FM	
We are able to make decisions about how to solve problems		FM		
We don't get along well together			M	F
We confide in each other	F	M		

FAD scores for the Van Jaarsveld couple:
Johan's response = M
Renee's response = F

	Strongly Agree	Agree	Disagree	Strongly Disagree
PROBLEM SOLVING We usually act on our decisions regarding problems	F	M		
After our family tries to solve a problem, we usually discuss whether it worked or not			FM	
We resolve most emotional upsets that come up	F	M		
We confront problems involving feelings	F	M		
We try to think of different ways to solve problems		FM		
COMMUNICATION When someone is upset the others know why	FM			
You can't tell how a person is feeling from what they are saying		FM		
People come right out and say things instead of hinting at them		M	F	
We are frank with each other		FM		
We don't talk to each other when we are angry			FM	
When we don't like what someone has done, we tell them	FM			
ROLES When you ask someone to do something, you have to check that they did it		FM		
We make sure members meet their family responsibilities		FM		
Family tasks don't get spread around enough		F	M	
We have trouble meeting our bills			F	M
There's little time to explore personal interests		F	M	
We discuss who is to do household jobs			FM	
If people are asked to do something, they need reminding		FM		
We are generally dissatisfied with the family duties assigned to us		F	M	
AFFECTIVE RESPONSIVENESS We are reluctant to show our affection for each other			M	F
Some of us just don't respond emotionally			FM	
We do not show our love for each other				FM
Tenderness takes second place to other things in our family			M	F
We express tenderness			M	F
We cry openly			M	F

	Strongly Agree	Agree	Disagree	Strongly Disagree
AFFECTIVE INVOLVEMENT If someone is in trouble, the others become too involved	F	M		
You only get the interest of others when something is important to them			FM	
We are too self-centered			FM	
We get involved with each other only when something interests us			FM	
We show interest in each other when we can get something out of it personally			M	F
Our family shows interest in each other only when they can get something out of it				FM
Even though we mean well, we intrude too much into each other's lives			FM	
BEHAVIOUR CONTROL We don't know what to do when an emergency come up			FM	
You can easily get away with breaking the rules			F	M
We know what to do in an emergency		FM		
We have no clear expectations about toilet habits			FM	
We have rules about hitting people		FM		
We don't hold to any rules or standards			FM	
Anything goes in our family			M	F
There are rules about dangerous situations	F	M		
GENERAL FUNCTIONING Planning family activities is difficult because we misunderstand each other			FM	
In times of crisis we can turn to each other for support	FM			
We cannot talk to each other about the sadness we feel			M	F
Individuals are accepted for what they are	F	M		
We avoid discussing our fears and concerns			FM	
We can express feelings to each other	F	M		
There are lots of bad feelings in the family			FM	
We feel accepted for what we are		FM		
Making decisions is a problem for our family			FM	
We are able to make decisions about how to solve problems		FM		
We don't get along well together			M	F
We confide in each other	F	M		