

CHILDHOOD LEUKAEMIA - FAMILY PATTERNS OVER TIME

by

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**Time present and time past
Are both perhaps present in time future
And time future contained in time past**

T.S. Elliot (in Llewellyn, 1978).

This dissertation is dedicated to my mother who passed away shortly before its
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SUMMARY

Childhood leukaemia is on the increase in terms of being reported as a chronic childhood illness, yet it 'puzzles' health experts as its medical cause is unknown and this poses considerable treatment challenges. It is suggested that this is because conventional views of childhood leukaemia, adhering to a Newtonian-Cartesian epistemology focus almost exclusively on biological factors ignoring the wider social context in which the problem is embedded.

An overview of the existing body of knowledge on the most widely researched areas of childhood leukaemia was presented and it was argued that a conceptual shift is required to achieve a more comprehensive understanding of the problem. This conceptual shift encompassed an ecosystemic approach.

This study was conducted within a holistic systemic epistemology. A qualitative approach employing a case study method to provide rich descriptions of the context in which two leukaemia sufferer's symptoms were embedded.

Key words: childhood leukaemia, context, ecosystemic epistemology, meanings, qualitative research, second-order cybernetics, patterns, somatic symptoms

CHAPTER 1

INTRODUCTION

General Introduction

**We are but whirlpools in a river
of ever-flowing water. We are not
stuff that abides, but patterns that
perpetuate themselves**

(Wiener, in Capra, 1996, p.52).

This quotation captures the essence of one of the central premises on which this dissertation is based: that an individual is not a 'thing' characterised by an intrinsic and immutable identity which contains another entity in the form of a symptom (Cottone, 1989). Rather, a closed network of interactions, the outflow of which gives rise to further interactions in a process of continuous circularity, constitutes an individual.

Wiener's statement intimates that each individual is connected to other individuals through a closed network of patterned conversations which is continually sustained by further conversations (Capra, 1996). Like Wiener (in Capra, 1996), if we do not view a person in terms of substance, then it would seem logically coherent to view systems not as 'things', but as communicational behaviours, symbolic expressions of a context of conversations in which a person is embedded.

It should be clear that this dissertation embodies a conceptual shift from traditional ways of viewing chronic illness (leukaemia).

With the advent of first-order cybernetics, research began to look at the pattern of negative feedback and positive feedback in families, with a view to describing the homeostatic mechanisms that kept conflict within the family. These patterns were described in a circular manner. Often the effects of these patterns were that the researchers who were involved with the family were excluded. Pattern description was a step in the direction of the new epistemology, although this research had not yet achieved the holistic and ecological heights of its successors such as second-order cybernetics and ecosystemic epistemology, which emphasised the patterns of relationships between phenomena, rather than the phenomenon itself, it did introduce the family's need for conservation.

From Explanation to Description

The case studies in this dissertation were designed to move away from the explanations of illness to a description of the ecosystem in which leukaemia is embedded. This was to capture as much of the multifaceted tapestry of the lives of the family members as possible. The primary subject matter was the ecology of two families with an ill child who was suffering from leukaemia.

The new epistemology conformed to the principles of reciprocity, circularity and holism and rejected the dualistic concept of a choice between two opposites. This epistemology was based on the Batesonian (1951) notion of the study of how we come to know what we know. As such, this epistemology accentuated the active, new participation of the knower acquiring new information (the researcher was relieved of the responsibility of discovering the truth).

Because of this epistemology the researcher was able to investigate, among other areas, the themes of conversation. In the light of this and because this study was not designed to discover an absolute truth, objective truth, the study has a pragmatic value for psychology. It creates alternative descriptions of that phenomenon that had

previously been explained in terms of singularity. The descriptions that result from this study may result in many descriptions/definitions of illness (leukaemia) some of which may be more useful than others.

This study also described the patterns that emerged out of the researcher's punctuation of her experience with the families, using theoretical concepts from various sources such as Minuchin (Structural family therapy), Anderson and Goolishian (Problem-determined systems), Second-order cybernetics and McDaniel (Medical family therapy/Biopsychosocial). This study does not aim to argue the validity of these theoretical positions/premises but uses them as other ways of describing family patterns.

The aim of this dissertation is to describe the patterns, themes and ecology of ideas that pervade a family in which leukaemia is embedded. The purpose of this dissertation is to offer an alternative way of viewing illness, particularly that of childhood leukaemia. This study expects to be humble, as it is only one step in the quest for what is plural, multidimensional and heterogenous.

A Brief Note on Newtonian Epistemology

The dominant epistemology underpinning scientific theories until the end of the 19th century, Newtonian epistemology assumes that all phenomena can be explained through the postulates of reductionism, linear causality and objectivity. In strict adherence to these assumptions, Western scientists have attempted to define and classify leukaemia, identify specific causes for the condition and develop appropriate treatments that will eradicate the underlying causes (Capra, 1983). As these endeavours suggest, one consequence of this analytical, reductionistic method is that mind and body are viewed as 'separate and substantially different entities' (Onnis, 1993, p.139). Another is that it has kept the sufferer in a passive patient role, whereby health professionals assume the responsibility for their treatment and well-being (Capra, 1983; McDaniel, Hepworth & Doherty, 1995).

Moreover, despite the numerous theoretical expositions and studies - some of which have been presented in the next chapter - which have been presented from a biomedical or a psychosocial perspective, chronic illness (leukaemia) remains somewhat 'uncharted' territory and continues to 'puzzle' health experts. Despite the appearance of furious activity, childhood leukaemia research is curiously static. People still tend to measure the things they measured 20 years ago.

Problem Premise and Aim of the Study

As will be evident in Chapter 2, theorising and research on childhood leukaemia have mainly focused on subsystems (separately) as a consequence of the child's illness and not as an interactive and interdependent unit. The South African context has proved no exception; studies have been very few and predominantly theoretical, concentrating on diagnostic issues, physiological causes and medical treatment options. Efforts to quantify sufferers' experiences by means of reductionistic cause-effect methodologies have resulted in the loss of potentially valuable information, which could have contributed towards a more comprehensive understanding of the phenomenon.

In short, the mind-body problem is complex and controversial. The reductionistic models have tended to ignore any aspects of the condition that cannot be reduced to biological or psychological pathology. This has yielded simplistic, dualistic, inconsistent findings and a limited, decontextualised understanding of the individual and his/her symptoms. Therefore, in agreement with Onnis (1993), the author believes that the mind-body unity requires a perspective of complexity that recognises and integrates the multiplicity of interdependent and interconnected components of the problem. What seems to be required is a biopsychosocial conceptualisation of childhood leukaemia that will take contextual factors into account, and include in the treatment approach the individuals who are closely involved in the ill child's world.

Adhering to a holistic, biopsychosocial stance, this dissertation proposes to explore the unique experiential world of the families with an ill child (leukaemia). The purpose of the study is to describe pertinent aspects of the context in which the child's illness is embedded, including the interactional patterns between the individual and significant others who are viewed as influencing, and being influenced by, the course of the problem.

This study will be conducted within an alternative and unifying conceptual framework - the ecosystemic perspective. Ecosystemic epistemology is based on systems theory, cybernetics and ecology, which means that it is attuned to holism, relationships, complexity and contextual interconnectedness (Keeney & Sprenkle, 1982).

Ecosystemic and Cartesian-Newtonian epistemologies are mutually exclusive (Fourie, 1996a) and thus yield different findings. Whereas the Newtonian paradigm is founded on a realist epistemology (i.e. reality is singular and absolute), the ecosystemic perspective embodies a constructivist epistemology (i.e. realities are constructed, indeterminate and multiple). Thus, in an ecosystemic perspective the focus shifts from 'entities' to the co-created linguistic realities or ecologies of ideas (Bateson, 1972).

This implies that the exploration of the context of leukaemia will essentially elicit a description of the interconnected constellation of ideas and attributes of the meanings about the ill child and leukaemia. This ecology of ideas will have been co-created by those individuals who interact with the family (ill child) about the problem, including the researcher. In ecosystemic epistemology, symptoms are relationship metaphors (Keeney, 1979) and therefore are not located exclusively in the body of the identified patient.

Design of the Study

A positivistic empirical approach underlies the majority of the studies about childhood leukaemia. From this position, leukaemia is viewed as a medical problem and as such as a 'semi-concrete entity with an objective, context-independent existence' (Fourie, 1996a, p.15). Traditional reductionistic approaches employing quantitative methods have tended to focus on the illness divorcing it from the sufferer (family) and his/her wider social context.

In moving away from the traditional approach, this study will widen its focus to capture a picture of the ill child's world as seen through the eyes of the parents (significant others). To achieve this, a descriptive, qualitative research approach using a case study method has been chosen. A qualitative approach employs a flexible, emergent research design and is therefore coherent with the constructivist viewpoint that reality or knowledge is a fluid process, which is socially derived through mutual consent (Gergen, 1985; Hoffman, 1990).

Sampling and Selection

In this study purposive sampling and convenience selection will be used (Lincoln & Guber, 1985). Participants will be selected who can (1) meet the study's specified criteria for inclusion as outlined in Chapter 4, and (2) can provide rich descriptions of the child's illness in the context of the family's life ecologies.

This study will not distinguish between leukaemia subtypes. To do so would be to revert to a reductionistic biomedical perspective and would reify the subtypes of leukaemia as entities with causal attributes. Rather, what assumes importance in this study are the participants' idiosyncratic definitions and descriptions of the child's illness, the descriptions of the participants' life ecologies, and the interdependence and interconnectedness of their life ecologies within the context of leukaemia over time .

Similarly, the complicated issues of whether an individual's illness (leukaemia) is 'organic' or 'psychogenic' is considered to be essentially irrelevant since this dissertation conceptualises leukaemia as part of the complex interactions between biological, psychological and psychosocial factors.

Data Collection

Information will be obtained by means of the unstructured interview. Open-ended, discovery-orientated questions will be used to encourage participants to tell their story. The researcher will also be guided by circular questioning (Penn, 1982, p.272-274). The interviews will be tape recorded and then transcribed. The aim of this is to look for patterns and themes until redundancies occurred as well as to ensure referential adequacy (Lincoln & Guba, 1985).

Data Analysis

Patterns and themes idiosyncratic to the participants will be generated during the conversational process. Additional patterns and themes may also be identified after the tape recordings have been transcribed and summarised. One of the implications of the participants' construction will be that they will have to be continually verified with the respondents to enhance the legitimacy of the study.

Chapter Review

This study will comprise a literature survey as well as theoretical components.

Chapter 2 provides the point of departure for this study. It surveys the existing body of knowledge relating to leukaemia according to the biomedical and psychosocial

models. In this regard the physiological mechanisms, psychological characteristics, social issues and cognitive factors associated with the problem will be discussed.

In Chapter 3 ecosystemic epistemology will be discussed - the theoretical foundation for this study. Some of the pertinent cybernetic concepts will be discussed. An ecosystemic conceptualisation of leukaemia will be provided within the context of a co-evolutionary, constructivist perspective. Other theoretical perspectives will also be furnished, such as Minuchin's Structural therapy model, Anderson and Goolishian's Problem-determined model and McDaniel's Medical family/Biopsychosocial model. These models are proposed as alternatives to, and as an advance on, the pure systemic model. By virtue of the ecosystemic approach of this study it does not argue the validity of the above theoretical perspectives/ premises but sees and uses them as valuable in describing the family patterns that would emerge.

In Chapter 4 the research plan to be used in this study will be described.

In Chapter 5 a rich contextual description (story) of the Kruger family will be furnished. This will include the conversational setting, the researcher's impressions of the participants, the description of the illness context and finally the story of each spouse about their life ecologies.

In Chapter 6 a second case study will be furnished. The Loudi family's story will be described. As with the above case study it will include the conversational setting, the researcher's impressions of the participants, the description of the illness context and the idiosyncratic stories of each spouse about their respective life ecologies.

In Chapter 7 an overview of the two case studies followed by the findings/results will be furnished.

Chapter 8 will be the concluding chapter to this dissertation. Recommendations for therapy and future research will also be considered.

Conclusion

Chapter 1 provides the reader with a lens through which to view the epistemological stance of the researcher. It is within this epistemology (i.e. a constructivist-ecosystemic epistemology) that the researcher hopes to provide a challenging way of viewing chronic illness (in this case childhood leukaemia).

Hopefully the variety of descriptions in the study will serve to excite the creative potential of the reader, so that in 'thinking about thinking' (Auerswald, 1987) about chronic illness (childhood leukaemia) the alternatives postulated here will be multiplied many more times.

The following chapter surveys the literature on childhood leukaemia.

CHAPTER 2

LITERATURE REVIEW OF CHILDHOOD LEUKAEMIA

Introduction

There is a quiet revolution occurring in the West regarding our understanding of how the universe (internal as well as external) works. The Western scientific tradition of reductionism has led us, since the time of Descartes and Kant, to understand ourselves as separate, autonomous individuals made up of parts that are themselves separate and autonomous (Minnix, 1987). This separatist attitude regarding mind and body has led to an apparently erroneous understanding of our role in our own physical health. There is an ancient tradition in all cultures which assumes that the mind and body are integrated aspects of human beings. Shamanic healing and Chinese medicine both base their methods of healing on the assumption that mind and body operate together (Capra, 1993). The development of Western science has led to the alienation of mind and body. This is the premise on which the biomedical model of health is based. Understanding the disease process from a traditional point of view has led to a reductionistic approach to illness.

Biomedical Model

Within the biomedical model a main cause of childhood cancer is thought to be a problem in the development of the immune system (Putman, Cohen & Constantine, 1983). Cancer cells are regularly produced by the body and killed by the immune system (Capra, 1993). If the immune system is not functioning properly, cancer cells continue to be produced and grow rapidly. Therefore, 'cancer is a malignant disease of unknown etiology, resultant upon the uncontrolled progressive proliferation of blood

cell precursors in the bone marrow and usually involving the blood at some stage in the disease' (Boucher, Davidson & Edwards, 1992, p.28).

This is purely a medical definition and one that has been used to convey the meaning of cancer as well as its 'causes'. The traditional approach has contributed much to medical progress, but has unfortunately endorsed a reductionistic view to care and 'cure'. From this traditional perspective the etiology of leukaemia will be looked at briefly. Boucher et al. (1992) claim that only where there has been verifiable exposure to large doses of radiation is the cause of leukaemia known, otherwise there is no known cause. There are a number of interacting factors that contribute to the cause of cancer from a traditional point of view. The following factors may be of importance. Firstly, viruses can transmit leukaemia in animals, and recently a virus (the Human T cell Leukaemia/Lymphoma virus, HTLV) has been incriminated in the causation of a type of leukaemia found frequently in Japan (Boucher et al., 1992). Secondly, exposure to radiation is a known cause of leukaemia, as evidenced by the high incidence of granulocytic leukaemia in survivors of the atom bomb explosion (Hiroshima). These survivors have been found to have chromosomal abnormalities following exposure to radiation. Thirdly, exposure to drugs and chemicals such as benzene may be followed by the development of leukaemia. Finally, Cooper and Johnson (1983) have disclosed that the abnormal activation of certain genes called oncogenes may result in cancer. These genes are found in normal cells, but do not cause cancer unless altered by mutation or amplified (Boucher et al., 1992).

Whatever the explanation for the cause of cancer from the above perspective cancer nevertheless has a great impact on the lives of those involved in the cancer experience. Childhood cancer is a disease that has an immense impact on the patient and the family and at best can be viewed as a chronic life-threatening illness (Koocher & O'Malley, 1981). It can be argued that in our fast moving society human existence seems to be laden with multiple uncertainties that normally command little attention in day-to-day life. In the past decade it has been recognised that uncertainty may be a significant factor in understanding human responses to the 'illness experience'. The

current interest in uncertainty research (Cohen, 1995) is an evolutionary process in response to biomedical and technological advances in the treatment of diseases that have changed the nature of the 'illness experience'. One such illness is cancer, representing one of the most frightening words in the English language. The word conjures up images of physical weakness, emaciation and pain. Much of the research dealing with childhood leukaemia has been from a biomedical point of view, as briefly indicated above. A disease classification that is based on purely biological criteria (as illustrated by the medical model) clusters illnesses in ways to meet the needs of medicine (Rolland, 1987). This nosology fits the world of anatomy, physiology, biochemistry, microbiology, physical diagnosis, pharmacology and surgery. In the view of the medical model a linear view of illness exists; A causes B. A different classification scheme may provide a circular link between the biological and psychosocial worlds, and thereby clarify the relationship between chronic illness and the family life-cycle process (Rolland, 1987).

In the arena of physical illness, particularly chronic disease, the focus of concern is the system created by the interaction (problem-determined system) of a disease with the individual, family and/or other biopsychosocial systems (McGoldrick & Carter, 1989). To place the unfolding of chronic disease into a developmental context, it is crucial to understand the intertwining of three evolutionary threads; the illness, the individual and family life-cycle patterns. This is a highly complex process that remains largely unexplored (Rolland, 1987).

This chapter surveys the existing body of knowledge relating primarily to childhood leukaemia, as conceptualised according to the biomedical (as described above), psychosocial and biopsychosocial models.

Empirical information about families of pediatric cancer patients is available from two sources. First, there is a body of clinical literature on families of children who have cancer (Koch, 1985). These authors have described family members' resentment, anger, guilt, fear of death and desires that the patient would die. The potentially

disruptive impact on the family's daily routines if the ill child was treated as an outpatient was also considered (Koch, 1985).

Descriptive Studies: Family Affect

A second source of information on families of pediatric cancer patients is derived from descriptive studies (Koch, 1985). Researchers who have used descriptive study methods have used projective measures and personality tests to compare siblings and mothers of children with cancer and other life-threatening and terminal diseases to one another, and to members of families of children with a chronic but not a life-threatening disease (Koch, 1985). In the latter literature (descriptive studies) it was found that no differences in anxiety, guilt, fear of the illness or of body image were apparent between the two sample groups. However, Farkas (1974) found that mothers of terminally ill patients were more depressed than mothers whose children had a life-threatening or chronic disease. In addition to this it was found that siblings of pediatric cancer patients were more socially isolated than the leukaemic child. This was particularly so in terms of expressing their emotions to their parents.

The focus of research to date has been primarily on family affect. The work of McDaniel, Hepworth and Doherty (1992) has also contributed significantly to the study of chronic illness in children. The approach to McDaniel's et al. (1992) work has been within a biopsychosocial framework or medical family therapy framework. This perspective has given researchers and therapists a 'new lens' for looking at illness in the family (to be discussed later in the chapter). However, in the former focus of research (i.e. family affect) it was found that five family patterns emerged when the data from open-ended interviews with siblings and parents were analysed. These were as follows:

Increased experience of negative affect

Following the diagnosis siblings experienced anger, sadness and fear. Descriptions of siblings' feelings about the patient converged on two themes: They worried that the patient might die; and The sorrow that they felt about the impact of the illness upon the patient.

Prohibiting displays of emotions

This was particularly apparent for anger and worry. When both the parent and the sibling(s) denied any affect, the family was labelled as prohibiting emotional expression.

Pile-up of stresses

This primarily involved the various family members' experience of the illness rather than the leukaemic child's experience of his/her illness. This meant that the various family members experienced the child's illness on all levels, that is, emotional, physical, psychological as well as social. In this regard the family members experienced the appearance or exacerbation of physical and emotional symptoms such as accidents, or injuries, and acting out behaviours following the diagnosis. McCubbin and Patterson (1983, p.96) have termed this a 'pile-up of stresses'. The diagram below illustrates how families adapt to chronic illness as perceived by McCubbin and Patterson (1983).

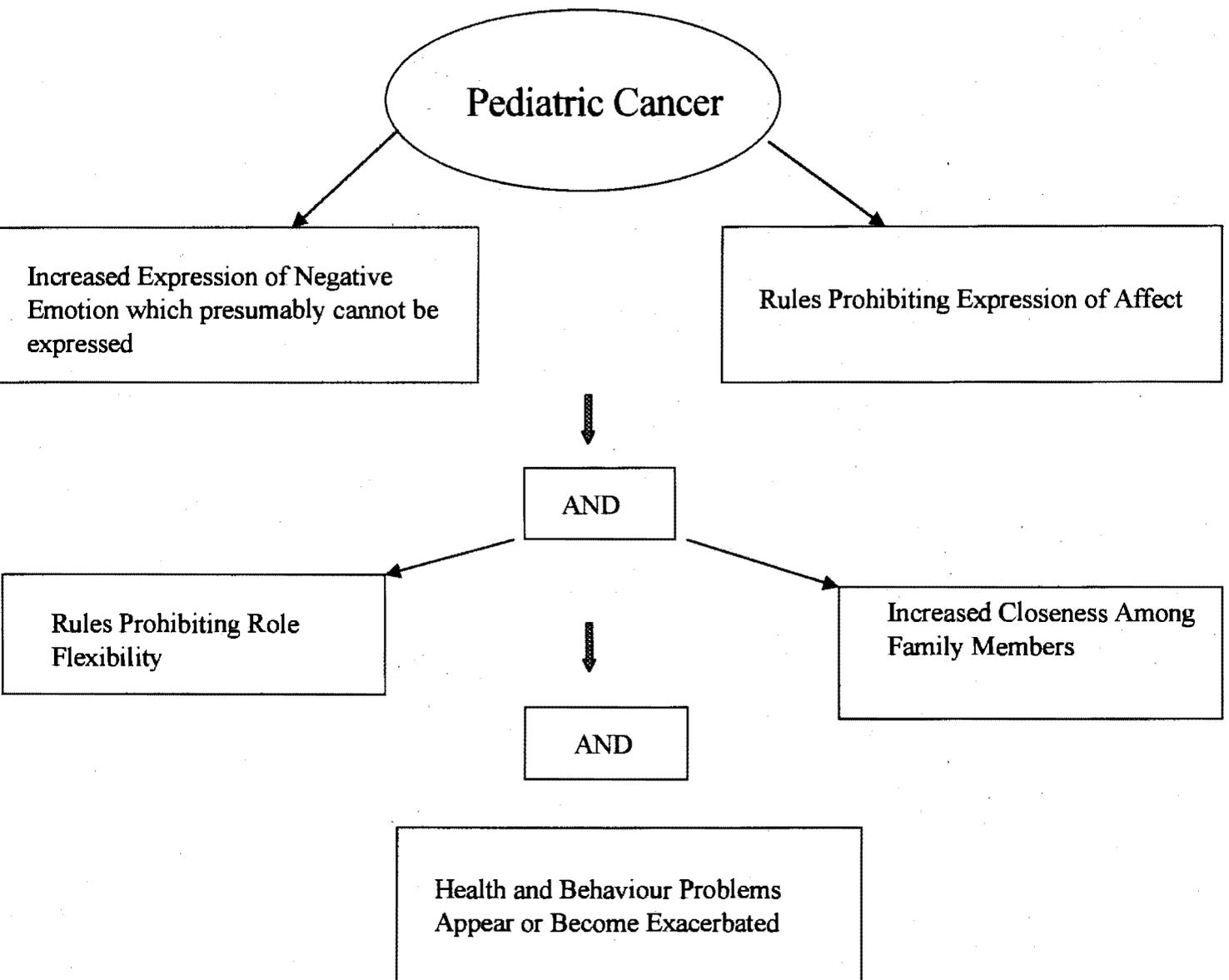


Figure 1: Model of family adaptation to pediatric cancer
McCubbin & Patterson (1983, p.56)

Role expectations

Roles have been defined as expectations regarding an individual's behaviour. Two themes pertaining to a fourth pattern emerged following changes in the roles of mothers, patients and siblings. These were as follows:

- Patient-centred families

The patient was given first priority in individual and family decisions. One manifestation of this rule was that increased attention was given to the patient, often at the expense (exclusion) of a sibling(s).

- Sibling maturation

The sibling was burdened with increased responsibility with respect to caring for the patient. This was largely due to parent illness or divorce or to the fact of both parents working. The sibling in this respect took on a parental role or role of a caretaker.

Increased closeness

The fifth pattern that emerged was that of increased closeness. Parents and siblings reported that the patient's illness had been associated with a strengthening of the family's cohesiveness. This increased closeness is viewed as a positive outcome, only insofar as it remains a balance between enmeshment and disengagement (Minuchin, 1974).

According to Koch (1985) the above demonstrates clearly that at least five family patterns emerge following the diagnosis of cancer; however, the understanding of how families change and develop has lagged far behind the understanding of individual development within the context of childhood leukaemia. It is argued from a systemic

perspective that families are not static systems; they evolve and change over time. Most family research has considered the family at only one point in the co-evolution of the illness and the family structure. For example, much attention has been given to the onset or diagnosis of the illness. Consistent with the fact that individuals, families and disease interact over a period, the need for prospective investigation of all the variables is crucial. These variables may include the illness, the family and the individual as a co-evolving system interacting with each other in a circular manner. Although the entire system is the overarching interest, understanding individuals, dyads and triads within families is also important. This is in opposition to the biomedical model that views interaction as linear and reductionistic. Therefore, this biomedical view advocates cause and effect relationships.

With this in mind the various areas of research focussing on leukaemia as well as some theoretical perspectives will now be considered.

The Leukaemic Child

Chronic illness in children is associated with a range of practical restrictions that potentially compromise everyday life for each member of the family. In addition, uncertainty about the course of the disease raises anxiety and other emotions. Stuber (1985) reported that depression in the ill child was rated very low. This meant that scores on a projective test were not significant enough to justify a diagnosis of depression in the ill child. The absence of reported depression has been interpreted primarily in three ways:

The first is that resilience, coping skills and support may eradicate depression in the ill child. Freiberg (1993) defines resilience as a multifaceted process by which individuals or groups exhibit the ability to draw the best from the environment in which they find themselves. In this regard Freiberg (1993) says that resilience may be drawn from the family, school and community. Butler (1997) found that 'bouncing back' from diversity is not a matter of rugged individualism or just having 'the right stuff' (p.123). Resilience is a systemic phenomenon that is forged out of a web of relationships. The

idea of resilience as a systemic concept appeals to the researcher, as it is a more encompassing view of the individual as part of a greater whole.

The second is that denial plays a major role in depression in the ill child. This has not yet been fully understood, but it has been assumed that denial by the ill child does not compromise his everyday living. In this regard the ill child uses denial as a survival mechanism or tool.

The third is that the methodological difficulties of self-report scales preclude 'accurate data' (as if there were such a thing).

In a study using clinical interviews, Kashani and Hakami (1982) reported that 17 percent of their sample of children with cancer met DSM III diagnostic criteria for a major depressive episode. Of significance here is both the fact that 17 percent of the sample had significant depressive psychopathology and that depressive experiences in the majority were not present. It is likely that both denial and methodological problems contribute to the difficulty of understanding depression in childhood cancer patients. Denial can be a protective coping mechanism, but less is understood in terms of characterising multiple family members and of how the family (re)organises itself around the denial of depressive symptoms, thoughts or feelings. Inclusion of other methodologies is the most pragmatic solution to understanding phenomena that may not be fully accessible by self-report questionnaires. Kazak and Nachman (1991) propose that the systemic approach might suggest that seeking evidence for depression in the child might not be appropriate. Rather than viewing depression as pathology isolated in an individual child, research could focus on the role of parents and families in reflecting or mediating the child's experiences, depression, anxiety or otherwise. This would mean extending one's view (binocular vision) to include the context in which the ill child finds him or herself.

As with depression, there is evidence that generalised anxiety may be denied (Kazak & Nachman, 1991). Researchers have traditionally not incorporated other

family members extensively in research programmes regarding the investigation or study of leukaemia, nor considered the ways in which families can promote adaptive coping mechanisms for anxious children. This may be an important factor to consider in that children may also mirror the anxiety of other family members. Most studies of long term survivors of childhood leukaemia indicate adequate overall functioning. Contrary to this, in a study of 118 survivors (ranging in age from 5 to 37) Koocher and O'Malley (1981) found that 47 percent of the children experienced adjustment problems, such as disruptive behaviour at school or acting out behaviours. Koocher and O'Malley (1981) suggest that factors such as type and course of illness, developmental period in which the child was ill, time since recovery and a generally optimistic outlook may help to differentiate more or less successful adaptation in the ill child. Most research on intervention strategies for working with depression and anxiety in the ill child has emphasised the importance of the child feeling in control and using control strategies for dealing with their physical discomfort (Kazak & Nachman, 1991). One such strategy is biofeedback. 'Biofeedback is a method learnt to control one's own physiological processes' (Green & Green, 1977, p.52). In addition to this there are many secondary effects on the child as a consequence of the leukaemia, such as the following.

Developmental Outcome

Children treated for acute lymphoblastic leukaemia (ALL), the most common cancer in childhood, are at risk for learning problems, including decreased IQ scores in mathematics, attention and memory, both during their treatment phase and after 'cure' (Coniglio & Blackman, 1995). Psychosocial problems, particularly behavioural problems and social skill deficits, were reported as well. These problems occurred across all age ranges but were most frequent in children who were less than four years old at the time of diagnosis (Coniglio & Blackman, 1995). It is estimated that up to two thirds of these children may have educational difficulties.

Educational and Developmental Effects

Many young children with leukaemia miss 10 to 20 weeks of preschool or kindergarten in the early stages of treatment. Most of the absences were caused by hospitalisations, clinic visits and the side effects of chemotherapy (Spinetta & Deasy-Spinetta, 1981). Many authors report a relationship between school absenteeism and educational outcome, with varying results. For example, Baghurst, Haskell, Rice, Sawyer and Toogood (1989) related three factors to later school difficulties in children who survived acute lymphoblastic leukaemia: (1) missed schooling, (2) emotional and behavioural problems and (3) deterioration in full-scale intelligence quotient (FSIQ) secondary to cranial radiation treatment (CRT). Meadows, Bartel, Morrero and Peckham (1988) on the other hand reported few problems with absenteeism after the initial period of the illness and, therefore, no significant relationship to ultimate educational outcome. Certainly, absenteeism contributes to the early educational progress or lack thereof, if not to full final outcome, for every child with leukaemia (Coniglio & Blackman, 1995).

IQ Deficits

Although early studies showed no decrease in IQ or achievement test scores after treatment that included cranial radiation treatment (Soni, Marten, Pitner, Duenas & Powagek, 1975; Whitt, Wells, Lauria, Wilhelm & McMillian, 1984), many studies refuted these findings (Eiser, 1978; Jannoun, 1983; Meadows et al., 1988). Much of the literature from the late 1970's and early 1980's debated the issue of whether or not cranial radiation treatment is the cause of adverse educational outcomes. Meadows et al. (1988) examined the findings of 20 such studies. The analysis of the data revealed that a mean decrease in full-scale intelligence quotient (FSIQ) of 10 points was found in patients treated with cranial radiation treatment. A greater negative effect on the full-scale intelligence quotient was found for children who were less than four years old at the time of the diagnosis (Cousens, Said, Stevens & Waters, 1988). However, most of these children were still functioning in the average range. As a result

of these findings most treatment regimens since the early 1980's have not routinely included cranial radiation treatment (CRT) (Deasy-Spinetta, 1988).

Psychosocial Problems

Psychosocial functioning, including self-esteem, peer relationships, behaviour problems, and prevalence of depression, have been studied in the survivors of childhood leukaemia. Many studies have reported good psychological outcomes in most children (Fritz, Amylon & Williams, 1988) despite the intense stress suffered by the child and family during the treatment years. Fritz et al. (1988) examined the relationship of demographic characteristics, including age at diagnosis and socioeconomic status, to psychosocial outcome in survivors of childhood leukaemia and found only a weak correlation. A much stronger correlation was found between psychosocial variables, such as family communication patterns and peer support during treatment and psychosocial outcome.

The leukaemic child is not the only member who has to deal with his/her illness, as the whole family is affected. Parents frequently raise concerns about the effects of the illness on siblings, yet they are rarely included in systemic research. Siblings also have to adjust to having a brother/sister that is ill. Most often than not these siblings are the 'forgotten-ones'.

"The Forgotten Ones"

While medical staff may be concerned about the impact of chronic illness on the parents and the ill child they tend to be less involved and concerned with the healthy sibling(s) (Chesler & Barbarin, 1987). Sometimes termed 'the forgotten ones', siblings can easily feel left out. Siblings of a child with leukaemia have been reported to experience somatic, academic and behavioural problems as well as a negative self-image and high anxiety (Barbarin, Carpenter, Copeland, Dolgin, Mulhern & Sargent, 1995). Siblings of children with leukaemia may experience similar difficulties to siblings

of other chronically ill or handicapped children. These difficulties may include the fact that relationships with parents change, and furthermore siblings are often confronted with other general restrictions as a result of the family's concern and preoccupation with the ill child. In order to minimize anxiety in siblings, parents may not routinely involve them in discussions or explanations about the disease or course of treatment. A heavy burden is placed on the healthy sibling(s) and they are often encouraged or even expected to carry on with their lives as if nothing untoward has happened. Thus, they shoulder considerable responsibility, sometimes made worse by an atmosphere of secrecy, created under misguided parental beliefs that they can shield their children from potentially distressing information.

In addition, chronic disease threatens the integrity of the sibling's relationship with the ill child, both directly and indirectly. The integrity of this relationship is affected directly by the fact that the opportunities to interact are reduced, as the ill child is physically less able to keep up with the healthy sibling (Havermans & Eiser, 1994). Less directly, siblings may perceive that they are treated differently, perhaps that they are left out and are less likely to do things with their parents. They hold a peripheral position, that is, they are on the 'outside looking in'. In all families, perceived differential treatment of this kind is related to heightened conflict between siblings (Boer, 1990). Despite this escalating conflict between siblings and the ill child, it has been reported that siblings tend to worry about the cause and visibility of the illness (Sourkes, 1981). In addition, Menke (1987) found that although parents and siblings agree that the situation is worrisome, they do not agree about the nature of worries and concerns. For example, siblings may express a desire to be informed about their brother's or sister's illness, while the parents do not see the need to share information regarding the illness (Havermans & Eiser, 1994).

There is a great deal of literature that suggests that siblings lack factual knowledge about their brother's or sister's condition. This is in contrast with other work (Menke, 1987), which suggests that siblings are aware of the social and psychosocial impact of the illness even though they are routinely excluded from discussions

concerning the ill child's condition. Horwitz and Kazak (1990) postulate that an awareness of the illness may result in increased opportunities for growth and development in the healthy sibling, because the disease may create situations in which a child may become aware of others' needs (Tritt & Esses, 1988). According to this perspective, heightened awareness can lead to a growth in empathy and altruism. Thus, siblings of chronically ill children may be expected to respond more positively and empathically than siblings with no opportunity to learn within the context of illness/disease. Empirical support for this viewpoint is growing (Horwitz & Kazak, 1990). Although not applying directly to Horwitz and Kazak (1990), a limitation of previous empirical work is that it has been based on parents' reports about siblings' behaviour.

While parents' reports are of interest in their own right, it may be less appropriate to rely on them as informants, if the issue is to understand the impact of chronic disease on healthy siblings. However, it can be argued from an ecosystemic viewpoint that the parents can comment on the entire system, as it is merely their punctuation of the system representing one more reality.

Studies that have focused on the responses of siblings themselves have been limited in the past because of the lack of availability of standardized instruments. A questionnaire to assess siblings' perceptions has been reported by Carpenter and Sahler (1991). The questionnaire included siblings' reactions on four dimensions:

(1) interpersonal (interpersonal interactions and relationships), (2) intrapersonal (how siblings perceive the disease as affecting them), (3) communication (parent-child communication) and (4) fear of the disease. These four dimensions comprise The Sibling Perception Questionnaire. The questionnaire was analysed quantitatively with the aforementioned items being allocated a scale of 1-10 for each item. The responses to the four items were also analysed qualitatively. The results from this analysis were as follows:

Carpenter and Sahler (1991) reported that siblings, who were described by their

parents to have adjustment difficulties, differed from those who were well adjusted children, primarily in terms of their responses on the interpersonal items, for example, 'I wish my parents would spend less time with my brother/sister'. Statements of this nature indicated high scores (7-10) on the interpersonal items. Furthermore, interpersonal relationships were perceived to be more affected by the illness. Poorly adjusted children perceived themselves to be ignored by their parents, unwanted and misunderstood. Havermans and Eiser (1994) obtained data from the Carpenter and Sahler (1991) study that raised two practical issues:

The first issue raised was that communication with parents was related to the general impact of the illness on the siblings' lives, suggesting that easy and open communication between parents and siblings is critical. On the other hand, those children who scored higher on the communication dimension also seemed to worry more about the death of their brother/sister. Siblings expressed considerable concern about the possibility of death, perhaps aggravated by the parents' inability to communicate openly about this issue. The second issue was that siblings were distressed by what they saw in hospital.

The above study is one of several which have shown an increasing interest in the effects of chronic illness on siblings. This interest reflects a growing awareness that serious illness in one family member may have significant impact on other individuals within the family. Research on sibling adaptation has been highly inconsistent. The inconsistency of findings regarding sibling adaptation to chronic illness may be partly accounted for by methodological variations and limitations. One such account or limitation is that the information pertaining to the adjustment of siblings has been obtained largely from parental reports and behavioural rating scales and less often from sources external to the family, such as the health-care team and teachers. Reports from siblings themselves have been derived largely from questionnaires, attitude or behavioural ratings and interviews (Menke, 1987; Spinetta & Deasy-Spinetta, 1981; Tritt & Esses, 1988).

On a more positive note, the siblings themselves have reported that they had

become more compassionate and caring, family members were closer to each other, they had experiences they otherwise would not have had and they felt that they had been helpful to the ill child and to their families. Although 27 percent of the siblings in the Carpenter and Sahler (1991) study reported that they had been more affected by the cancer experience than other siblings in the family, it cannot be determined from the data if they perceived the illness experience to be a positive or negative experience in their lives.

The differences in responses were most often related to the age of the siblings or to an age by gender interaction. Older siblings were far more likely to be described as positive perceivers (i.e. they found the experience of being in the context of illness enriching) than younger siblings were. Tritt and Esses (1988) also found that older siblings of children with a variety of chronic diseases were reported to be more patient, understanding and sensitive to the ill child in the family. In addition, older siblings were more likely to have had more independence and support from activities outside of the home that could buffer the effects of having a seriously ill child in the family. Younger children, by contrast, were much more dependent on the family for activities and support, as they are more vulnerable and are therefore perceived to be negative perceivers.

Sahler, Roghmann, Carpenter, Mulhern, Dolgin, Sargent, Barbarin, Copeland and Zeltzer (1995) found that although siblings in the above study had a higher incidence of behavioural problems than controls from the general population, as measured by the Behaviour Problem Index, the group at highest risk for problems were boys from 6 to 11 years of age. Other studies such as Spinetta and Deasy-Spinetta (1981) also found that young school-aged boys with an ill brother or sister were particularly vulnerable to adjustment problems. Furthermore, younger siblings had the greatest difficulty expressing their thoughts and feelings and were most frequently unable to give a response. It can only be speculated as to whether this indicates a lack of awareness from their perspective, an inability to express their point of view or a combination of these factors. The absence of a strong relationship between siblings'

responses and level of adaptation proved disappointing in this study. The lack of a relationship between the siblings' responses and the level of adaptation suggests that the selected siblings' expression of feelings and thoughts is a poor predictor for those at potential risk or those likely to be 'immune' to problems. McCubbin and Patterson (1983) postulated that a family's (or individual's) perception of a stressful event influences adaptation, and seems not to be reflected consistently in the adaptation of the positive perceivers in the above study of Carpenter and Sahler (1991). However, the reporting of positive effects of a stressful event retrospectively may represent a very different process from reporting a positive attitude at the time of the stressful event.

Recent research on family adaptation to chronic childhood illness has revealed that the strengths of individuals and families should be considered in understanding how families adjust within the context of leukaemia (Horwitz & Kazak, 1990). Sibling behaviour and family characteristics are addressed with respect to normal development and functioning, allowing for identification of competencies and family patterns relating to them, as well as helping to identify sibling and family difficulties (Kazak, 1989). Given this, Horwitz and Kazak (1990) argue that there are competencies involved in successful adaptation that need to be identified.

In this respect Horwitz and Kazak (1990) studied a relatively homogeneous sample of three-to-five-year old siblings and parents of pediatric oncology patients, to determine the competencies involved in successful adaptation to the illness experience. The sample was compared to preschool siblings and parents of healthy children on standardized measures of psychological adjustment. It was concluded that the preschool siblings of children with cancer showed no major behavioural or social problems as compared with siblings of healthy children. Furthermore, the former group demonstrated psychosocial assets including positive self-perceptions, social competence and the capacity for pro-social behaviour. Pro-social behaviour includes the ability to comfort, praise, share, help, show affection and so forth. These results are

consistent with studies showing strong self-concepts and little or no psychopathology among siblings of children with a variety of medical conditions.

It has been argued that research on young siblings of ill children has been limited, despite long-standing recognition of siblings' mutual developmental influence (Horwitz & Kazak, 1990). The existing research indicates that siblings are likely to show a mixture of problems and competencies (McKoeber, 1983). This may mean that siblings are not maladjusted, but they may show externalising behaviour problems, such as aggression or school difficulties, or internalising symptomatology, such as unhappiness or anxiety (Breslau, Woitzman & Messinger, 1991).

Because there is anecdotal evidence that having a sibling with a chronic condition may enhance social skills, Horwitz and Kazak (1990) sought to investigate pro-social behaviour more systematically, using developmental literature as a foundation. Observational studies of young siblings demonstrated that they actively share, help, cooperate and comfort one another and that these behaviours are stable over time (Dunn & Munn, 1986). It is then argued that it is important to know if the rate of pro-social behaviour differs when one sibling is ill. It was found that the pro-social reports of having an ill sibling might enhance socialisation (Ferarri, 1984; Taylor, 1980; Tritt & Esses, 1988). Although pro-social behaviour has sometimes been interpreted as a burden imposed upon siblings or as 'attention-seeking', Horwitz and Kazak (1990) offer no support for harmful effects on siblings, as siblings seem to be generally psychologically well adjusted.

Research on sibling adaptation has been conflictual, clouded by methodological difficulties, including the criteria taken to ascertain adjustment. Parental reports provide data on one member of the system yielded by another and are valuable in this regard (as seen from an ecosystemic perspective). However, these data can be biased (seen from a positivistic perspective). Because siblings are often excluded from, or seen as ancillary to a study, the quality of data collected is sometimes compromised. In this regard it is suggested that research using sibling self-reports would appear to be crucial. Parents have been the spokespersons for the entire system, yet they have

stories of their own as their lives are affected at every systems level (i.e. interpersonal, intrapersonal, psychological and social). In this regard the parental system is also faced with major adjustments. These adjustments may include striving to maintain the conservation of the system despite the many stresses encountered.

Parental Adaptation /Coping

The following is an account of parental adaptation/coping as well as the stresses involved in having a child with a chronic and sometimes life-threatening disease such as leukaemia.

Kazak and Nachman (1991) found that parental reactions to childhood cancer are influenced by many variables, including personality and previous experiences with illness and care-taking in each spouse. Family-of-origin issues may also be critical, influencing the particular coping styles employed by each spouse and the manner in which the family reorganises itself to meet the needs of the ill child. The picture that emerges depends not only on the personal predisposition of each parent but on how they interact with those of the spouse and other family members against the backdrop of pre-illness family functioning. Research on parents has uncovered general concerns such as gender differences and coping styles. Cook (1984) studied changing role expectations in the context of chronic illness. Cook's (1984) study highlighted the trend for mothers to assume primary care-taking responsibility, whilst fathers assumed increased care for other siblings, and functioned stoically as breadwinners or financial managers of the system. Furthermore, mothers' experiences were coloured by increased social isolation, more intense involvement with the ill child and medical staff and a focus on shielding others. Fathers, on the other hand, expressed crucial issues concerned with competing obligations of work and family and isolation from hospital personnel. Wives feared increasing emotional distance from their husbands, and husbands reported feeling alienated from the ill child and worried about their wives' over-involvement (enmeshment) with the ill child.

Despite the emerging picture of parental and marital adjustment in terms of role definition there are several major methodological obstacles in this literature. One such obstacle is not to consider the quality of the marital relationship prior to the illness. The importance of considering the quality of the marital relationship prior to the illness is of major significance, as it might indicate whether or not the illness context has exacerbated the dynamics of the relationship or has created a 'new' relationship altogether. Such assessments are made on the basis of retrospective reports or by observation/self-reports in the early stages of treatment of the ill child. This can provide important data on marital functioning and hold promise as a strong predictor of later adjustment. Following a social-ecological approach, Kupst, Natta, Richardson and Schulman (1995) have reported on a six-year prospective study of family coping and adaptation to childhood cancer. The ability to cope was assessed using self-report questionnaires and semi-structured interviews. The focus was to provide a prospective assessment of how families coped with a leukaemic child, as well as to provide a psychosocial intervention.

The results indicated that good coping 'runs in families'. Those families that looked best, six years after the diagnosis, could be predicted from earlier evaluations of family coping prior to the illness. This research also highlights a period of the most intense distress and disruption immediately following the diagnosis. Furthermore, the course of cancer will vary by disease, severity and individual characteristics, making it difficult to generalise exactly what families are responding to at any given point in time (Kupst et al., 1995).

Of particular relevance to families with chronically ill children is the fact that these are 'normal families' coping with a demanding and distressing situation. Although it was once assumed that the stress of having an ill child would have a negative impact on families and result in psychopathological reactions in family members, this deficit orientation toward families has now been challenged repeatedly, in research showing similarities between families with and without a leukaemic child. Refining and diversifying concepts of normality, specifically with regards to what it means to cope

'normally' with an abnormal event, is critical to assessing and understanding these families. A related question that affects research design and interpretation and that applies to many studies, is the extent to which the absence of psychopathology can be accepted as evidence of coping. Kazak and Rostain (1989) propose that measures of psychopathology do not address coping and the lack of pathology should not be accepted as evidence of good coping.

In another longitudinal study of children with leukaemia, Kalnins, Churchill and Terry (1980) used participant observation methodology to show that most families experienced a wide range of stressors besides the diagnosis of cancer, emphasising the need to look more broadly at such situations, particularly at the social context. Kazak and Nachman (1991) reported that through studies such as the aforementioned (i.e. Kalnins et al., 1980), an understanding of family interaction is beginning to emerge.

Stresses

An important factor determining whether the experience of childhood cancer (leukaemia) is ultimately destructive or growth producing for family life may be the coping styles each parent employs to deal with stress, and the congruence of the spouses' perceptions, emotions and behaviour, in response to the illness-related events. Most conceptions of stress and coping focus exclusively on the immediate responses of individuals (Lazarus & Launier, 1978) and only tacitly acknowledge that coping is a process that evolves over time. It is appreciated that coping is a complex and not fully understood phenomenon. Therefore, it is not surprising that research in this area reflects a variety of perspectives and definitions of what constitutes 'adequate' coping.

Kalnins et al. (1980) suggest that a number of over-arching factors contribute to instability within the family system in which cancer forms part of the family's tapestry. For example, the cost of medical care, the vicissitudes of the child's physical condition and the extended parental absences often associated with childhood illness disrupt the

entire family's ongoing routine, and require alterations in the couple's role definitions. Moreover parents' and siblings' intense emotional focus on the condition of the ill child may alter the frequency and energy with which the family members express caring and support for one another (Barbarin, Chesler & Hughes, 1988). Family members respond to stresses not only as individuals, but also as part of an interactive network. Coordination of family members' emotional and adaptive responses is required if the entire family is to cope effectively as a unit with the illness (Barbarin et al., 1988). Therefore, conceptualisations of stress and coping are inadequate if they ignore the context of the family as an interactive network (Masters, Cerreto & Mendlowitz, 1983). Bateson (1972) and Jackson (1965) examined this context (i.e. family as an interactive network) in their research on the congruence of the spouses' affective, cognitive and behavioural patterns in response to normative tasks and stressful situations. An early analysis of the congruence of these patterns indicated a complementary relationship among marital partners. For example, Jackson (1965) observed that husbands were high in the instrumental, task-orientated and problem-solving domains and wives were high in the expressive and emotional domains. Burke and Weir (1976, 1977, 1979) suggest that this complementary relationship among spouses may also extend to their coping behaviour. Some researchers (Cook, 1985; Jackson, 1965) have suggested that little work has been done to relate the congruence of these coping strategies to outcome measures, such as parents' perceptions of each other or their satisfaction in the marital relationship.

Parents' assessment of outcomes such as their marital quality and their perceptions of support from the spouse are important because they have a direct relationship with the parents' psychological well-being and the ability of parents to care for the ill child (Swift, Siedman & Stein, 1987). Swift et al. (1987) explored how parents experienced the stress related to childhood cancer and how their ways of coping with such stress were related to their assessments of marital outcomes. The results from this study suggest that the effects of childhood cancer upon the marriage and the quality of family life are not necessarily debilitating. A majority of parents indicated that their feelings towards each other remained unchanged or changed in a positive

direction. In addition, a majority of parents reported that their families had become closer as a consequence of the illness and its treatment. In contrast to this, earlier findings have suggested reports of negative effects on the family. The more optimistic researchers such as Barbarin et al. (1988) have accounted for this in several ways. Firstly, their entire sample was composed of parents of living children, while other studies included a much higher proportion of parents who had lost a child to cancer. The parents of the deceased children experienced more stress and held more negative views of their family relationships. Alternatively, the divergent findings may lie in the 'pile-up' phenomenon described by McCubbin and Patterson (1983). Because of the threat to the child's survival, the couple may not be attentive to the evidence or sources of discord and, consequently, may continue to evaluate the marriage favourably, hence the 'pile-up' phenomenon. McCubbin, Cauble and Patterson (1982) suggests that the child's health status and the passage of time may be critical determinants of how favourably parents of children with a chronic illness evaluate their marital relationship.

As questions regarding the child's survival become settled, the 'pile-up' issues rise to the surface, contributing to a sense of marital distress, further increasing the likelihood of dissatisfaction and discord within the spousal relationship. The reports of stress and coping all portray the reconstructed reality of people in a long-term crisis, people who may desire to present an overly optimistic view of their family life (McCubbin et al., 1982). They also represent the experiences and feelings of parents at a single point in time. Without follow-up data it is impossible to tell whether parents' experiences might change over a longer period.

However, the data makes a convincing case for going beyond the individual to view the family as an interactive system with shared stresses and interdependent roles. From this perspective, family processes such as the congruence of parental coping (for example, father becomes the manager/provider and the mother becomes the primary caretaker) mediates the link between the stress of the illness and outcomes, such as marital functioning. Although the data is not without limitations, it advances our

understanding of the marital effects of the different ways in which families reorganise themselves to cope with a chronic/life-threatening illness.

The majority of studies about the impact of childhood leukaemia on the marriage suggests that while the divorce rate is not necessarily elevated in these families, marital satisfaction does seem to be lower (Hauenstein, 1990; Kazak, 1989; Sabbeth & Leventhal, 1984; Zimand & Wood, 1986). In fact, parents of cancer patients appear to have a slightly lower incidence of divorce than other couples (Forster, O'Malley & Koocher, 1981). These authors argue that there is no dissolution of the system. In light of this a controversy exists with regards to whether the parental system experiences more or less marital difficulty than is the 'norm'. Some authors have found an increase in marital dissatisfaction and discord (Kaplan, Grobstein & Smith, 1976); whereas others (Kupst & Schulman, 1988) have reported that marital relationships remain stable or tend to actually improve during the course of the child's illness. Nonetheless, it has been demonstrated that in families of pediatric cancer patients the quality of the marital relationship is significantly related to overall family coping (Kupst & Schulman, 1988). Thus, it is important that the parents' relationships be investigated more thoroughly. The existing literature on family adjustment to childhood leukaemia identifies a number of coping strategies typically employed by parents, for example having an affair (Billings & Moos, 1981). However, little attention has been paid to the interactions between parents in the process of coping. In addition to the focus on parental coping there are a number of other factors that impact on the functioning/adaptation of the system, and these may be termed concurrent stresses.

Concurrent Stresses

During the course of a detailed longitudinal study carried out by Kalnins et al. (1980), 45 families having a child with leukaemia were followed for a period of two years from the time of diagnosis. Kalnins et al. (1980) discovered that a variety of problems arose concurrently with the illness or secondary to it.

It was discovered in the course of many contacts with the parents that their feelings about their child's illness, and their ability to cope with it, were closely tied to the existence of other concurrent problems in the family. During periods of remission, parental fears about the leukaemia receded into the background and the other concurrent stresses (such as the financial burden incurred by the family) were perceived as more troublesome than the leukaemia itself. During periods of relapse the additional problems became the proverbial straw. The picture that emerged indicates that the impact of leukaemia on the family needs to be viewed within a broad perspective on stress in general, rather than simply as stress arising from the child's illness, as proposed by Kalnins et al. (1980).

The above study clearly indicates that families with a leukaemic child are likely to face one or more problems in addition to the stress of caring for their ill child. These events include some over which the family has little or no control, for example, the illness or death of a family member other than the child with leukaemia, loss of employment, or a variety of exacerbations of the leukaemic child's condition arising from complications related to the leukaemia.

Further, the findings that only two of the 45 families experienced divorce or separation concur with other more rigorous and extensive studies on the effects of chronic childhood illness on the family. The implication of the various studies on the effects of chronic and life-threatening illness on the family is that the illness rarely precipitates family disintegration, but rather exacerbates already existing problems or unstable relationships (Kalnis et al. 1980). The range of complexity and the frequency of stresses reported in this study argue strongly for regular reviews of families by all professionals who are or could be involved in the provision of services. If no concrete steps can be taken, then at least family behaviour/ interaction can be understood from an alternative perspective, such as the ecosystemic framework.

Procedure-related distress

The course of treatment for childhood leukaemia is stressful for patients and parents alike, a point that has been reiterated a number of times in this literature review. In view of this statement much of the research on the child's distress during the leukaemia experience has focused on behaviour during invasive procedures (e.g. lumbar punctures (LPs) and bone marrow aspirates (BMA)). Self-reports and observed behaviour such as crying, screaming, verbal expressions of pain and fear, verbal and physical resistance and asking for help indicate that procedures are both painful and frightening (Kazak, Brophy, Johnson, Boyer & Sher, 1995). The research on parental and family functioning in pediatric oncology tends, in contrast (to the research related to procedure-related distress), to assess more global aspects of family functioning and often neglects parents' perceptions of the salient aspects of treatment. The extent to which distress is associated with certain procedures in the treatment of leukaemia remains unresolved. Jay and Elliott (1985) reported that there was a decrease in distress in the parents and the ill child over time, as there was habituation to the treatment procedures. However, Katz, Kellerman and Siegel (1980) found no correlation between observed distress and the time since the child was diagnosed. This included a time period of six years from the time of the diagnosis. For parents, invasive procedures are among the most traumatic aspects of treatment (Jay & Elliott, 1990). Research on distress during treatment procedures provides a detailed analysis of the changes in distress experienced by the child and parent across the different stages of the treatment procedures (Fife, 1990). However, there is a lack of contextual data on parental perceptions of the treatment experience and the extent to which procedural distress affects general family adaptation. As with other major stresses and serious childhood health conditions, family coping is variable across families (Kazak et al. 1995).

Treatment - Stress Variable

The impact of childhood cancer on the family, and identifying relevant dimensions of family adjustment that pertain to the treatment experience, is obviously important (Miller, 1980). Two important areas that have been considered are the quality of life of the ill child and parenting. The quality of life for children with cancer encompasses the physical, social, emotional, behavioural and educational domains. The quality of life is unquestionably affected negatively during the early stages of treatment, although the impact of treatment on the quality of life over the course of treatment is less clear. There is mixed evidence as to the course of parental distress during treatment (Fife, Norton & Groom, 1987). However, literature on the treatment of the ill child (particularly the treatment procedure as a stress variable) has generally neglected the notion of parenting and the way in which the disease and its treatment impact on parenting roles and behaviours.

Kazak et al. (1995) presented data on parental perceptions of procedure-related distress in a cross-sectional study of children in the treatment of leukaemia. In developing a self-report instrument for assessing parental perceptions of procedures, Kazak et al. (1995) assumed that parents' perceptions of their child's distress, their own distress and their perceptions of medical services may affect their experiences with invasive procedures, such as lumbar punctures. In addition, overall parental adjustment to chronic childhood illness is a multivariate process (Kazak et al. 1995). Furthermore, the context of procedures during treatment is a rich one for understanding the process of adaptation to serious childhood illness. A study by Kazak et al. (1995) demonstrated the importance of parental satisfaction, involvement and distress in assessing the treatment milieu. The data from this study documented how mothers and fathers at a large treatment centre perceived the procedures of lumbar punctures (LPs) and bone marrow aspirates (BMA). The sample comprised patients with leukaemia in their first remission. Parents may have habituated to their children's procedures but they did show distress across phases of treatment. A self-report questionnaire was

introduced in this study to assess three distinct factors - satisfaction with their child's care, parents' own involvement and distress, and their perceptions of their child's distress.

The consequent data supports the development and refinement of measures that assess the specific contextual aspects of the experience of childhood illness. One seeming contradiction in the data relates to the generally high satisfaction ratings with the medical care/staff, made concurrently with high ratings of distress regarding their child's well-being. In essence this study verifies that both mothers and fathers experience high levels of distress during their child's invasive procedures for the treatment of leukaemia. This was the case even when parents were very involved in their child's care and when they reported general satisfaction with the medical team's attention to them and their child. The data highlights the importance for the continuation of the provision of psychosocial support to families of children with leukaemia throughout the course of treatment, rather than assuming that distress subsides after adjustment to the diagnosis. The uncertainty of the situation may persist, increasing the distress experienced by the family.

Life expectancy - An uncertainty

In a study carried out by Cohen (1995), an explanatory account of the behaviour of families living under conditions of sustained uncertainty due to the unpredictable course of their child's illness was reported. Several commonly occurring events were found to precipitate increased parental anxiety by triggering a heightened awareness of the uncertainty concerning the child's survival. The triggers included:

Routine medical appointments:

Although the frequency of medical evaluation varies with the disease, its severity, and the treatment protocol, all children with chronic, life-threatening illnesses are examined at regularly scheduled intervals and may also have diagnostic and/or

therapeutic procedures performed routinely. Days or even weeks, prior to the scheduled medical appointment, the fear that parents may have pushed to the back of their mind begins to intrude as they consider the possible outcomes. Parents worry about what the doctor will find, or what the tests will reveal, intensifies as the day approaches (Cohen, 1993a).

Body variability:

Because the onset of most chronic illnesses in children is rarely dramatic in the early stages, parents usually do not consider the child's initial presenting symptoms to be the harbinger of a serious illness. Most often, they apply a lay explanation that minimises the symptoms and suggests a familiar home treatment or remedy (Cohen, 1995). Their initial misdiagnosis of the seriousness of the child's problem causes parents to fear making another 'mistake' that could jeopardize their child's survival. This fear impairs their ability to appraise any subsequent variation in the child's behaviour as benign (Cohen & Martinson, 1988). An increase in an infant's crying, a decrease in appetite, an alteration in energy levels, or the occurrence of symptoms suggestive of even a minor illness, such as a cough or a fever, may then trigger intense distress. Parents wonder whether the behaviour represents normal variability or whether it is a possible indicator that the disease has recurred or is progressing. No longer able to dismiss or normalise their concerns, they may worry excessively or seek immediate medical treatment.

Keywords and provocative questions:

The creation and reflection of reality are ultimately linked to language. Through language, knowledge, values, beliefs and expressions are constructed, modified, and reconstructed (Cohen, 1995). Parents of chronically ill children have the harsh reality of the unpredictability of their child's status periodically thrust into conscious awareness by the use of particular words and phrases that have become part of the medicalisation of survival. Terms such as 'high risk', 'remission' and 'long-term survivor' may be unprovocative to those in the health care professions; however, to many parents words such as these make explicit what they already know but would rather not think about -

that their child can never be considered cured nor can the child's continued survival be assured. Very early in the illness experience, parents come to appreciate the power that particular words such as 'high risk', 'remission' and 'long-term survivor' have in triggering heightened uncertainty. They frequently learn to communicate with professionals and other parents of ill children in a manner that minimises their response to the uncertainty of having an ill child (Cohen, 1995; Deford, 1983).

Nighttime:

Horwitz (1982) stated that 'Unbidden perceptual experience, so common in intrusive states after trauma, occur with highest intensity and frequency when the person is relaxing his or her control, as when lying down to sleep' (p.56). Although this study confirms that nighttime is the time when parents experience some of their most intense fears - the data suggests that these fears are triggered by the absence of distraction, rather than the relaxation of conscious control.

Horwitz (1982) presented these triggers with supporting data from parental interviews and autobiographical accounts, as a set of causes, contexts, conditions, and interactions that account for predictable variation in the intensity of parental awareness of uncertainty. It is highly likely that some of these triggers are culture-bound and that variation will be found in different cultural contexts, particularly in those societies more tolerant of uncertainty and ambiguity. The findings reported constitute one aspect of the grounded theory of living under conditions of sustained uncertainty for families who have a child with a chronic, life-threatening illness. The theory explicates the stages of the prediagnostic period and links the variation found in parental responses to the diagnosis and to the nature and duration of the uncertainty experienced during this time (Cohen, in press). It also describes the emergence of uncertainty from a unidimensional to a multidimensional source of parental stress (Cohen, 1993b) and explains how parents mitigate the stress caused by uncertainty by managing several interactive dimensions of daily family life (Cohen, 1993a). Awareness was one of the dimensions that emerged from the data. During periods when the disease was stable certain triggers (as discussed) predictably heightened parents' awareness of

uncertainty, causing them to experience increased distress despite the absence of an actual crisis. The notion of triggers is a conceptual category that is related to the more general concept of awareness and is integral to the theory of living under conditions of sustained uncertainty (Poole, 1980).

The above study generated a substantive theory that, although limited in scope, begins to explain and predict the emergence, sources, and management of parental uncertainty within the context of a chronic, life-threatening, childhood illness. The trajectory framework developed by Glaser & Strauss (in Cohen, 1995) offers theoretical perspectives for understanding the course of chronic illness that situates findings within a larger theoretical framework. The trajectory framework proposes that all chronic conditions follow an uncertain course that varies and changes over time, and that the course for a particular individual can only be seen (or graphed) retrospectively. It is a framework that affords 'insight' and understanding into the problems particular to chronicity (Corbin & Strauss, 1991).

The above study (Cohen, 1995) proposes that the uncertainty of the child's illness trajectory gives rise to sustained parental uncertainty. Uncertainty can also be understood within the trajectory framework as a second chronic condition situated within and dependent on the first. Cohen (1995) found that the parental trajectory has many commonalities among families, but each family's trajectory will also show variation from that of other families, some even providing examples of negative cases. For example, one family in the Cohen (1995) found visits to the doctor a confirming experience that they looked forward to every three months. The example mentioned is one of a negative case. However, factors related to negative cases have yet to be fully explored. For any family, the uncertainty trajectory can be expected to change over time, and like the illness trajectory, can only be seen in retrospect. For example, routine medical appointments may trigger less anxiety after a stable period of many years whereas new triggers, such as a fever, may cause heightened uncertainty if the child's condition has become less stable. The trajectories of chronic conditions can be shaped and managed and the symptoms or problems controlled to some extent (Corbin

& Strauss, 1991), as parents learn to manage their responses to uncertainty by trial and error learning, as well as by intentional acts. In fact, many parents who are aware of the seriousness of their child's illness and are trying to attain (or retain) some degree of family 'normality' by consciously controlling that awareness, are misunderstood by health professionals who mistakenly assess the family's behaviour as denial (Cohen, 1995).

Overholser and Fritz (1990) noted that unfortunately researchers have largely ignored the emotional and interpersonal consequences of childhood cancer. The diagnosis of cancer in a child is associated with a variety of persistent and pervasive stresses (Kalnins et al., 1980), disrupting the functioning of the entire family (Adams, 1978). When examining stress, one can identify both short term and long term effects. The short-term effects of the diagnosis of cancer in a child are obvious and severe, but the diagnosis also has an immediate and devastating impact on the family (Lansky, 1985; Lindamood & Wiley, 1983). The long-term effects are less clear and they seem to be subtle, yet they apparently continue even when the child survives. It is argued that knowing the long-term impact is vital to understanding the adaptation process involved in survivorhood (Overholser & Fritz, 1991). When examining the stress of cancer on the family at least three important domains of impact can be identified: personal distress, marital discord and financial burden.

These domains will be discussed accordingly.

Personal distress refers to the impact within the individual, which involves the emotional reactions typically experienced as a result of the child's illness - anxiety, depression, loneliness, helplessness and hopelessness (Overholser & Fritz, 1991).

Marital discord refers to the conflict between husband and wife that is triggered by the child's illness. A child's chronic illness often has a negative effect on the parents' marriage (Sabbeth & Leventhal, 1984). Some studies that have examined the impact of childhood cancer on marital functioning have relied on relatively gross measures such as statewide divorce rates (Overholser & Fritz, 1991). Consequently this has led to disagreement among some authors in that they argue that childhood cancer is

associated with increased divorce rates (Stehbens & Lascari, 1974), whereas others find no such increase (Overholser & Fritz, 1991). Peck (1979) even reported a tendency for the marriage to be strengthened by the experience of having a child with cancer. Such crude estimates of marital functioning may not be appropriate because marital problems do not always culminate in divorce and having a physically disabled child is not necessarily associated with higher rates of marital discord (Kazak, 1987). The financial burden is a pragmatic issue concerning the economic problems caused by the child's illness. The direct medical costs of treatment can become a major stressor for the family (Lansky, Black & Carns, 1982). In addition, indirect, non-medical costs such as food, transportation and (child-care) expenses incurred during the course of treatment aggravates the situation even further. With all these factors impinging on the system the couple might look elsewhere for support; this could include the extended family, the community or the church as other forms of support. However, if these external sources of support do not exist, this lack of support could be a stressor in itself.

Social Support - Stresses

When examining any stressor, one can identify variables that protect a person from the adverse effects of stress. Two important moderating variables have been discussed in the literature: social support and coping styles. Social support refers to the perceived availability of friends and family members to help a person cope with the stress, as the former can act as buffers against the onslaught of the stress. Although research on social support is not without problems the available evidence suggests that social support is associated with a reduced incidence of physical and psychological symptoms (Ganster & Victor, 1988; Wortman, 1984). Furthermore, social support (community, peer groups and so forth) may buffer the negative impact of stressful life events, thus protecting the person from the adverse effects of stress (Cohen & Wills, 1985). In relation to cancer, the availability of socially supportive relationships has been associated with better adjustment in parents of children who are in remission or in treatment for cancer (Overholser & Fritz, 1991).

Although families with a child who has cancer experience a variety of stresses (Kalnins et al., 1980), some authors believe that these families lack adequate social support, which makes it difficult for them to cope with the various stresses (Pearse, 1989). Although these results are inconclusive (Overholser & Fritz, 1991) they do point to the importance of social support for a family that is coping with a life-threatening illness (Quinn & Herndon, 1980). Furthermore, socially supportive interactions can help parents learn more effective ways of coping with their child's illness (Overholser & Fritz, 1991). Coping styles are the cognitive and behavioural response patterns used to manage life's problems. Researchers, such as Nir and Maslin (1981), have begun to emphasise the importance of individual and family coping styles in relation to medical and psychological treatments. These researchers Nir & Maslin (1981) have acknowledged the importance of information-seeking strategies in providing parents with a sense of control over the illness and its treatment. Nir and Maslin (1981) argue that such attempts at intellectual mastery or coping style may help to overcome the feelings of passivity and helplessness that parents commonly experience.

Psychosocial Adjustment

Although a number of investigators have begun to examine the effects of childhood cancer on the family, Overholser & Fritz (1991) have argued that no one has attempted to understand how family adjustment to cancer is related to psychosocial adjustment variables after successful treatment. In a quantitative study to assess the above, Overholser and Fritz (1991) found that coping styles during treatment can have important implications for the psychological and social functioning of both the child and the parents, long after the treatment ends. The fact that mastery scores were related to adaptive functioning in a variety of areas suggests that mastery and coping skills are vital to the psychosocial adjustment of families that are coping with chronic illness. Mastery implies active involvement and requires a sense of power and control that is not readily available to medical patients or their families (Nir and Maslin 1981). Earlier research has shown that maintaining a sense of control is important for the adjustment

of both children and parents coping with cancer (Overholser & Fritz, 1991). Parental mastery was significantly related to the long-term adjustment of both the parents and the child. Thus, the manner in which a family copes with the illness has a significant impact on the long-term outcomes of adjustment.

It has been argued that although the direction of the relationship cannot be inferred from a cross-sectional design, one can reasonably speculate about the causality (a linear construct) of various relationships. For example, personal strain caused by the child's illness apparently increases the parent's irritability and aggressiveness, which in turn may reduce the support received from family and friends. A downward spiral may come into play - that is, negative emotions make socialising more difficult, and problems with socialisation add to a parent's emotional distress. Conversely, an increased ability to establish and maintain socially supportive relationships should reduce a parent's reliance on a particular person for emotional support and reassurance.

A Family Phenomenon - Adaptation

A family with a child with leukaemia has to primarily face three problems:

- (a) The fear and sadness experienced secondary to the suffering, as well as the possibility of the child's death.
- (b) The family's limited abilities to satisfy all of the patient's needs.
- (c) The guilt feelings triggered by the disease.

The Circumplex Model of Marital and Family Systems (Olson, 1986) is among the theoretical frameworks predicting family adjustment to stressful life events. It incorporates two dimensions, that is, adaptability (the family system's flexibility and ability to change) and cohesion (the degree of emotional separateness or connection in a family) (McCubbin, 1990; Olson, 1986). Within the Circumplex Model of Marital and Family Systems it was thought that moderate degrees of adaptability and cohesion

were associated with better family functioning (Olson, 1986). Recent investigations suggests that cohesion and adaptability are related to individual family members' adjustment to chronic illness (Daniels, Miller, Billings & Moos, 1986; Fife et al., 1987). Therefore adaptability and cohesion may differ in families with an ill child (Kazak, Rebor & Snitzer, 1988).

For example, since the affected child demands a great deal of attention, his or her mother places her duties in relation to the rest of the family members on a rather secondary level. As a consequence, a rigid mother-child alliance is established which interferes with her spousal role, and the father, in turn, adopts a rigid attitude, becomes careless, and remains isolated from his wife (McCubbin, 1990). Inasmuch as their life as a couple is completely blocked or compromised they find it difficult to communicate their 'real' feelings to one another. On the other hand, the siblings may find it very difficult to express their feelings of rivalry and hostility toward the patient, the latter becomes the unique centre of attention in the family, and the parent's overprotection induces the patient's isolation from his or her brothers, sisters and friends (Olson, 1986). In other words, as soon as the diagnosis is known, the family undergoes a profound crisis that gives rise to a series of adaptive mechanisms. This may result in a functional adaptation by recognising (among other aspects) the real and painful nature of the child's disease. On the other hand, it can be a rather dysfunctional adaptation that will facilitate the family's breakdown and the appearance of ongoing symptoms in all family members. These observations evidence the important role of family therapists in the assistance of the child with leukaemia and his or her family. Accordingly a study by Horwitz and Kazak (1990) was undertaken to determine the nature of the changes in the structure and functioning of the leukaemic child's family, in order to propose clear goals in the therapeutic management of such families. In order to evaluate the family structure and organisation, an interview was arranged with the patient and one or both parents who accompanied the patient to the hospital. The interview encompassed a series of open-ended questions in an attempt to discover the family changes that occurred once the diagnosis of leukaemia became known.

The results of the above study suggest that the family of a leukaemic child reorganises its structure in a common diagnostic pattern, in which several changes were observed. First, there was a family tendency to isolate from the rest of the surrounding world, and the family limits became diffused with regard to the families-of-origin. In the process of this reorganisation, the paternal subsystem is invaded either by the maternal grandmother or by the oldest daughter (or son) to whom the parents have given authority over the rest of the children, and thus she (or he) becomes the 'parental child' (Horwitz & Kazak, 1990). The ill child is also included in the parental subsystem, and along with the mother acquires authority and a controlling position through his/her disease. Furthermore, the leukaemic child influences the couple's relationship, even in the intimate area of their lives, which may easily explain the increased rate of divorce after the child's death. It is important to point out that although all family members declared the existence of a feeling of togetherness, the individual limits did not disappear. On the contrary, these limits became closed and rigid. This was due to the fact that all the family members were locked up in their own thoughts of guilt, sadness and fear, and were absolutely unable to externalise their feelings (Horwitz & Kazak, 1990).

It is possible that the observed reorganisation might be present in any other type of family in which there exists a disease representing a serious threat to a child's life. Thus, these changes represent an example of a functional adaptive pattern. However, under various circumstances, this pattern may lose its functionality, become rigid and stereotyped, and consequently symptoms will appear. These circumstances include:

A possible explanation for the family's disintegration in two of the cases in the above study (Horwitz & Kazak, 1990), secondary to the disease, could be the accentuation of the already present conflicts among the parents as a consequence of the mother-child alliance, which implies an important separation between the parents. On the contrary, the establishment of this adaptive pattern could promote better family functionality when:

- There was an already marked family tendency to disengage prior to the disease.
- The mother or the patient had a rather peripheral and/or low hierarchical position.
- The parents had a symbiotic relationship.

The psychotherapeutic goals should be directed towards the avoidance of rigidity in this adaptive pattern, thus facilitating the displacement of the family structure towards better levels of functionality (Minuchin, 1974). The literature concerning the impact on the family of having a child with leukaemia has focused to a great extent on the dual issues of how parents cope with their child's illness and on the measures which can be instituted to help them come to terms with their child's potential death. It has been recognised that leukaemia has pervasive effects on all family members and on many aspects of family functioning. This stretches from the time of diagnosis until well after the child's death (as well as survivorhood). Some studies have found that parents of leukaemic children complain of a variety of somatic problems including fatigue, insomnia and lack of appetite (Lascari & Stenbens, 1993). McCarthy (1995) noted that just over a third of a sample of 64 mothers of a leukaemic child were receiving mild tranquilizers, anti-depressants or sleeping tablets. This then prompted the question - is having a child with cancer experienced as a post-traumatic event for parents? The following represents the investigation into such questions.

Post-traumatic Investigation

Although the prognosis of most childhood cancers has improved dramatically in the past 20 years, pediatric malignancy continues to be life-threatening. The diagnosis and treatment of leukaemia is widely understood to be emotionally, as well as physically stressful for children and their families, although studies still report controversial answers to the question of how long the emotional sequelae persists. The figure below is a family systems model of post-traumatic stress response to childhood cancer. A descriptive explanation follows:

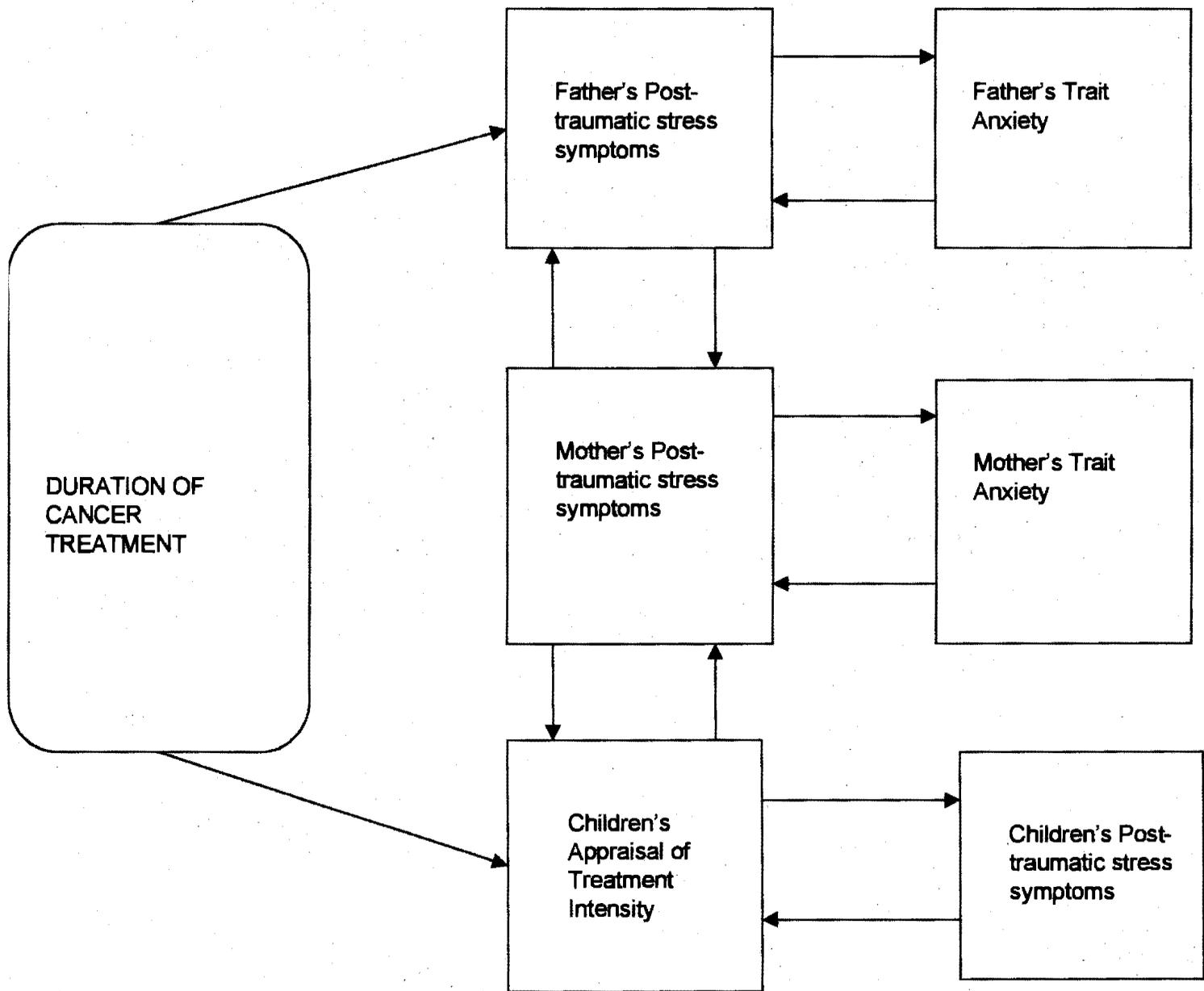


Figure 2: A family systems model of post traumatic stress response to childhood cancer. Adapted from Stuber, Gonzalez & Menke (in Stuber, 1995, p.96)

Recent studies on childhood cancer survivors and their parents suggests that childhood cancer diagnosis and treatment might be better understood as traumatic, rather than merely stressful, with the potential to precipitate symptoms of post-traumatic stress in pediatric patients and their parents. Furthermore, there is evidence that the traumatic response of children and their parents may be interactive, with the mothers' responses influencing the interpretation children make of events, and the children's responses influencing the mothers' responses (a reciprocal process of interaction). This would be consistent with the concept of family responsivity detailed in the theoretical model of family interaction described by Stuber (1995). In this study (Stuber, 1995) embarked on answering several questions:

The first question asked was, whether or not pediatric cancer is a traumatic event.

In using the criteria set out by the medical model, specifically the DSM IV, it was found that the experience of cancer is an extremely traumatic event. The actual diagnosis and treatment is experienced as the traumatic event. Perhaps the most interesting point is that these initial studies suggest that parents are at far greater risk of long-term post-traumatic symptoms than are the pediatric cancer survivors.

The second question asked was, what is the traumatic event.

The data described by Stuber (1995) supported the general concept that *something* about pediatric cancer is traumatic for children and their parents. The assumption in the DSM IV is that it is the diagnosis and the threat of a life-threatening illness is what constitutes the trauma. However, this is not as clear as one might initially think. There are several studies suggesting that, at least for children, the treatment may be more traumatic than the diagnosis. By combining the verbal and non-verbal responses of pediatric patients, it was found that many children did not appear to appreciate the severity of the threat to their lives while undergoing active treatment for cancer. A substantial number of children viewed the treatment as more difficult than the actual threat to life.

The third question asked was, what are the interactional responses.

Children, particularly younger children, often look to their parents to determine how to judge a situation. Parents in turn can be expected to respond to their children's behaviour, particularly distress or pain, as well as to their own appraisal of a situation. One would expect, therefore, to find a complex set of interactions in the way in which parents and their children respond to the cancer experience.

One way of interpreting these findings is that the more anxious mothers are, the more likely it is that they will respond to the diagnosis and treatment in ways that lead to deeper appraisal of the intensity of treatment for their children and greater symptomatology for themselves (Stuber, 1995). That is, the mother's ability to interpret the event is partially dependent on her general level of anxiety, and her presentation of the event will influence the child's appraisal of the event. The child may therefore mirror the mother's behaviour.

In turn, the child's response to the event (for example pain and/or fear) will have an impact on the mother's acute and possibly long-term response to the event. Thus, there is a feedback loop in which the mother's anxiety, the child's appraisal and the mother's response interact. It appears clear that there is a significant interaction between the child and the mother. This interaction lends itself to the concepts of interdependence, circularity and reciprocity. In the above study (Stuber, 1995) the role of the father is less clear. It is possible that the father may serve some sort of modulating function for the mother, as well as responding to her distress. Therefore, Stuber's (1995) study concluded that the response of families to pediatric cancer appears to be an interactive process in which the child's response and parent's responses shape one another. Stuber (1995) suggests that further research is needed in this area of interaction between family members within the context of leukaemia. However, part of this process could be that parents tend to blame each other or seek other causal attributions for their child's illness.

Causal Attributes

Pediatric cancer patients and their parents often attribute causes to cancer despite the fact that physicians tell them the cause is unknown. Rolland (1987) speaks of an internal locus of control and an external locus of control by which parents and patients attribute causes of the illness.

An internal attribution of the cause of the illness is biological/physiological in nature (no control over the illness), whereas an external attribution of the cause of the illness is given to external factors such as bad nutrition (control over the illness).

According to Attribution Theory (Kelley, 1967) people search for reasons for the occurrence of events that threaten or change their status. These kinds of causal attributions are motivated by efforts to understand and make sense of events and thus to cope emotionally and to gain some sense of control. Therefore, causal attributions are an important means of understanding the early stages of people's adjustment processes, particularly in cases of serious and life-threatening illnesses. As threats from the illness increase in severity, patients have an increasing need to fabricate beliefs about the reasons for their illness. Furthermore, the irrationality of their beliefs increases in direct proportion to the seriousness of the illness (Bearison, Sadow, Granowetter & Winkel, 1993). Stoekle and Barsky (1980) defined the causal attribution of illness as reflecting both 'the cognitive processes by which an individual arrives at an explanatory belief and also ... the explanation itself' (p.224). Because the meaning(s) that patients construct for their illness affect how they respond to it psychologically (Bearison et al., 1993), physicians intuitively use their patients' attributions as a way of understanding the patients' adjustment and ability to cope with their illness (Katz, 1984).

Thirty years ago, when the etiologies of most cancers were unknown, many adult cancer patients blamed themselves or others for their illness and interpreted the illness as a form of punishment (Abrams & Finesinger, 1953; Bard & Dyk, 1956; Chedoff et al., 1964). Because childhood cancers have unknown etiologies, we could expect

children and their parents to make similar kinds of causal attributions. Chedoff et al., (1964) found that parents of children with cancer were placated by explanations based on self-blame or blaming others because that was a way for them to avoid the intolerable conclusion that no one is responsible for their child's illness (cancer). Children who have cancer also struggle to make sense of the cause of their illness. According to Bearison et al. (1993) children who do not question why they have cancer are denying, to varying extents, the emotional impact of the disease. Because questions such as Why me? have no answer, how children resolve them is a marker of their ability to adjust to the chronic uncertainties of the illness and its treatment (Katz, 1984).

Because making a causal attribution about a life-threatening and uncertain condition such as cancer is a means of coping with the illness, Bearison et al. (1993) hypothesised that:

- Causal attributions would be significantly associated with other means of coping - that external types of attributions would be related to more positive kinds of coping and internal ones would be related to less positive kinds of coping.
- Not making a causal attribution would be associated with more positive kinds of coping because it would reflect the acceptance of the physician's statement that the cause of cancer is unknown.
- In cases where there is a match between children and their parents according to whether they make the same causal attribution, both would cope more adaptively than would mis-matched children and parents, who make different causal attributions.

The differential findings in support of external versus internal kinds of causal attributions are consistent with general causal attribution theory. This means that individuals maintain their self-esteem by attributing positive achievements to internal

factors and negative events to external factors (Snyder, Stephan & Rosenfeld, 1978; Whitley & Frisze, 1985; Zuckerman, 1979). Because a cancer diagnosis is a negative event, attributing its cause to external factors is consistent with maintaining the patient's self-esteem.

Internal attributions, which typically reflect a sense of guilt and self-blame, correlate with the patients' difficulty in accepting the diagnosis and facing the uncertainties of treatment. Furthermore, to the extent that patients attribute the cause of their illness to internal factors, they unrealistically assume responsibility for the progress and outcome of their treatment, which in turn exacerbates their fears associated with medical uncertainties. In contrast, externalising the cause is more consistent with a patient's need to trust the medical staff for treatment and outcome. In other words, an external cause for cancer is more consistent in form with the mode of treatment.

At first glance the above findings may indicate a greater need for physicians to monitor their patients' understanding of medical conditions, and thus monitor the patients' misconceptions. Patients and parents who made external types of causal attributions coped significantly better than did patients and parents who, consistent with the physician's counsel, made no causal attributions. Physicians might be wise to be cautious about disabusing patients with irrational notions about the causes of their cancer.

The Biopsychosocial model will now be considered as an alternative reflecting stance in viewing chronic illness.

Biopsychosocial Model

The above literature review demonstrates that research in the area of childhood leukaemia is fragmented, in that very seldom, if at all, the entire family system is considered. Other factors such as the social context, biological factors and the psychological effects of the illness on the entire family have not been considered as an interactive whole. In this regard McDaniel et al. (1992) have been instrumental in the

research of chronic illnesses. Medical family therapy (McDaniel et al., 1992) is a systems approach to psychotherapy with patients and families experiencing a medical illness, trauma, or disability. The aforementioned model uses biopsychosocial systems theory (Doherty, Baird & Becker, 1987) to interweave biomedical and psychosocial factors into the fabric of chronic illness. Close attention is paid to medical illness and the role that illness plays in the emotional life of the patient and interpersonal dynamics of the family (McDaniel, Mikesell & Lusteran, 1995). The cornerstone objectives of all medical family therapy are to promote agency and communion. Increasing agency means increasing a patient's and family's sense of effectiveness in managing the illness and other aspects of their lives. Communion refers to the need to attend to the communicational and emotional bonds that can be frayed by the challenges of pain and illness. McDaniel et al. (1992, p.213-215) identified several issues especially pertinent in the case of childhood illnesses.

Parental guilt

Since parents see themselves as their children's protectors in life, they often feel personally responsible in some way for their child's illness. This guilt may be demoralising for parents and may show itself in anger against other family members, or against health professionals for their failure to cure the child.

Grief over losing 'normal' childhoods and imagined futures

When family members realise that the illness is chronic, which means, it is here to stay, they mourn at having to relinquish their dream of having a healthy child. When this grief begins at the child's birth, as in the case of many genetic disorders, it can complicate the process of bonding with the ill child. When family members realise that the illness will limit the child's life expectancy or the child's quality of life as an adult, there is additional grieving and anger over being cheated out of future hopes and plans.

Fear of 'contagion'

Because of fear and ignorance, other parents, even relatives, may avoid the child and family out of fear of the child's severe illness (such as cancer). They fear that somehow the ill child will contaminate their child.

Developmental issues

Depending on the child's developmental position, the timing of the onset and exacerbations of a chronic illness can have serious long-term implications. The illness or how it is handled by the family can 'freeze' a child developmentally. Just as with individual development, expected family transitions can be delayed or stopped by a childhood illness. Transitions that occur normally for other families, such as a child leaving home, can become excruciating decisions for parents with a chronically ill child.

Vulnerability to health professionals

Parents experience a unique vulnerability to perceived criticism or lack of support from health professionals, who have the task of keeping the child alive and as healthy as possible. This vulnerability occurs particularly in chronic disorders such as cystic fibrosis and diabetes, in which parental actions and supervision frequently show measurable results in the child's condition. When parents are sometimes held accountable for poor outcomes, they feel as if they are being told that they are bad parents.

According to McDaniel et al. (1992) research on childhood chronic illness is limited or minimal particularly on how family interaction affects biological activity in children. Many research studies have associated marital conflict with behavioural adjustment problems in children (McDaniel et al., 1992). Gottman and Katz (1989) state that health-related physiological processes in children are shown to be linked to the

quality of the parental relationship. This relationship was found when they investigated the effects of marital discord on four-to-five-year old childrens' physiological health, physiological arousal, stress-related hormones and peer relationships. Using complex laboratory procedures to assess marital and family interaction, along with a variety of physiological measures, the researchers (Gottman & Katz, 1989) found the following: Children of maritally distressed couples have higher levels of chronic stress (as indexed by high levels of stress-related hormones in their urine), higher levels of illness (as reported by mothers) and higher levels of physiological arousal (as measured during the laboratory interaction tasks). According to McDaniel et al. (1992) this study was significant in that it demonstrated that health-related physiological processes in children were shown to be linked to the quality of the parental relationship.

There is mounting evidence for the linkage between certain family interaction processes and children's physical well-being as well as psychological well-being. The original psychosomatic family model stimulated much useful clinical work and some subsequent research and theoretical development in this area.

Chronic childhood illness can tip the balance toward the side of the demands - physical, emotional, social, financial - leaving the family's resources and capabilities depleted and inadequate. The family then goes into crisis and must find a way to rebalance itself (McDaniel et al., 1992). Because chronic childhood illness can unbalance families in many areas, a therapist working with subsystems in the family can be invaluable (McDaniel, Campbell & Seaburn, 1990). As with any childhood health problem, the more severe and disabling the disorder, the more stress on the family.

McDaniel et al. (1992) highlights several important aspects of working with families when the chronically ill family member is a child. The following table illustrates the special assessment issues in childhood chronic illness.

Table 1: *Special assessment issues in childhood chronic illness*

McDaniel, Hepworth & Doherty, (1992, p.220-225)

<p>What beliefs and meanings do family members bring to the child's health problems?</p>	<p>The health beliefs of the parents, grandparents, other relatives and close friends may also be important factors for the family. Similarly, the splits and controversies in beliefs among family members are important.</p>
<p>Has the child's illness become part of dysfunctional triangles in the family?</p>	<p>Sometimes the child's illness becomes part of dysfunctional triangles in the family. These triangles may take the form of detouring, in which parents retain their unity by focussing on the child, or cross-generational coalitions, in which one parent forms an alliance with the child against the other parent.</p>
<p>How are other relationships being attended to?</p>	<p>The most common interaction family difficulties in childhood chronic illness begins when one parent usually the mother becomes the main caregiver for the child. As the father or other adults become more disengaged over time from the mother-child dyad, other relationships in the family-marital, father-child, parents-to other child, extended family, friendships - begin to erode.</p>
<p>How are the siblings functioning?</p>	<p>Siblings are often the neglected figures in the families of chronically ill children. Siblings are often kept out of the information loop in the family</p>

	(Seligman, 1988).
What part of the problem is developmental and what part is illness-related?	A problem may have both developmental and illness-related components. Children with chronic illness are naturally going to challenge their limitations and their medical regimen from time to time. Sometimes the illness is just the playing field for a normal, but irksome, family struggle.
How are the parents relating to health professionals?	When a family has a member with a chronic illness, the family also has a 'chronic' relationship with health professionals: both are part of the family's life more or less forever. Parents feel particularly vulnerable to – and may resent – non-supportive behaviour from health professionals. The situation becomes even more difficult when parents triangulate medical staff into their family conflicts.
How supportive is the family's social support network?	Ultimately, children are raised not just by their parents but by an extended support network of family, friends, neighbourhood, school, church and community. Raising a chronically ill child is so difficult for most parents that their support network must be active and committed.

McDaniel et al. (1992) points out that what they have learned since the 1970's is that childrens' health is biologically, as well as psychosocially, part of their family relationships. Childrens' bodies, like all of our bodies, are tuned to the resonance of family rhythms and when something goes wrong with their bodies, the reverberations

penetrate deep into the consciousness of families and health professionals alike.

Other aspects of the medical family therapy/biopsychosocial model will be discussed in Chapter 3.

Conclusion

Research in the area of chronic illness, particularly that of childhood leukaemia has covered many aspects of the disease. However, the body of literature is so vast and beyond the scope of this dissertation. The above review contains aspects of research in the field of childhood leukaemia that the researcher has deemed important. These aspects range from the biomedical explanation of leukaemia, the leukaemic child, the sibling(s), parental adaptation, causal attributes for illness, leukaemia as a family phenomenon to, finally, a biopsychosocial/medical family therapy explanation of chronic illness. These various areas of study with the exception of the biopsychosocial model, have been somewhat limited in their view of illness in that very little emphasis is placed on the processes of the illness in relation to other contexts such as the social context, family and the illness (biological) context.

Existing research on families and health includes (minimal) consideration of the illness, the family system and the dynamic interface between the two. Although sound research exists on the impact of childhood chronic illness on families (as indicated in the above literature review), particularly from the health psychology literature (Kazak & Nachman, 1991), family research is yet in the early stages of development with regard to chronic illness. If both disease and family are understood as complex - fluid systems, then it may be fruitful to examine, not the disease per se, but aspects of its co-evolution with the family system.

The following chapter discusses ecosystemic epistemology (the theoretical foundation for this study and the point of departure for the researcher). Some pertinent cybernetic concepts will be discussed with an emphasis on second-order cybernetics.

An ecosystemic conceptualisation of childhood leukaemia will be provided within the context of a co-evolutionary, constructivist approach.

CHAPTER 3

ECOSYSTEMIC EPISTEMOLOGY

Introduction

Some tools of thought are so blunt that they are almost useless; others are so sharp that they are dangerous. But the wise man will have the use of both kinds (Bateson, 1979, p.34).

This chapter will provide a description of the ecosystemic approach followed by a discussion of some of the key principles of second-order cybernetics, representing an alternative worldview. Before concluding the chapter, an ecosystemic conceptualisation of childhood leukaemia will be furnished. Other theoretical perspectives such as the Biopsychosocial model, Anderson and Goolishian's Problem-determined model, the Psychosomatic model and Co-evolutionary model will also be discussed.

The Dominant Worldview De-throned

It is important to note that during the 20th century, revolutionary trends in physics - specifically, Einstein's relativity theory and quantum theory - highlighted the limitations of Newtonian science in understanding complex phenomena. For instance, the observation that light may appear as electromagnetic waves or as particles depending on how it is observed, made uncertain the classical assumptions of objectivity and the reality of matter (Capra, 1983). A discussion of the discoveries and assumptions of quantum physics is beyond the scope of this dissertation. What is important to note is that quantum physics led to a dramatic revision of our concepts of reality, destabilising the very foundations of traditional thought. The result was the emergence of a radically

different worldview which, while not necessarily negating Newtonian thinking, nevertheless captures the essential interdependence of all phenomena and can be described through words like 'organic, holistic and ecological' (Capra, 1983, P.66).

Traditionally, psychology was concerned with those elements of the old science that allowed for traits of pathologies to be viewed as real, measurable and predictable. Within this view, temporal reality suggested that there was a clear linear relationship between two events that occurred sequentially in time. An acceptance of this linearity justified the focussing on singular events in time and space and the attribution to those events of causal power. Truth and its discovery, then, became a viable option for the observer. This epistemological stance led to what Keeney (1979) called 'psychiatric nomenclature' (p.118) and the classical medical model of psychopathology. Efforts to explain symptomatic behaviour have usually been based on either a medical or psychodynamic model. The former attributes emotional or mental distress to a biological malfunction or illness. Within this domain treatment milieu the focus consists of finding an etiology of the so-called illness (a typical linear construct) and then instituting a treatment, such as drug therapy. These two models (medical and psychodynamic) typically see symptoms as a malfunction arising either from biological or physiological causes (medical perspective) or from a repressed event in the past (psychodynamic perspective). In both these models the individual is the locus of the malfunction. Therefore, treatment regarding the integration of other systems was not considered.

In the case of living systems such as in the family it is not possible to assign cause-and-effect factors or place any linear markers at all. As Bateson stated:

A brain does not think. What thinks is a brain inside a man who is part of larger systems residing in balance within their environment. What thinks is a total circuit (in Hoffman, 1981, p.8).

As Bateson (1979) stated: the shift from a single person treatment to a multiple person treatment unit 'brings with it a new epistemology and ontology, that is a new way of thinking...' (p.242). The fundamental change is from interpreting behaviour from linear cause-and-effect sequences to conceptualising behaviour as resulting from a reciprocal causal system of interaction. In a reciprocal causal cycle each person's behaviour both influences and is influenced by the behaviour of others in the system. Within this cycle a person's thoughts, feelings, attitudes, communication patterns (i.e. verbal and non-verbal) and behaviour are reflexive and organised often without the participant's awareness. Because of his epistemological stance, Bateson (1979) could not conceive of pathology in terms of the traditional medical model. The focus widened to include the context within which the pathologist (for example, doctor/oncologist) and individual (client/patient) behaved. This wider focus also included parts of families or even the whole family. Hoffman (1981) argues that in the context of the family and its existing relationships, one would see something quite different. One would see communications and behaviours from everybody present, composing many circular loops that played back and forth, with the behaviour of the afflicted person only part of a larger recursive dance. The Newtonian view would see causality as linear forces acting unidirectionally upon things.

This movement encouraged by Bateson led to a description of pathology, not an explanation of it. The focus was on the context of pathology and in so doing it introduced the concepts of interrelatedness, wholeness and patterned events that implied a sense of movement. When descriptions of causality moved into the realm of circularity, to the extent that 'any view of reality was only a punctuation of uninterrupted sequences of interchanges' (Watzlawick, Beavin & Jackson, 1967, p.54), the notion of uncertainty became even more prominent. Due to the arbitrary nature of punctuation as a description of the reality experienced by the observer, this uncertainty was further intensified by the complexity of the context onto which the punctuation was imposed. The context was a recursive-patterned picture with no beginning or end. This led to seeing human behaviour no longer as statistically measurable, but as a living system. According to Le Roux (1987, p.6) 'living systems are permanently in a state of flux'. A

system does not necessarily have a fixed status; essentially the designation of a system is a distinction drawn by the observer. As a prelude to the rest of the chapter(s) let us consider the following scenario.

'The knife slips, there is a small cut, a bandage is applied, healing takes place.

What is the illness?

A question that often appears simple to answer and is at other times bewilderingly complex:

All as it was before. Or is it? Is there a tiny scar? No matter! But it's on the face. Still no matter. But she's a young girl. Ah! well then, too little context has been provided for the story to be satisfying' (Auerswald, 1985, p.267).

On several occasions we sense that *something* is wrong with the story, the wound fails to heal or we hear that this is the third accident she has had this month. In these instances we might have the disturbing feeling that the boundaries of the phenomena were incorrectly drawn, that is, they were not sufficiently inclusive. The correct boundaries in space do not adhere to the events, which after all are chosen (languaged) by the storyteller; rather, we choose what story to tell by our purposes in relation to it. The emergency-room team, the police investigators and the psychiatrist all elicit and tell different stories about the stab wound. More elegantly, it can be said that they construct different realities (Bloch, 1987).

Once again, what is the illness? How are we to define its extension in space and time? The initial role of the non-blaming ecological detective will be used to define the above. In the words of Auerswald (1985), 'the initial task in this context, is to seek out and identify the ecological event-shape in the space that includes the situation that led the family to issue a distress call' (p.279).

The term ecological event-shape is used to describe a virtual space, which is the universe of all possible elements that could be included in a problem-defined system. It is infinite and unknowable; out there as it were, where mystery resides. Partial knowing through language is the activity of the non-blaming ecological detective which leads to the construction of one among many possible realities, the problem-generated or problem-defined system (Auerswald, 1985). The problem-defined system (corresponding to the term 'situation' in the Auerswald definition) is a languaged event; that is, it lies within the space of the event-shape, always includes the observing system and is to be parsimoniously defined.

In the language of biological evolution we could say that the target pattern (illness) modifies its context (the family) to form a relational pattern (ecological niche). This is referred to as the portable reality (Bloch, 1987). It is of course equally valid to say that the family relational pattern modifies the illness pattern. This represents a circular or reciprocal pattern of interaction between the family and the illness. The choice, of which is to be considered the target pattern and which is to be considered the context, rests with the purpose of the observing system.

How then should a system and its context be demarcated from all else? How should systems be demarcated from each other? And how should they be connected to each other? This in fact constitutes a single question that acknowledges two kinds of distinctions: between what is within a system and outside of it and between the components that evoke a system. Gertrude Stein may be quoted on this subject: when she was asked, it is said, on the occasion of viewing a California scene, if she was 'borne over there', her reply was there is no there over there (in Bloch, 1987, p.281). What we choose to call context is arbitrary. Therefore, the disease in the body as context reflects our viewing stance.

We may at this point set forth the co-evolutionary perspective in the form of an axiom. To the extent that an illness is chronic, it must change elements of its context

in the direction that will reduce any discrepancy (improve the 'fit') between the illness behaviour (target system) and the context. The context is then the evolving factor. Over time as the disease pattern takes on meaning for the family, repetition and the frequency with which it occurs are critical for establishing a stable (chronic) pattern. It can be argued that nothing is exactly repeated, as there is always some degree of changing fit between the elements of a pattern under consideration. It is precisely in this regard that an important additional element of chronicity enters into the system. The target pattern in this case (leukaemia) is recruited into maintaining the stability of other systems or subsystems.

Ecosystemic Epistemology: A Paradigm of Pattern

The shift in scientific thinking introduced by the revolutionary discoveries of quantum physics is mirrored in the ecosystemic paradigm. In contrast to the Newtonian emphasis on linear causality and subject/object dualism, the ecosystemic approach attunes itself to holism, relationship, complexity and contextual interrelatedness since it is a conceptual framework based on systems theory, cybernetics and ecology (Keeney & Sprenkle, 1982).

Capra (1983) defines a system as '... an integrated whole whose properties cannot be reduced to those of its parts' (p.266). Thus, general systems theory emphasises a shift from focussing on the parts to viewing the whole system. 'Cybernetics,' a term coined in the 1940's by mathematician Norbert Wiener, refers to the 'science of control and information feedback in systems' (Loos & Epstein, 1989, p.153). According to Keeney (1983a, p.61), 'cybernetics' refers to the science of pattern and organisation which is distinct from any search for material, things, force and energy as associated with classical science.

As an alternative epistemology to conventional ways of knowing, the ecosystemic paradigm proposes a communicational/mental world of abstract 'ideas' and

their relations. Bateson (in Keeney, 1983b, p.47) points out that communication events are 'triggered by difference'. Thus, for instance, the difference between what an employee receives for a promotion (no increase in salary) and what he expected to receive (an increase in salary) may prompt him to interact (differently) with his employer. A difference, therefore, entails a relationship of change between two parts. Accordingly, communicational events, or information, can only be understood and described using conceptual tools that highlight process, pattern, relationship and form (Keeney, 1983a).

Like ideas, pattern and form have no 'realness' and thus cannot be discussed as though they do; neither can they be quantified (Keeney & Sprenkle, 1982). The ecosystemic approach developed from the study of families, as opposed to individuals, in the context of socio-cultural systems (Auerswald, 1985). Researchers including Bateson and Jackson conceptualised an individual's behaviour and symptoms as related to the family's organisation (Anderson, Goolishian & Winderman, 1986) through recursive feedback processes. Subsequently the family therapy movement emerged from this theoretical position with its own distinctive language, one in which cybernetic concepts served as elegant metaphors for understanding family processes in a systems framework that preceded seeking the truth, insight, causal factors, or intrinsic forces (Anderson & Goolishian, 1987; Doherty, 1991).

Some of the cybernetic concepts that this researcher deems particularly pertinent to an ecosystemic epistemology will now be discussed, followed by a discussion of other theoretical perspectives.

Feedback

'Feedback refers to the process whereby information about past behaviours is fed back into the system in a circular manner' (Becvar & Becvar, 1996, p.64). In early cybernetic thinking the family was regarded as a closed system feeding information back on itself in the form of a symptom. This was viewed as a control mechanism or

governor in a cybernetic loop of mutual causality and circularity which prevented change by conserving family stability, role and relationship definition (Anderson & Goolishian, 1987; Anderson et al., 1986). At the level of simple or first-order cybernetics (to be defined later) both positive and negative feedback processes are said to occur. Whilst negative feedback opposes change-producing fluctuations in a system, thereby preserving the status quo, positive feedback is an error-activated process that introduces systemic alterations (Becvar & Becvar, 1996). These feedback processes or self-corrective mechanisms are assumed to inhere in all families, providing stability for the whole family organisation (Keeney, 1983a).

The assumption that a symptom served a homeostatic function was associated with a first-order cybernetics viewpoint. This notion was later rejected by Bateson (in Loos & Epstein, 1989) as a reductionistic flaw in that it emphasised only one part of a recursive interaction, or whole circuit, which excluded the participation of the observer (Atkinson & Heath, 1990; Hoffman, 1985; Keeney, 1982). In other words, at the level of first-order cybernetics, the system is considered analogous to a black box with input and output relations, and the observer (in a separate black box) remains outside of it (Becvar & Becvar, 1996). The black box view of systems articulates a lower-order of recursive process, one in which the outsider is seen as being able to observe the system objectively and to unilaterally control or manipulate it (Atkinson & Heath, 1990; Keeney, 1983a).

Keeney (1983a) points out that feedback processes are hierarchically (recursively) arranged in complex systems so that while simple feedback maintains the symptom in a family, higher-order feedback (feedback of feedback) preserves this lower order recursive process. Higher-order feedback is associated with a second-order cybernetics viewpoint (to be defined below).

Recursion

In cybernetic epistemology the emphasis is on reciprocity and recursion. Whole

systems are organised in a circular or recursive fashion where every part interacts with every other part. Consequently, individuals and events are viewed in the context of their bi-directional interactions and reciprocal influence (Becvar & Becvar, 1996). In this regard, Bateson (1972, 1979) defines a cybernetic circuit as a recursive linkage of difference which is transformed by information or 'news of difference' (i.e. 'a difference which makes a difference') (Keeney, 1983b, p.47). A consequence of this recursiveness is that information can redundantly inform (inform or loop back on) itself in a circuit, which creates what Bateson (1972) calls 'ideas'.

Relationship/Double Description

Two individuals interacting together mutually influence one another, each punctuating the flow of interaction from his/her frame of reference. When the views of both members are combined, however, a pattern that connects them emerges giving an impression of the whole interactive system (Keeney, 1983a). According to Bateson (in Keeney & Roos, 1992), a systemic view of human interaction can only be discerned from multiple descriptions. In this regard, Bateson (1979, p.146) notes that:

**It is correct to begin to think of the two parties
to the interaction as two eyes, each giving
a monocular view of what goes on, and together
giving a binocular view in depth.
This double view is the relationship.**

Therefore, to preserve a sense of the whole, it is essential that our descriptions do not dissect interactions into parts (Keeney, 1983b; Keeney & Sprenkle, 1982). Bateson (in Keeney, 1983a) argues that to speak as if a relationship is located in one person is to create a 'dormitive principle'. For example, to describe someone as dependent is to fractionate a description of the relationship by isolating and reifying some 'characteristic' with assumed residence 'inside' one of the parties to an interaction (Keeney, 1983a). The ramifications of this perspective for viewing symptoms are

significant, for when one widens the lens to focus on the matrix of ongoing relationship patterns; the assumption that the individual contains pathological processes disappears, along with blame and cause-effect thinking.

Context

One of the fundamental assumptions of the systemic orientation alluded to thus far, is that phenomena do not have an invariant existence but rather can take on different forms depending on the context against which they are viewed (Bopp & Weeks, 1984). Context is linked to meaning and in a communication world, words and actions - indeed all mental processes - derive their meaning from the network of relationships or context in which they occur (Bateson, 1979). Thus, this study assumes that the experience of the illness called leukaemia can be understood and transformed only by considering and working with the social context in which leukaemia occurs.

The epistemological leap from describing human behaviour as predictable to describing it as uncertain, certainly necessitated the application of models of behaviour that could accommodate this shift. The first of these models (first and second-order cybernetics), drawn from the sciences and technology, followed an evolutionary course that mirrored the developments within the family therapy field (Fasser, 1989). The following theoretical models are used to describe (somatic) symptoms as communications. Therefore, there is no focus on the etiology of diseases or symptoms. This means that there are no implications that the symptoms are caused mainly or exclusively either by psychological, social or by biological factors, but rather that the symptoms are a result of a combination of these factors (Fourie, 1995).

Second-Order Cybernetics

This model was adopted as an advance on the simple cybernetic model, as it introduced the concept of the observing system. The basic concern over the disadvantages of applying a first-order approach to human phenomena was that 'it

failed to prescribe higher-order punctuations that connect the therapist or observer to the client or the observed' (Keeney, 1983a, p.153). This limitation carries the potential danger that the observer may attempt to purposefully control the observed system (Atkinson & Heath, 1990; Keeney, 1983a).

Von Foerster (1984), when proposing the idea of the observing system, questioned the prevailing attitude toward science and its claim of objectivity. Second-order cybernetics focused on 'non-pathologising' explanations of so-called dysfunction. Auerswald (1969) proposed such a non-linear, non-pathologising paradigm when he wrote of an 'ecological epistemology'. Von Foerster (in Hoffman, 1992) reveals that from a cybernetics of cybernetics or second-order cybernetics perspective, the therapist is inextricably a part of the system under observation - a central premise of constructivism (Golann, 1987, 1988). Thus, a second-order, constructivist perspective removes the dualism between observer and observed so that the two separate black boxes become one whole recursive system (Keeney, 1983a) with the emphasis falling on the observing system (Boscolo, Cecchin, Hoffman & Penn, 1987; Golann, 1987). One of the implications of shifting to a second-order 'observing system' perspective is that it is no longer possible to observe and describe a system objectively as if it exists 'out there' because as Keeney (in Loos & Epstein, 1989) tells us, the act of observing complex situations, alters the observed as well as the observer. This perspective stems from early findings in quantum physics that indicated that observation and description do not occur independently of the observer's construction processes (Fourie, 1996a). Indeed, description is assumed very often to reveal more about the observer than about the system being observed (Golann, 1987; Loos & Epstein, 1989).

Before discussing the concepts of second-order cybernetics, constructivism will be defined more fully.

Constructivism

'Constructivism means that all knowledge of the world is the result of our own constructing, ordering, inventing, languaging, creating, constituting processes, and not the result of our discovery of how the world really is' (Held, 1990, p.180). In short, it is

impossible to observe reality as it is - assuming that a stable reality exists. Instead reality is invented (Watzlawick, 1984) through the individual's ability to create mental images (Howard, 1991). For example, a brain does not function like a camera, carrying pictures of the objects we 'perceive' but rather, generates ideas about objects, ideas which are by the perceiver's existing attributions of meaning and idiosyncratic ways of experiencing von Glasersfeld (in Watzlawick, 1984). Nevertheless, because the individual is unaware of his act of creation, she/he experiences the world as something that exists 'out there' (Watzlawick, 1984).

The relation of constructivism to ecosystemic thinking will be highlighted further in the following discussion of some of the most important concepts of second-order cybernetics.

Autonomy

From this second-order-perspective, systems are autonomous, because they alone determine their own actions (Hoffman, 1990; Varela, 1979). Because human system are autonomous and organisationally and informationally closed (Dell, 1985), the perceived (i.e. what we 'see' in a system, such as interactions between and among elements in a system) can only exist as ideas (Fourie, 1993). According to a second-order-perspective, if a system loses its autonomy, it is destroyed as a system. Therefore, it will always strive to conserve its autonomy. From this perspective, then, symptoms reflect ideas about the conservation of autonomy. One should remember that conservation of autonomy is only an idea of the observer and not a concrete reality (Fourie, 1993). The second-order concept of the conservation of autonomy can be used to consider any symptom.

Conservation of autonomy is a general concept; systems have idiosyncratic ways in which such conservation can be seen to be attempted (Fourie, 1993). Therefore, conservation of autonomy manifests itself differently with different families and with different people. Different symptoms convey different general ideas by virtue of their particular way of manifestation and the characteristic responses to them from

other members of the system (Fourie, 1993). Therefore, the second-order-view is that, in coupling structurally, two (or more) living systems autonomously attribute to each other's actions certain meanings. To say that systems are viewed as autonomous is not to say that they are seen as isolated. Rather, the second-order-view is that, in coupling structurally, the one system perturbs the other (i.e. they are in contact), but the meaning ascribed by the particular system (i.e. the one that was 'bumped') to the perturbation by the other, is considered as generated autonomously by that system (Fourie, 1995). Therefore, in second-order cybernetics, our interactions with a system represent 'perturbations' rather than 'inputs' to remind us that our behaviour cannot be 'instructive' (Anderson et al., 1986; Becvar & Becvar, 1996; Keeney, 1983a; Keeney & Sprenkle, 1982). If a system (e.g. a family) compensates, it will change its structure but its organisation or identity (as a family) will remain invariant (Keeney, 1983a; Keeney & Sprenkle, 1982), otherwise it will cease to function as a system (as already mentioned).

A system's highest order of feedback control regulates and maintains its autonomy (Keeney, 1983a). In speaking about autonomy, therefore, first-order terms such as 'homeostasis', 'feedback', 'circular organisation' and 'change' are replaced with notions such as feedback of the system's own feedback, homeostasis of homeostasis, and change of change (Keeney & Sprenkle, 1982).

Self-reference

Since systems are recursively organised with every part interacting with every other part, the whole cybernetic system interacts with itself and is, therefore, a self-referential system (Keeney, 1983a, 1983b). In other words, living systems recursively feed upon themselves (Keeney, 1983a) and, since they can only be described to be informationally and organisationally closed (Dell, 1985), behaviour, according to this second-order cybernetic perspective, is a product of the interactions among the components of the system (i.e. a function of the system's internal structure) serving to conserve the organisation of the system (Griffith, Griffith & Slovik, 1990).

Structure-Determinism and Structural Coupling

In the last decade or so, systems thinking has changed from a focus on interaction within families to what is often called second-order cybernetics (Fourie, 1993). In this newer mode of thinking, systems are seen as self-regulating and informationally closed (Fourie, 1993). This means that a system's behaviour is determined solely by its structure, that is, by the way it is put together, and not by any outside influences or interaction (Efran & Lukens, 1985; Maturana, 1975, 1991). Whereas outside influences might perturb the system, the way the system would respond is determined not by the perturbation, but by the system's own structure (Keeney, 1982). If two (or more) structure-determined systems get together from a second-order perspective they are considered to be unable to influence one another directly. But in their reciprocal perturbation they are conceptualised as coupling structurally to form a larger composite system, which can then in turn be seen as self-organised (Maturana, 1975; Maturana & Varela, 1987). Their structural coupling can take place only through the exchange of ideas (Anderson and Goolishian, 1988).

However, structure-determined systems have to be considered as influential in space and time (in the past this was especially so for communities as opposed to biological units). They also existed in a medium made up of other structure-determined systems. The mutual influence between the systems could be considered as the fit that existed between them. When the systems interacted or fitted in a way that was mutually satisfying then they could be described as structurally coupled. This fit or structural coupling ensured the survival of the system in that medium. When the structural coupling was inadequate and there was no fit, the system died. Seeing that living systems are considered to couple through both verbal and non-verbal communication, (somatic) symptoms can be viewed as communication about the conservation of the system's autonomy in the face of a perceived threat (such as an illness - in this case leukaemia).

An important point to note is that the notion of structural coupling prevents constructivism from being mistaken for a solipsist 'anything goes' approach whereby all (constructed) realities are considered equally valid. As von Foerster (in Hoffman, 1985, p.384) points out, reality is a 'consistent frame of reference for at least two observers'. Thus, notwithstanding the impression that is sometimes created, constructivism does not postulate that all realities are equally legitimate or useful.

Our ideas about the world are largely shared ideas, shaped by culture and language (Hoffman, 1985), even though each individual creates a slightly different reality according to his or her own unique biological make-up, experiences, attitudes, etcetera (Becvar & Becvar, 1996). This means that the validity of a particular reality is determined by the way it fits with the beliefs, attributions, and presuppositions etcetera, of the people participating in its co-creation (Fourie, 1996a).

When the aforementioned ideas are extended to the domain of therapy and research, one realises that (1) therapist/researchers are unable to describe any therapeutic/research situation without including themselves in the description; (2) 'different couplings cause different, but compatible, worlds to emerge' (Elkaim, 1990, p.69). Therefore, if the constructions co-created by members of the therapeutic system present a solution to a problem, it simply means that they happened to fit with the ideas and meaning systems of those members. In other words a consensus was co-created and not that the therapist found the right solution/answer (Elkaim, 1990).

Language and the Construction of Meaning

Language, the one unique behaviour that human structurally-determined systems employed, facilitated structural coupling. It allowed contact to be generated between disparate systems, and thereby the building of what Maturana called a consensual domain (Le Roux, 1987, p.49). The consensual domain described, for the systems, an illusion of reality. Language, therefore, allowed human systems to 'share the medium (which includes self and others simultaneously within which the

perceptions occur' (Le Roux, 1987, p.47).

Within this medium every system was both observer and observed, both object and subject. Inherent in this way of seeing the organisation of living things was the relative nature of truth and reality. As stated at the beginning of this section on second-order cybernetics, the inclusion of the observer as an integral part of the system made the acceptance of an objective reality in the tradition of Newtonian Science impossible. It thereby increased the uncertainty introduced by the adoption of a new science epistemology.

Using the above concepts, a conceptualisation of childhood leukaemia will be furnished. It is an attempt to show the links/connections within the leukaemia context.

An Ecosystemic Conceptualisation of Childhood Leukaemia

In contrast to the traditional assumption that problems reside within the individual, ecosystemic thinking conceptualises leukaemia as a problem that exists in a network of meanings constructed by those persons who interact around the issue (Griffith et al., 1990). In coherence with the notion of structural coupling, leukaemia is an indicator of the sufferer's 'ecology of relationship-s' (Keeney, 1983a, p.124). In this sense, 'the symptom, though physical, acquires a 'symbolic' significance that expands from individual symbol to become a family metaphor' (Onnis, 1993, p.142).

Seeing that it is a physical symptom frequently accompanied by intense pain and discomfort, it may sound nonsensical to argue that leukaemia, like any other problem, is a constructed reality existing only in language (Anderson & Goolishian, 1987). However, without detracting from the perceived realness of the pain, or the possibility of an underlying pathophysiological contributor, the ecosystemic perspective argues that the participants involved in the illness experience, including the sufferer and those individuals who have to deal with his/her discomfort, inadvertently perpetuate the problem by the story they co-create about it (Griffith et al., 1990). This story contains

their private explanations about the way mind and body communicates to produce the leukaemia. As such, it substantiates and organises the symptoms as well as everyone's behaviour in relation to the problem (Griffith et al., 1990; Sluzki, 1981, 1992). As Sluzki (1981, p.275) puts it: 'symptom-maintaining patterns... ensure family rituals and routines, they introduce order, they become cherished markers of collective identity'.

According to the ecosystemic perspective leukaemia is not regarded as existing in a system, individual or otherwise - or even in social objectivity (Hoffman, 1985). In this regard, Anderson et al. (1986) refer to problem-determined systems. A problem-determined system is defined by those individuals who actively communicate (or try to communicate) about something that is a problem for them, regardless of whether their ideas, beliefs, perceptions and experiences about the issue and its solutions concur (Anderson & Goolishian, 1987; Anderson et al., 1986; Loos & Epstein, 1989).

When the conceptual lenses are widened to include members of the larger system, it becomes clear that they too are afflicted by the sufferer's symptoms (Onnis, 1993), and that the story they construct provides them with a sense of meaning about the problem. However, it also restricts them from perceiving events which do not fit with their beliefs and attributions, preventing the emergence of alternative ideas, problem-solving behaviours and patterns of interaction (Griffith et al., 1990). In other words the, the leukaemia becomes stable and chronic as the discourse around it coalesces. This is compatible with Keeney's (1983a) argument that pathology is 'a sort of escalating sameness' which results from 'a system's effort to maximise or minimise a particular behaviour or experience' (p.123). What is the reason for a system maximising or minimising a certain behaviour? The answer can be found in the concept of autonomy which, as was pointed out earlier, must be conserved to ensure a system's survival. This brings us to Fourie's (1996b, p.56) contention that symptoms are 'communications about the conservation of autonomy in the face of perceived threat'.

Every behaviour can be regarded as a system's attempt to conserve its

autonomy or identity. According to Fourie (1996b), symptomatic behaviour represents an extreme attempt by a system to preserve its life as a system. Fourie (1996a) further argues that the autonomy which sufferers of somatic disorders (and their families) attempt to conserve in verbal and non-verbal language can be viewed as an ambivalent one. In terms of this theory, therefore, chronic illness can be regarded as linguistic expressions of the ambivalence or conflicting discourses in which the sufferer and members of his/her social context participate(s).

At this point in the dissertation, it is necessary to expand on how leukaemia and its context become intertwined and evolve together.

A Co-evolutionary Approach

The ecosystemic approach encapsulates a co-evolutionary model, in which systems are viewed as continuously changing in unpredictable and non-linear ways. This perspective is succinctly expressed through Ilya Prigogine's concept of 'order out of chaos' (Anderson et al., 1986). According to this theory, a system experiences fluctuations around its range of stability. At any point in time, a fluctuation may become amplified, surpassing the system's existing threshold of stability and pushing it into a new dynamic range of functioning. According to Prigogine, Nicolis and Babloyantz (in Dell & Goolishian, 1981) and Prigogine and Stengers (in Anderson et al., 1986), many paths of change are available to the system as it becomes unstable, the direction chosen being determined by chance. The ramification of this evolutionary process, according to Prigogine et al. (in Dell & Goolishian, 1981), are that one cannot control or predict when or how the system will be reorganised; one can only 'bump' the system in the direction of instability by 'perturbing it'.

In this evolutionary systems model, symptoms are conceptualised as a 'critical point of instability' (Onnis, 1993, p.142) which can signal an opportune moment for a system to grow toward new and more complex levels of organisation. However, this optimistic view of symptoms is tempered somewhat in the case of chronic problems, for

→ Yes, I agree. There are people who come from warm home environments, but still has problems. I don't really agree with the 79 Jack that one individual's symptom is an indication that the whole system is unstable

if symptoms are enduring, it means they have successfully modified the context in such a way as to improve their fit with the wider system (Bloch, 1987). Bloch (1987) explains that at its onset, a chronic problem may represent a random, destabilising event that is relatively uncoupled with its context, and thus has little meaning for the family system. Over time, however, as the symptoms recur they become anchored to, and take on meaning for, the family, the individual, and/or the health-care systems. In turn a consensual domain develops, the symptomatic pattern is repeated; the process is recursive. Thus, the problem and aspects of it (for instance, the conflicting discourses in which family members participate) co-evolve together, changing each other and improving their mutual fit over time so that a self-maintaining pattern (in this case, leukaemia) forms (Bloch, 1987). As a result, symptomatic patterns may endure even though the original context no longer exists (Sluzki, 1981). In maintaining the view of interconnectedness and holism the biopsychosocial model will be discussed.

The Biopsychosocial Model

The biomedical model, which accounts for disease by means of biochemical factors without considering social or psychological dimensions, separates mind from body (Engel, 1977, 1992). Biomedical practitioners tend to ignore the person who has the disease (McDaniel et al., 1992). It was this separation of biological elements of disease from the person that led Engel (1977) to propose the psychosocial contexts in which disease occurred. The biopsychosocial model acknowledged the hierarchical, interdependent relationships of biological, psychological, individual and family systems. According to this perspective multiple levels of systems are affected simultaneously. The description of isomorphism across the hierarchical levels urged a systemic understanding of the relationship between the biological and social spheres (Engel, 1980). The biopsychosocial model was therefore presented as a framework for understanding how psychophysiological responses to life interact with somatic factors. In Whitaker and Malone's early writings, a biopsychosocial model, although not termed as such, provided the theoretical basis for the science of psychotherapy. Any change in a part of the organism, regardless of whether the change occurs in the province of

the physiological, genetic, chemical or psychological, results in changes which affect every other aspect of the total organism. The dynamic continuity between these different levels of integration means that 'any change in a lower level will result in corresponding changes in higher levels, and vice versa' (McDaniel et al., 1992, p.18).

The fundamental tenet is that all human problems are biopsychosocial systems problems. 'There are no psychosocial problems without biological features and no biomedical problems without psychosocial features' (McDaniel et al., 1992, p.26). This is indicative of the recursive relationship that exists between and among events. Nowhere is this more evident than in the treatment of somatising patients and their families (McDaniel et al., 1992). The biopsychosocial model postulates that there is a language component involved in communication that manifests itself as a symptom. The language used to construct problems, identifies, and relationships is a language of the body. Rather than using emotional language to express emotional distress within the system, somatic language is used to describe all difficulties, whether emotional or physical (McDaniel et al., 1992). The role that illness plays in the emotional life of the patient and the resulting interpersonal dynamics are of importance (Bloch, 1988). The biopsychosocial systems model allows clinicians to avoid the trap of 'somatic fixation', which is prevalent among patients, and 'psychosocial fixation', which is common in psychotherapy (McDaniel, Campbell & Seaburn, 1989). Somatic fixation is embedded in our beliefs and cultural language that dichotomise the constructs of mind and body (McDaniel et al., 1989). Either kind of fixation reduces a complex problem to its physical or its emotional components; this Cartesian mind-body split is what the biopsychosocial model tries to integrate with the tenets of systems theory (Bakan, 1969).

Language and Experience

The language of somatisation is part of a life-long coping style that functions like a chronic illness; it ebbs and flows, depending on other physical and emotional stresses and strains (McDaniel et al., 1995). The legitimacy of any emotional language

is strongly denied as a means of describing a problem(s) (Kellner, 1990). Some family cultures lack any language for emotional expression (McDaniel et al., 1995). Children in these families receive attention for physical pain but not for emotional pain. This approach conditions members in the system to experience any need or problem as physical, and physical symptoms become their language for a range of experiences (McDaniel et al., 1995). The problem is then expressed as non-verbal communication in the form of a symptom (McDaniel et al., 1995). Families with this means of expression share patterns of interaction that seek to anaesthetise emotional pain. In this regard the language of bodily discomfort is spoken. Cartesian dualism pervades the language and the meanings used to describe illness experiences. The notion that a physical symptom must have a primarily organic cause, or that an emotional feeling is primarily determined by psychological experience, is widely accepted in our society (McDaniel et al., 1995). The idea that mind and body are an integrated, related, communicating whole has only recently and tentatively been considered (Kellner, 1990). Meanwhile the members of a family system continue to live at the centre of the mind-body split. They find themselves in distress and this is further compounded by the fact that we do not understand them.

Social/Problem-Determined Systems

Anderson and Goolishian (1988) maintain 'that communication and discourse define social organisation and that reality is a product of changing dialogue' (p.378). Maturana and Varela (1987) hold that there is no information exchange in communication, but that humans communicate according to how they are structured, and not according to the social organisation in which they are embedded.

Anderson and Goolishian (1988) postulate that our very acts in language create the objects of our worlds; that is, through language a co-created world is brought forth. From this notion Anderson and Goolishian (1988) infer that the organisation and structure of a system are the result of dialogical exchange. In other words, this points

to the fact that social organisation is the result of communication, which is in contrast to earlier beliefs that communication is a product of social organisation. The work of Anderson and Goolishian (1988) is therefore premised on an understanding of systems as not existing in an external, unilaterally determined social reality, but as existing in language interaction and in 'the rhetoric and metaphorical narrative of our theories' (p.379).

In the light of this, one is required to look beyond systems that are predefined on the basis of social role/structure and to look rather at systems that are in 'active linguistic coupling' (Anderson & Goolishian, 1988, p.379). The implication of this epistemological stance is that languaging about problems makes systems, and that it is not systems that make problems. Gadamer (1975) borrowed the notion of the 'infinity of the unsaid' from Lipps, who stated that any linguistic account carries with it a 'circle of the unexpressed' (Anderson & Goolishian, 1988, p.380). Therefore, every communicative action carries with it unspoken meanings, and possible new interpretations that need to be expressed and articulated. Since all communicative actions can be seen to encompass infinite sources of possible new expressions and meanings, therapy as a 'problem-dissolving system' (Anderson & Goolishian, 1988, p.379) was defined as:

A process of expanding and saying the 'unsaid' - the development, through dialogue, of new themes and narratives and, actually, the creation of new histories. Therapy relies on the infinite resources of the 'not-yet-said' in the narratives around which we organise ourselves in our conduct with each other. This resource is in the 'circle of the unexpressed.

Language Systems and the Construction of Meaning

The emerging sense of communication as language systems has at its core the belief that reality is a social construction by means of language. By language we do not mean the sounds that we make with our mouths, or the marks we make with our

pens but, rather, the role of language in determining meaning (Maturana, 1978; Ryle, 1949; Wittgenstein, 1963), and in the function of language as a form of social participation influenced by history and culture (Gergen, 1985; Watzlawick, 1984). Therefore, the essence of language (words) is derived from the added dimension of meaningfulness. Anderson and Goolishian (1987) argue that only in language is there that identity we call meaning. Language can only take on meaning in human action and, therefore, meaning is interactional, is local in nature, and is always changing. Human systems are language systems and, simultaneously, meaning-generated systems.

Meaning and understanding are socially and inter-subjectively constructed (Anderson & Goolishian, 1988). By inter-subjective it is meant that reference is made to an evolving state of affairs, in which two or more people agree that they are experiencing the same event in the same way (Anderson & Goolishian, 1988). This indicates that there is consensus around the problem. The problem is then maintained through this consensual domain, through the medium of words and other communicative actions, such as the expression of a symptom. When people are struggling with each other it is not surprising that they will have multiple opinions, resulting in distinct and different descriptions of 'the problem' (Anderson & Goolishian, 1988).

The Newtonian era presented with a belief of a 'truth'; however, moving from certainty to uncertainty implies that there is no universal validity to meaning. The notion of meaning in any system can therefore be viewed as a co-construction between one or more parties. Human systems can then be viewed as meaning-generating systems. Language is viewed as interactional coordination, the dialogical creation of inter-subjectivity (Anderson & Goolishian, 1988). It is sometimes difficult to remember that language is not simply a convenient picture of the world. It is more as La Rouchefoucauld (in Lacan, 1968) has said, 'We could not experience love as we do if we had not learned to talk of love' (p.85). Language is therefore the transformation of experience, and at the same time it transforms what we can experience. In this sense,

language both modifies, and is modified, by experience (Anderson & Goolishian, 1987). Auerswald (1987) pointed out that every event is a language-event. There is therefore a multiplicity of languages, histories, causes, understandings and realities. Gergen (1985) has pointed out that the identifications of any given action (human exchange) are subject to infinite revision. This process is without limit and never ending.

We essentially live our lives in terms of our interpretations, our attributions of meaning. These attributions are, in the final analysis, no more than linguistic inventories that name the things we take to be real and identify the objects that can populate our realities. We create our realities through naming (identifying objects) and then taking action based on these identifications (Anderson et al., 1986). It is the taking of action that makes our realities interactive and communal. Given this, problems are no more than a socially created reality that is sustained by behaviour mutually coordinated in language. Problems are then a reflection of a particular meaning that arises inter-subjectively, between persons engaged in discourse around those meanings for which there is alarmed concern and a concurrent insistence on a change that is not forthcoming. As Wittgenstein (1963) has indicated, words can be thought of as pieces of a game, a game that we play with each other - a form of linguistic activity. For Braten (1987) this activity is located in the dialogue of perspectives in and between individuals, within the reality they create and in which they exist. In this view, meaning and reality are inter-subjective and evolve from dialogue with oneself and others.

In light of these views, the participants' ideas and beliefs about their experience with a leukaemic child will be dialogically co-created in this study through the epistemological lenses of both the researcher and her research participants.

Problem-determined Systems

The problem-determined system may be an individual, a couple, a family or any combination of individuals who are communicatively interactive, and organised around

a shared languaged problem. A problem-determined system is defined on the basis of discursive interaction (Anderson et al., 1986). According to Anderson and Goolishian (1987), the social system is distinguished by the problem and is constituted by those who are languaging about the problem. Thus, the problem defines or distinguishes the system; the system as determined by social organisation does not distinguish the problem. These are called problem-determined systems; and they exist only in language.

Membership of the problem-determined system

Membership of a problem system includes all who are languaging about that which is thought to be a problem; that is, all individuals who are actively involved in communicative interaction form the membership of the problem-determined system. This communication is expressed in a verbal or non-verbal manner. The core feature of such problem-determined systems is a signal of distress by an observer about what a significant person is doing, saying or thinking (Anderson et al., 1986). The communicated implication of such distress is a demand for a change in how someone is behaving, thinking or feeling. The discourse of the observer and the observed around this issue forms the ecology of ideas which define the membership of the communicating system. Membership in these problem-determined systems can overlap different social structures and is not to be defined on the basis of social structures. Problem-determined systems may be formed through communications based on relationships of loyalty and kinship, such as families (Anderson & Goolishian, 1988).

The problem-determined system is defined by the fact that there is a problem, not by the fact that there is a consensus around the problem or its solution. Therefore, each member has his or her own linguistic reality about the problem (there may be some consensus among some members, but not necessarily among all) (Anderson & Goolishian, 1987). It is important to note that although consensual domains denote consensus about certain matters, agreement is not necessarily forthcoming; nor are consensual domains static, since ideas and actions are continually evolving through

ongoing reciprocal perturbations within the system. Therefore, seeing that living systems are considered to couple through verbal and non-verbal communication, symptoms can be viewed as communications about the conservation of autonomy, as mentioned by Fourie (1995).

Psychosomatic Model

General systems theory proposes principles of structure, process and organisation as primary factors influencing the functioning of biological and social systems (Buckley, 1968; Von Bertalanffy, 1969). The biological factors were addressed by positing disease activity as being interactive with family patterns (Wood, 1994). Minuchin's (1974) structural family therapy model followed suit, defining family structure as the invisible set of functional demands that organises the ways in which family members interact. Repeated transactions establish patterns of how, when, and to whom to relate (Minuchin, 1974, p.51). The key organising concept in this family model is the construct of (boundary), defined as 'the rules determining who participates when, and how' (p.82). The structure of the family is governed by two general principles. The first principle holds that families everywhere have some sort of hierarchical structure according to which parents have greater authority than children do. An important aspect of this perspective is the notion of reciprocity and complementarity (Friesan, 1995). Accordingly, if there is an overly competent parent in a family, the other parent may be described as incompetent. Thus, each quality is therefore a complement to the other.

The pioneering contribution to family systems and medical issues was Minuchin, Rosman & Baker's (1978) psychosomatic family model. This model is based on structural family theory, and clinical and research observations of families of children with uncontrolled childhood diabetes, for which organic explanations had been ruled out. Minuchin et al. (1978) proposed that psychosomatic families characterise patterns

of enmeshment, overprotection, rigidity, poor conflict resolution and triangulation of the child. Wood (1992) later found support for some elements of the psychosomatic family model, particularly triangulation and marital dysfunction, in accounting for disease activity in children with chronic disease. Although this model has sometimes been misunderstood to imply that family patterns cause disease, the psychosomatic family model posits a circular process whereby family patterns and disease mutually maintain each other (Wood, 1992). It capitalises on the multi-level feature of system constructs in order to integrate individual biological, psychosocial and family levels into a heuristic theory of pathways, by which family patterns of interaction, and individual family members' physiological function, influence one another (Wood, 1994).

None of the above characteristics alone seemed sufficient to spark and reinforce psychosomatic symptoms. But the cluster of transactional patterns was felt to be characteristic of a family process that encourages somatisation. The four family characteristics, as mentioned above are enmeshment, overprotectiveness, rigidity, and lack of conflict resolution. These concepts will be discussed accordingly.

'Enmeshment refers to an extreme form of proximity and intensity in family interactions' (Minuchin et al., 1978, p.112). It has implications at all levels: family, subsystems and the individual. Individuals get lost in the system of the enmeshed family. The boundaries that define individual autonomy are so weak that functioning in individually differentiated ways is radically handicapped.

The overprotectiveness of the psychosomatic family shows in the high degree of concern of family members for each other's welfare. This concern is not limited to the identified patient or to the area of illness. Nurturing and protective responses are constantly elicited and supplied. Family members are hypersensitive to signs of distress, covering the approach of dangerous levels of tension or conflict.

Rigidity in these families is seen as maintaining the status quo. In periods when change and growth are necessary, the family experiences great difficulty. The

accustomed methods of interaction are retained.

The rigidity and overprotectiveness of the psychosomatic family system, combined with the constant mutual impingement characteristic of pathologically enmeshed transactional patterns, make such families' thresholds for conflict very low. Each psychosomatic family's idiosyncratic structure and functioning dictate its way of avoiding conflict. Many psychosomatic families deny the existence of any problems because they are highly invested in consensus and harmony, while others disagree openly, but constant interruptions and subject changes obfuscate any conflictual issue(s) before it is brought to salience (Minuchin et al., 1978).

These are the four general structural and functional characteristics which have been identified as typical of families with psychosomatic children. However, while they are descriptive of a stress-inducing family context for a vulnerable child, the identification of these characteristics by themselves only falls within a linear explanation. The observation of the circularity of feedback necessitated a move to a new order of explanation.

Viewed from a transactional point of view, the patient's symptom acquired new significance as a regulator in the family system. Within the psychosomatic family context, the symptomatic child is involved in parental conflict in particular ways (Minuchin et al., 1978). This factor, then, is the fifth characteristic of a psychosomatic family. The effectiveness of the symptom bearer in regulating the internal stability of the family reinforces both the continuation of the symptoms and the peculiar aspects of the family organisation in which it emerged.

Therapy based on this framework is directed toward changing the organisation of the family. The family is an open system in transformation; that is, it constantly receives and sends inputs to and from the extra-familial, and it adapts to the different demands of the developmental stages it faces (Minuchin et al., 1978). Minuchin et al. (1978) argues that a scheme based on viewing the family as a system, operating within

specific social contexts, has three components:

The structure of the family is that of an open system in transformation.

The family undergoes development, moving through a number of stages that required restructuring. The family adapts to changed circumstances so as to maintain continuity and enhance the psychosocial growth of each member (in Wood, 1994, p.55).

According to this model a family is a system that operates through transactional patterns. Repeated transactions establish patterns of how, when and to whom to relate, and these patterns underpin the system. These repeated operations constitute a transactional pattern (Minuchin et al., 1978). Thus, the system maintains itself. It offers resistance to change beyond a certain range, and maintains preferred patterns as long as possible. The family structure must be able to adapt when circumstances change. Further, it must be able to transform itself in ways that meet new circumstances, without losing the continuity that provides a frame of reference for its members.

The family system differentiates and carries out its functions through subsystems. In this model subsystems can be formed by generation, by sex, by interest, or by function. The following are concepts that the researcher deems important.

Boundaries

The boundaries of a subsystem are the rules defining who participates, and how. The function of boundaries is to protect the differentiation of the system. Boundaries can be defined as disengaged (inappropriately rigid boundaries), clear boundaries (normal range), and enmeshed boundaries (diffuse boundaries). Boundary, in general system terms, is the concept that refers to the differentiation of subsystems according to the nature of their interaction (Simon, 1962). The idea of subsystems in this model

includes:

The spouse subsystem

The spouse subsystem is formed when two adults of the opposite sex join with the express purpose of forming a family.

The parental subsystem

A new level of family formation is reached with the birth of a child.

Sibling subsystem

The sibling subsystem is the first social laboratory in which children can experiment with peer relationships. Within this context children support, isolate, scapegoat, and learn from each other.

Hoffman (1981) states that the above delineation/process seems very logical and very simple, as though one began by saying, 'What are the organisational characteristics of a family?' The assumption underlying this model is that a symptom is a product of a dysfunctional family system, and that if the family organisation becomes more 'normal' the symptom will automatically disappear. Minuchin's conceptual framework owes much to systems theory; yet it leans very little on the cybernetic paradigm (Hoffman, 1981).

Coalitions and Binding Interactions

Penn (1983) postulated that the epistemology of organisation we call 'family' closely followed Bateson's construct of a 'pattern through time', meaning that members of a family form relationships with one another over the generations, and that these relationships are specific patterns identifiable to that family. Through time, these

relationships shift, as the context of the family changes, and the pattern modifies, expands, entertains new options, or holds fast. Continuation, perseverance, the familiarity of their pattern are the expectations families hold for their future together, but like people who live in a town that is constructed on a fault in the earth, they never anticipate an earthquake. Neither do families foresee or include a debilitating or chronic illness in their future. When it occurs, the natural changing of their pattern of relationships is interrupted, if not frozen in place.

Alternatively, a change in family structure - as when a child leaves home - may 'attract' an illness which interferes with the leaving process (Penn, 1983). Some relationships are bound to change, others may not (Penn, 1983).

It is as though the quake tears a fissure in the earth, separating the family from its familiar ground, its pattern. Families with chronic illness are extremely resistant to change (Penn, 1983). These families were observed to have two distinct coalition configurations surrounding the families, as well as within the families (Penn, 1983). The expected coalitions form inside the family (parent and child); however, due to the permeable boundaries of a family with chronic illness, coalitions also occur outside the family dynamics between a family member and a member(s) of what has been called 'the referring context'.

Coalitions inside the family

Haley (1963) has described coalitions in pathological systems as those which cross generational boundaries and are denied or kept secret. In families with chronic illness, a different kind of coalition is observed. These coalitions cross generation boundaries but are not denied or kept secret in the usual sense. In fact, they look adaptational, that is, directed by the demands of the illness. However, they are frequently fastened by the nuclear family by means of a special set of interactional events around illnesses in the past which, until the present illness, have been folded darkly away.

The difference between what Haley (1963) describes and the coalition 'pairing' in families with chronic illness is that in these families there is an open transaction for the parent and child alliance - it does not have to become covert since the system is not considered pathological; there is no secrecy, no disqualification of meaning, and the parents do not change sides as they do in pathological systems. The family both sees and does not see the other attachment, the other coalition, as though it were a blind spot in an otherwise intact visual field.

The coalition in the nuclear family looks open and adaptational, but is fuelled by coalitions in the past, which, though not secret, are totally divorced from the family's understanding of their present dilemma. As the system presses to continue on its evolutionary course, the family may seek treatment, though not around the illness they have endured, but around the behavioural problems that resulted - marital distress, role reversals and so forth. The nature of this period is that the system tries to do both - to move on and to stand still, to maintain the old structure while plotting a renewed course. At this point one could say that the illness had recovered but the family had not.

Generational Patterns and Binding Interactions

It is important to understand the generational patterns in the family around illness, for it is there that the parenting couple has learned the values, expectations and meaning which illness holds. Since each parent comes from a different family, these meanings may be discrepant and, if they remain unstated, the present dilemma is underscored by the couple's learned differences around illness.

Binding Interactions

A particular form of binding interaction exists in families with chronic illness (Penn, 1983). Certainly the illness has the potential to supply a negative context which the family feels helpless to change. When change is anticipated it is usually negative

change, death or further deterioration. To introduce the possibility of another change of any sort, especially a structural one like the dissolution of a coalition, increases the family's resistance and serves to reinforce the present, albeit painful structure. Penn (1983) has called these interactions around coalitions 'binding' because they are rigidly committed to one course and one outcome; it is as though the characters in the sequence are literally bound together.

Conclusion

We live in a universe in which causal trains endure, survive through time, only if they are recursive. They survive - that is, literally live upon themselves (Bateson, 1972). Bateson isolates two particular villains: one is linear thinking, which appears to assign a cause and often ends up assigning blame. The scientific tradition of reductionism has led us to understand ourselves as separate, autonomous individuals made up of parts that are themselves separate and autonomous. This separatist attitude regarding mind and body has led to an apparently erroneous understanding of our role in our physical health. The second villain is any form of dualism. The context of childhood cancer is not solely biochemical. It is also personal and familial. Feedback then occurs among all parts of the system, that is, the child's body, the child's personal self, and the family that makes these levels interdependent (Minnix, 1987).

↳ I'm sceptical to agree that cancer has something to do with family interactions... genes atleast.

The above models have been an attempt to demonstrate this interdependence and recursiveness among all elements within the system. However, a further element has been considered: the researcher's involvement in drawing distinctions in the system under investigation. The following chapter is an account of the methodology used by the researcher in the acquisition of information for tracking the family process over a period, within the context of leukaemia.

CHAPTER 4

RESEARCH PLAN

Introduction

Stories reveal how people punctuate their world and therefore provide a clue for discovering their epistemological premises (Mischler, 1986, p.263).

**Stories are habituations. We live in and through stories.
They conjure worlds. We do not know the world other than
as a story world. Stories inform life. They hold us together
and keep us open**

(Howard, 1991, p. 192).

Traditional Cartesian - Newtonian epistemology has formed the bedrock of developments within the behavioural sciences. One classic example is the Cartesian split between mind and body which, since its incorporation into Western thought, has produced numerous theories and research projects concerned with hypotheses about mind and body interaction, and generally aimed at identifying which causes which (Colapinto, 1979). However, the issues relating to the behavioural sciences are so complex that despite the wealth of 'empirical evidence' that has been amassed in these disciplines, paradigmatic agreement remains elusive (Auerswald, 1985). 'The epistemological "cracks" remain not only in the form of unexplained phenomena, but also between the plethora of paradigms' (Auerswald, 1985, p.5).

The approach to childhood leukaemia by the conventional models of illness has proved no exception, as reviewed in Chapter 2. In that chapter, the mind-body dualism is

reflected in the numerous narrowly defined perspectives in which the conceptual 'whole' is reduced into its putative constituent elements. The result of this conceptual fragmentation is a lack of consensus as to whether mind or body takes causal precedence, a perpetuation of the 'body is machine' notion, and a concomitant failure to treat the whole person (Capra, 1983). In sum, an inadequate understanding of how to address the problem of childhood leukaemia exists.

The present dissertation describes the problem of childhood leukaemia from an ecosystemic perspective, using a qualitative rather than a quantitative methodology. Since it is a unifying conceptual framework which emphasises contextual and attributional factors, an ecosystemic perspective not only provides a reconceptualisation of childhood leukaemia, but also espouses a view of science that is incompatible with many of the assumptions underlying the positivistic scientific methods of the traditional Western paradigm (Hoffman, 1990).

The main feature of quantitative and qualitative research will now be compared briefly in order to elucidate the rationale for the use of a qualitative methodology in this dissertation.

Quantitative versus Qualitative Research

According to Selvini - Palazzoli's idea (1989, p.86) that 'human beings are qualitatively different from a cell and the family is qualitatively different from an organism' a movement away from the hard sciences was indicated. In this regard the methodology of the natural sciences could no longer suffice.

Qualitative research differs fundamentally from conventional quantitative methods in its conceptions about 'reality', 'truth', 'knowledge' and 'objectivity'. Rooted in positivism, quantitative approaches insist on unequivocal knowledge, based on the assumption that

reality can be discovered (Atkinson & Heath, 1987, 1991; Fourie 1996; Hoffman, 1990; Lincoln & Guba, 1985; Shapiro, 1986).

Positivism severely constrains the possible uses or purposes of science, to prediction and control. Indeed, what is often called the pragmatic criteria of success in science is that it should lead to increasingly successful prediction and control. To attain an accurate map of reality, quantitative research is a method-centered undertaking designed to either support or reject postulated hypotheses.

Accordingly, stringent efforts are made to remove every aspect of subjectivity and researcher's bias from the inquiry since it is believed that values are distinct from facts and will only contaminate the data (Atkinson & Heath, 1987; Lincoln & Guba, 1985; Shapiro, 1986). Moreover, to be able to measure the data so as to arrive at an unequivocal outcome reflecting the 'truth', the intricate complexities of social relationships and contextual factors must be eliminated or controlled as far as possible (Fourie, 1996; Keeney, 1979).

In recent times the so-called 'hard' sciences of physics and biology have called positivistic methods into question (Wassenaar, 1987). Bateson (1972) proposed that the researcher move from the domain of explanation to that of description. Auerswald (1987, p. 321) further made the suggestion that a research design that was to make the shift to the new epistemology should be involved in accepting 'a set of new rules... to define reality'. These rules would allow for a monistic universe, one in which the need to choose between two opposing extremes was obviated. Dualism and the rejection thereof would allow the researcher to accommodate the both and choices, or alternatively the choice of not to choose. Therefore, the notion of certainty would be discarded, allowing the researcher the flexibility of the heuristic application of 'truth'.

With positivistic methods being challenged, psychologists may be even more

justified in questioning the applicability of Newtonian research criteria to psychological phenomena, especially when, as Lincoln and Guba (1985, p.114) point out, 'it is difficult to imagine human activity that is context-free'. In this regard the qualitative, or naturalistic research paradigm could be regarded as more suitable for investigating social science phenomena since it relies on the research participant's perspectives to make total sense of complex situations and interactions (Moon, Dillon & Sprenkle, 1990). According to Keeney (1983a, p.195) we create contexts that provide meaning and structure for what we do; meaning is part and parcel of all human experience and therefore needs to be communicated.

Since meaning is contextual, not atomistic, qualitative and descriptive research explores complex interrelationships amongst events in their meaning - creating natural settings (Lincoln & Guba, 1985). With this in mind, it is not surprising that qualitative approaches associated with new paradigm research and dialectical science turn the tenets of the traditional scientific paradigm upside down. For instance, quantitative research's assumption that the 'right' method will yield the truth is merely a myth. Instead, the qualitative paradigm emphasises multiple kinds of knowledge obtained through a variety of methods (Gergen, 1985). Therefore, there is a multivariate of truths. This is because the qualitative paradigm recognises that 'the rules for what counts as what are inherently ambiguous, continuously evolving and free to vary with the predilections of those who use them' (Gergen, 1985, p.268).

In addition, the new science paradigm recognises that 'reality' and thus understanding, is continuously changing from moment to moment (Bopp & Weeks, 1984). These assumptions translate into flexible research designs, which evolve in response to data (Moon et al., 1990), and inductive data analysis (Lincoln & Guba, 1985). Inductive proof, unlike deductive proof of atomistic science, cannot be conclusive since it seeks to generate theory through rich descriptions of phenomena, not to confirm hypotheses (Lincoln & Guba, 1985).

As the aforementioned implies, descriptive, qualitative approaches do not subscribe to the notion of 'objectivity'. Instead it is assumed that any social phenomenon can be described 'accurately' from many view point(s) and, paradoxically, that any point of view can only be partial (Atkinson & Heath, 1991; Lincoln & Guba, 1985). In addition, as Lincoln and Guba (1985) point out, new paradigm approaches recognise that observers tend to see and construct what they want to find. According to Bateson (in Colapinto, 1979, p.428), 'there is no such thing as a 'neutral' or 'uncontaminated' grasping of 'reality' but rather a patterned approach to it after a set of categories that regulate both our perceptions of and our action on reality'. Thus, Minuchin, Rosman and Baker (in Colapinto, 1979) remind us that the researcher's frame of reference determines which data are highlighted, which are ignored and the way in which they are arranged (Keeney, 1979). Clearly, then, subjectivity and investigator bias are intrinsic to the research process and cannot, and should not, be eliminated but rather should be made explicit and taken into account as far as possible (Lincoln & Guba, 1985; Moon et al., 1990).

Congruence between the Qualitative Paradigm and Ecosystemic Epistemology

Epistemology is concerned with the cognitive operations involved in acquiring knowledge. Therefore, epistemology underlies the research approach that is used in an investigation (Wassenaar, 1987). Ecosystemic epistemology specifies that observers actively participate in constructing their observations and that the act of observing influences what is observed (Atkinson & Heath, 1987; Hoffman, 1990). Thus, observation is always theory-laden and self-referential although, as pointed out earlier, positivistic science contends otherwise. In this regard, Keeney and Morris (1985, p.549) states that qualitative approaches represent 'a shift from a monological paradigm in which the observer is not allowed to enter his descriptions, to a dialogical paradigm in which descriptions reveal the nature of the observer'. Therefore, consistent with the constructivist view that all observations are selfverifying, qualitative research does not set

out to prove observations, but to generate new theoretical principles (Keeney & Morris, 1985).

Moreover, the coherence between qualitative research and ecosystemic epistemology is evident in the emphasis both place on social context, recursion, self-reference, whole systems and multiple realities (Atkinson & Heath, 1987; Moon et al., 1990; Sells, Smith & Sprenkle, 1995).

In descriptive and qualitative research, the whole self-referral system includes researcher, research participant(s), research problem and other aspects of the inquiry context, in simultaneous recursive interaction (Keeney, 1979). From a second-order cybernetics view, the two separate systems comprising the researcher and research participants come together to form a new and larger composite system.

In qualitative research, open-ended exploratory interviews can be used with the intention of generating rich descriptions and emergent themes (Sells et al., 1995). According to Hammersley and Atkinson (in Fourie, 1996a), research results are not 'facts' representing a fixed reality; consistent with a second-order perspective, they are social constructions co-created by both the researcher and respondents in the flow of an evolving conversation in a particular social context.

Finally, qualitative research is believed (by the researcher) to be more appropriate and effective than traditional positivistic methods in struggling with, and preserving the tangled complexity of meaning-generating, problem-determined systems and in accounting for how systems change. As such, qualitative research is believed to approximate the world of the clinician more closely.

The Focus of the Study

This study aims to fill a gap in the research literature on childhood leukaemia by shifting from an emphasis on intra-psychic factors towards an understanding of contextual elements. A more holistic understanding of the family's experience, exploring how an individual's illness (leukaemia) and the context in which it occurs have evolved together to derive a fit that stabilises each other (Bloch, 1987), is what this investigation seeks. This 'fit' will have evolved out of the 'ecology of ideas' (Bateson, 1972), which have been organised around the problem theme. Since leukaemia is viewed as communications whose meaning is unique to the idiosyncratic interpersonal context of the problem, there is no focus on etiology, cause-and-effect, truth or proof.

What assumes importance in this study are the recursive connections between the leukaemia and the leukaemic child's ecology, including his/her interpersonal relationships (family). Against this background the study furnishes a descriptive account of the network of ideas and attributions of meaning(s) that the 'cancer family' attributes to the problem.

In keeping with ecosystemic reasoning the study does not seek the 'objective truth' about the participants, their illness condition and relationships. As Lincoln and Guba (1985, p.212) state: 'The outcome of naturalistic inquiry is a reconstruction for the multiple constructions that various respondents have made'.

Consistent with a second-order cybernetic perspective, the theoretical perspective of this study, the researcher cannot stand outside of the system but is intrinsic to it and, thus, must be included in any description of it. As Keeney (1979, p.124) says: 'the therapeutic situation is therefore a whole system consisting of the simultaneous interaction of all parts'. These simultaneous interactions self-referentially identify, define and constitute the whole system. Therefore the researcher's and participants' relationship and interactions, at a specific time in a particular context, creates the whole system.

It is important to note that this study does not focus on finding solutions to the problem of childhood leukaemia - this would be an expression of linear control and reductionistic thinking, an approach endemic to medicine and other schools of thought such as psychodynamics. In this study it is assumed that the researcher and participants view the world and make sense of their experiences in idiosyncratic ways. Therefore, both the researcher and the respondents bring their own realities to the inquiry context. It is only through language/dialogue that the researcher and research participants actively collaborate to co-create the reality of the problem.

The co-evolution of ideas from these recursive interactions results in what Maturana (1975) called a 'consensual domain' (explained in Chapter 3). Since the researcher is a newcomer to the problem-determined system, she will have a somewhat different perspective to that of the research participants, and thus she might be able to introduce alternative constructions and meanings.

The idea that the introduction of alternative constructions and meanings should perturb the system and its existing ideas is by no means certain, and thus change is not guaranteed (change could mean any therapeutic intervention(s)/perturbation(s) that might influence the system to function 'better'). Firstly, living systems are unpredictable and cannot be influenced directly since they are structure-determined, as was noted in the previous chapter. Thus, the system's response to any perturbation will be determined by the structure of that system, not by the perturbation. Nevertheless, it is assumed that different perturbations will elicit different responses from a particular system. Secondly, an ecosystemic perspective does not conceptualise change in a finite, linear manner, but as part of an ongoing process. Therefore, deciding what is an outcome is rather arbitrarily determined by the time period of the inquiry and the researcher's and participants' definition of outcome (Wassenaar, 1987).

Some Important Ideas which Formed part of the Researcher's 'Reality'

The researcher believes that although the aim in qualitative research is to form close relationships with the participants, the individual 'structures' of the researcher and participant determine how they will couple or fit with one another at any point in time.

Patterns and themes are distinguished by an observer and cannot be reified (Keeney, 1982) since different observers will identify different patterns, punctuating them into sequences in different ways depending on his/her frame of reference.

The researcher's thinking embraces a dialectical outlook which views any particular reality as transitory and events/phenomenon as embodying a complex interaction of bipolarities, inconsistencies and oppositions (Bopp & Weeks, 1984). As Rychlak (in Bopp & Weeks, 1984, p.51) comments: 'the 'external thing-in-itself' (i.e. discrete entities) associated with traditional conceptualisation is now a many-in-one'. The following encompasses the research method used by the researcher.

The Research Method

Since the research design of a qualitative, naturalistic inquiry unfolds as the study develops, it is not possible to formulate a research design in a conventional manner. Nevertheless, data collection and analysis are guided by the research questions that also may change as the study progresses. The epistemology to which the research problem is defined determines the research method and the particular way in which the observed is organised, in order to generate what will be regarded as knowledge (Keeney, 1979; Wassenaar, 1987).

In this investigation the problem of childhood leukaemia will be explored and described using case study illustrations. This is coherent with an ecosystemic,

constructivist epistemology. Only by employing a case study design could due consideration be given to the uniqueness of the life ecology of an individual and his/her family.

The Case Study Method

In case studies we are concerned primarily with disentangling confusions, making sense of the different types of information welling up from the different layers of consciousness, finding meaning in the complex communication with which we are bombarded when we try to understand another person (Higgings, 1993, p. 84).

Naturalistic investigations take an emic position; that is, they tend to provide a reconstruction of the respondents' meanings. Positivistic research, on the other hand, generally focuses on etic inquiry, whereby the research is directed towards the construction that is brought to the study a priori. Therefore, the case study is more appropriate for emic inquiry (Lincoln & Guba, 1985).

According to Platt (1988) it is the case study that provides the reader with 'human interest', as well as a more humanistic mode of presentation than that of the traditional scientific or quantitative style. Dalayne (1991) states: 'the case study is an excellent research tool in that the case study material tends to involve and pull the researcher and reader into the particular event or context under investigation'.

Furthermore, the case study provides a 'thick description' of contextual information and is thus an effective means for conveying the interplay between researcher and respondents, an interaction which influences data interpretation and reporting (Lincoln & Guba, 1985). By presenting a vivid, lifelike description, by offering a vicarious experience of the inquiry setting and by allowing readers to achieve a personal understanding through

their own tacit knowledge, the case study permits an assessment of transferability (Lincoln & Guba, 1985). 'The reader has an opportunity to judge the extent of bias of the inquirer, whether for or against the respondents and their society or culture' (Lincoln & Guba, 1985, p.359).

'Historically the case study has been the foundation of clinical investigation in a number of fields, but fell into disfavour with the increased focus on empiricism in clinical research' (Trepper, 1990, p.6). One of the disadvantages of the case report from a positivistic perspective is that generalisation and prediction cannot be made from the research 'findings'. However, an ecosystemic perspective does not regard this as a limitation since every research context differs, because individuals have different 'structures' that are continuously altered through experiences and varying circumstances. Whereas this approach aims to increase complexity, prediction and generalisation are considered to 'represent a special case of reductionism' (Lincoln & Guba, 1985, p.117).

Recruitment of Research Participants

Purposive sampling and convenience selection was used in this study (Lincoln & Guba, 1985). The case report material in the next two chapters was obtained from two families with a leukaemic child. The families were contacted through various sources, such as an article in the Sunday Times newspaper, the Cancer Association and by word of mouth. Before the interviews took on a life it was confirmed that the participants would welcome the invasion or intrusion that the researcher would undoubtedly present.

The researcher made initial contact with the participants by telephone and briefly explained the nature of the investigation. Once she was satisfied that the families met the research criteria, their co-operation and participation in the study was solicited.

Inclusion Criteria

The families had to fulfill the following inclusion criteria. These criteria were formulated using previous research as a guide line.

1. The leukaemic child had to be between the ages of 6 and 18 years of age. This age range was decided upon because most of the literature dealing with childhood leukaemia looked at children in this age range. Furthermore it would allow for comparison between this dissertation and the literature that has been presented.
2. The leukaemic child had to be in remission. The fact that the child would be in remission would make it 'easier' for the researcher to interview him/her.
3. The ill child should have had leukaemia for approximately two years. This was for convenience so that the researcher could focus on the present, the time prior to remission as well as the time prior to the child falling ill, but not ignoring other contextual or historical factors - such as the spousal relationship before the marriage.
4. There should be at least one or more siblings. This criterion was included so that the researcher could also look at the interaction between the ill child and the sibling(s) as well as for comparative purposes with other studies.

Consistent with an anti-reductionistic stance, this study did not distinguish between leukaemia subtypes.

The first family that the researcher came into contact with was the Kruger family. The family unit consisted of Piet (father), Maria (mother), Paul (ill child) and Liesel (daughter). They are a highly successful family with Maria being a Clinical psychologist in private practice and Piet an Attorney/Consultant.

The second family interviewed by the researcher was the Loudi family. This family unit consisted of Nazir (father), Kousa (mother), Aziz (ill child) and Yasmin (daughter). Kousa is a qualified Nursing Sister whilst her husband is a Medical Doctor in private practice as well as a consultant. More will be said about these families in the following chapters.

The researcher was only able to interview the parents as the participants expressed their concern that her 'intrusion' would not be good for both the children. Since the ill child was in remission they feared that the interview would be disruptive/perturb and/or might trigger 'something'. However, it was also the intention of the researcher to interview the sibling/s as well as the ill child - this was not possible. A condition set down by the families was that under no condition was the researcher to interview the ill child and/or the sibling/s (as per the aforementioned reason). Each interview was then conducted separately with each spouse as the respective couples had either been going through a separation or their divorce was pending, and therefore did not want to be interviewed as a couple.

The researcher had to respect the wishes of the participants. Apart from this being ethical the researcher feared losing the participants. The process of obtaining the participants was long and tedious as well as extremely difficult. Several participants had already decided that they no longer wanted to take part in the study after having entered into an agreement with the researcher. The reasons that were given were that they had decided that it would not be a good idea to be interviewed or one of the spouses was totally against the interview. In most cases it was the wife who had declined the interview.

It was considered ethical practice to ensure that each participant signed a letter of consent (see Appendix A) prior to the interview with the researcher. The letter briefly outlined the aims of the research project and details pertaining to the individual's participation. The letter also contained the assurance that all information supplied by the participants would remain confidential and would not be communicated to anyone not directly involved or connected with the study. (To ensure anonymity, all names and identifying details have been changed in the case report material provided in the following chapters). The participants were further informed that the researcher was interested in finding out what effect their child's illness had on their day to day functioning and relationships, as well as their views about the origin of the problem and how they coped with it. Finally, the respondents were informed that the researcher could not guarantee

that any benefits (in terms of a 'cure', relief or otherwise) would be derived from their participation in the study.

Source and Format of Data Collection and Analysis

A series of open-ended questions were used to conduct the interviews. The interviews (two interviews per couple) each lasted approximately two hours per spouse and were carried out in the respondents' homes. There were a total of four two-hour interviews (8hours). The unstructured interview allowed for the co-construction of the participants' reality between the researcher and the respective families. However, the researcher was also guided by the technique of circular questioning, as suggested by Penn (1982). By constructing the interviews around circular questioning, the researcher hoped to capture the complexity of the evolution of the family and its component relationships. According to Penn (1982, p.267-280) circular questioning served to accomplish a type of description that Bateson (1972) explained in the following way:

In order to proceed from one level of description to another, an act of double description is required, or views from every side of the relationship must be juxtaposed to generate a sense of the relationship as a whole. Double description, according to Bateson (1972) is the relationship.

The circular questions employed by the researcher were as follows (Penn, 1982, p.272-274):

- Coalition alignments in the present
- Tracking questions
- Questions of classification (ranking)
- Questions of comparison
- Agreement questions
- Subsystem comparisons

– Explanation questions.

To create a collaborative context with more equitable roles between researcher and respondent, the interviews were designed to resemble a conversation more than a strict/rigid question and answer interview. The interviews were flexible and flowed in the particular direction that each conversation took. There was little planning prior to each interview. Lincoln and Guba (1985, p.60) point out that 'planning is less a matter of prediction and control than of detecting errors (twists, shifts, unexpected developments) and responding to them'. The interviews investigated factors such as, the onset of the problem, the spousal relationship (their stories of their life ecologies, the spouses' description of their child's illness and the treatment(s) sought. Each conversation was tape-recorded, listened to and then transcribed. The researcher studied the transcriptions for patterns and recurring themes (content analysis). Patterns and themes are distinguished by the observer and cannot be reified (Keeney, 1982). This means that since different observers will identify different patterns, punctuating them into sequences in different ways will depend on their frame of reference. These multiple realities embedded in data are complementary rather than contradictory. Since there is no single, tangible and objective reality, when the reader discovers a different reality from the researcher he/she should not be uncomfortable because they hold different values, which will make each see what is relevant for his/her context. In this regard, the researcher found Keeney's words compelling: 'we are free to carve the world as we like as long as our carvings are remembered to be approximations for the more encompassing patterns from which they were demarcated' (Keeney, 1982, p.162).

It is important to note that the researcher's thinking embraces a dialectical outlook which views any particular reality as transitory and events/phenomena as embodying a complex of bipolarities, inconsistencies and oppositions (Bopp & Weeks, 1984).

Data Analysis

**Data is the substance of things hoped for, the evidence of things not seen
(Lincoln & Guba, 1985, p.38).**

It must be pointed out that data collection and analysis were not two separate activities for they essentially occurred simultaneously throughout the project, utilising inductive analysis. Inductive analysis may be defined most simply as a process for 'making sense' of field data (Lincoln & Guba, 1985, p.24). Qualitative data analysis can be seen as a search for general statements about relationships among categories of data; it builds grounded theory.

The interviews were further analysed in the following manner:

1. Research participants, the researcher's peers and thesis supervisor were debriefed so as to keep a check not only on potential biases but also on focus. This process involved exposing oneself to a peer for the purpose of exploring ideas that the researcher had in mind. The research participants were debriefed once the transcribing had been completed and also during the process of transcribing. This was done to ensure, as far as possible, that the researcher did not deviate from what the participants had said. The researcher engaged in conversation/discussion with peers and from these exchanges - ideas, opinions and thoughts were generated. Some of the ideas and thoughts have informed this dissertation. The researcher's dissertation supervisor played a fundamental role in giving the researcher focus and sharing ideas. This was accomplished mainly through discussions and written material that was given to the supervisor.
2. Data was also compared and conceptualised with literature pertaining to leukaemia.
3. The researcher also looked for patterns and recurring themes during the continuous analysis of the data.

4. A final interview included an opportunity for feedback between the families and the researcher regarding their experience during the process of the interviews.

Conclusion

This chapter introduced the notion of the need for change from traditional methodology to methodology that was in line with the epistemology of the new physics. This necessitated a comparable research methodology.

Although leukaemia is an illness of the body, it acquires a meaning that 'if decoded reveals a knot of suffering in which biology, emotion, interpersonal relationships, and the rules of communication relative to the context in which they appear are all entwined' (Onnis, 1993, p.141).

Employing an ecosystemic approach as its theoretical foundation, this study aimed to create a conversational context to facilitate both the exploration and the evolution of ideas and meanings attributed to the families'/individuals' experience of leukaemia. The case descriptions occur in the following two chapters.

CHAPTER 5**CO-CONSTRUCTED STORIES ABOUT****THE KRUGER FAMILY**Introduction

This chapter and the next contain two case descriptions of families with a leukaemic child.

In presenting the participants' stories, the setting of the interviews will be described as well as the researcher's impressions of the participants. Each participant's history/story will be sketched, followed by a discussion of the context of the problem. Further, a discussion of what evolved from the conversations, as seen from the participants' perspective, will follow. The case descriptions are then summarised in a conclusion. To ensure confidentiality the names and identifying data of the interviewees have been changed.

It must be reiterated that the observations and descriptions presented have been punctuated according to the researcher's particular epistemological frame of reference (see Chapter 4) in interaction with the rest of the system. As such, they do not represent 'objective' statements about the participants or their symptoms. This is consistent with ethnographic research practice (Lincoln & Guba, 1985). As co-constructed scenarios, therefore, the case descriptions not only tell a story about the participants but they also reveal the researcher's value system, way of thinking and of making sense of the world.

It should be noted that the researcher chose to write the case reports in the first person, rather than in the third person. This highlighted the collaborative stance she

adopted. She also wanted to encourage dialogue between the readers and the text and believed that this style made the stories more engaging or 'reader-friendly'.

The Kruger Family - Case Description

The Conversational Setting

Two two-hour long interviews were conducted with Maria and Piet separately (see Chapter 4). There was a great deal of tension between the couple as they were going through a separation and in this regard wanted to be interviewed separately. They felt that by being interviewed as a couple would further add fuel to an already tense and uncomfortable relationship. The interviews were then conducted in their attractive double-storey, villa-styled townhouse in the affluent suburb of Houghton.

The interview with Maria took place in an eclectically styled kitchen over a cup of coffee and subsequently moved into a well-appointed sitting room. The interview with Piet took place in his study, whilst he had a beer.

Although I was only exposed to the downstairs portion of the house, the house seemed quite large and well-appointed. It was very tidy with modern, yet comfortable furnishings and a welcoming ambience.

My Impressions of Maria and Piet

Even though the interviews were conducted separately and on different days, both Maria and Piet met and greeted me in the same manner. At each meeting the greeting ritual was quite formal. I was met in the driveway with a formal handshake. This greeting was also extended to my husband who was responsible for dropping me off and picking me up from the Kruger family's home. I was then escorted into their home.

I felt uncomfortable and out of my depth. In retrospect this was not due to the fact that I doubted myself in terms of interviewing the Kruger family, but more so by the fact that I felt intimidated by the obvious wealth with which I was surrounded.

Nevertheless, this feeling subsided as Maria had a friendly disposition which made me feel welcomed and comfortable. She was down to earth, 'open', and I felt comfortable speaking to her. Piet also had a friendly disposition, although he seemed reserved and a little guarded. My discomfort towards Piet took much longer to subside than it did with Maria.

Piet was not a big man in stature. He struck me as a practical, strongly charactered, logical thinking person. He also impressed me as a solid, forthright man. I felt intimidated and never felt completely at ease with Piet. I believe my lack of confidence in interacting with him stemmed partly from my own biases around issues, such as gender and age difference, and certainly life experience also. These biases stem from my own experience within my family-of-origin context, particularly around my eldest bother. We share an age difference of approximately nineteen years. This has had a significant impact on my life in that I constantly felt that I had to prove myself in whatever I did. The fact that I was constantly criticised (by him) did not help either. I also felt that I was being judged in whatever I did. In short, he was the dominant male figure in my life and to me represented older males and their views towards younger females. Hence, my discomfort with Piet, I believe.

Leukaemia Description

Paul (12), the older of two children and Liesel (11), had been well for most of his life. It was not until he was about nine years old that he became ill. The first signs of the problem began with physical symptoms such as headaches, vomiting, tiredness (fatigue) and high fever. These symptoms were not treated with urgency. However, when they

persisted Paul and Maria then sought medical assistance. After several examinations and blood tests, he was diagnosed with leukaemia. Paul then had to leave school, as he required twenty-four-hour-a-day care. To complicate matters Paul was regarded as a high-risk patient because his first remission was over a four-week period as opposed to the usual six-week remission period.

The problem did not seem to escalate over the next few months. However, Paul still had to be monitored, first on a weekly and then later on a monthly basis. Paul attended the Johannesburg General Hospital every two weeks to have his blood count taken. Part of his treatment regimen was that he attended an out-patient's clinic to be monitored. During this time his treatment involved drug therapy - chemotherapy.

Since the family had been going through such a stressful period I could not or rather was not allowed by the parents to speak to Paul. The couple felt that I might cause more stress (perturb) to the children if they were interviewed. They were more concerned that Paul would not be able to handle the stress of the interview as journalists were constantly interviewing him (through his illness he had become somewhat of a celebrity). Therefore, the risk of allowing Paul to be interviewed seemed too great. More so the threat of interviewing Paul on his own seemed to have concerned his parents particularly, Maria. It could be assumed that this concern was two-fold: firstly, there was concern for Paul's well-being and secondly, the concern of what might be revealed to me. The parents were very protective over their children and were adamant that I would not be allowed to interview Paul and Liesel. Therefore, I was unable to gain information as to how he (Paul) understood his illness and attributed meaning to it. His story will therefore be told through the eyes of his parents.

Maria attributed Paul's illness to God's will. This was congruent with her religious upbringing. Piet on the other hand believed that 'cancer is a random path of life and it can strike without warning'. Piet made it clear that he had certainly not thought of causes or

meaning(s) in order to make more sense of the illness and its healing process. He was totally against the idea that it could have been God's will, as Maria felt. These different views constituted Maria's and Piet's idiosyncratic ideas and values around illness which were influenced by their past experiences with illness and caretaking within their families-of-origin (Kazak & Nachman, 1991).

Therefore, the social system was distinguished by the problem and was constituted by all those who were languaging about the problem - a problem-determined system (Anderson et al., 1986).

The couple described Paul's leukaemia as 'mind, body and soul destroying'. The physical pain that Paul has to endure when he is ill is immeasurable. There are also frequent hospital visits where he has to endure the physical side effects of chemotherapy. The after effects are extreme nausea followed by chronic fatigue and the loss of hair. When Paul began losing his hair Maria felt as though her heart had been ripped out. The decision was made to shave off Paul's hair to avoid the heartbreak of him losing his hair. To make Paul feel 'normal' his classmates also shaved off their hair (i.e. when he was strong enough to return to school).

The leukaemia pattern seemed variable; sometimes getting involved in his daily activities (friends, movies, etc.) prevented him from focussing on the pain and resulted in 'spontaneous remission'. At other times, Paul would experience pain that would steadily worsen and could last for days. It was during these times that nothing seemed to help Paul. Maria recalls that Paul would not want any of them to get close to him. This could have been because he was in so much physical pain. When Maria, Piet and Liesel (Paul's younger sister) were rejected by Paul they in turn would reject each other and find their own space. It could be hypothesised that Paul rejected his family as a result of his own ambivalence around wanting closeness and distance. The other reason could have been that he was in genuine physical pain and needed his own space to deal with it. Paul's behaviour (illness) seemed to serve as a gauge (modulator) in determining how the other

members of the system would respond to each other and to him. The effectiveness of the symptom bearer (Paul) in regulating the internal stability of the family reinforced both the continuation of the symptom and particular aspects of the family organisation in which it emerged (Minuchin et al., 1978). Maria, being Paul's primary caretaker, felt more rejected than anyone else, and understandably so, because she defined her relationship with her son as 'sacred ground'. In order to cope effectively with this distress call a mutual decision was taken by Maria and Piet that she become Paul's primary caretaker, and Piet took the responsibility for managing the finances (Cook, 1984; Jackson, 1965).

The family conceded that they were at their wits' end as they had to devise many ways to overcome Paul's illness - this would imply getting Paul 'well'. Initially there was extensive reliance on medical expertise, but then this shifted to: 'what can the family do to get him better'. The family became involved in active communication about the problem, and in so doing they were awarded membership of a problem-determined system (Anderson et al., 1986). It was instilled in Paul that 'if you are going into hospital, you are going to come out'. This was a shared family belief and one that gave the family hope. It was during these times of intense family interaction and bonding that Paul seemed to do well, as though his illness receded into the background.

Maria: The family's overinvolvement seemed to propel Paul into a state of wellness.

Maria: When Paul knew we were working together as a family...he would do much better.

By taking responsibility for Paul's well-being Maria had gotten Paul involved with many celebrities and he even had the privilege of meeting Madiba (President Mandela). Through Paul's involvement with the Reach for a Dream Programme, he and his family visited Disney World. Paul's world began to get bigger. He even took part in an advertisement that sensitised people to the leukaemia experience.

During Paul's frequent visits to hospital, a strong relationship began to develop with the medical staff. Paradoxically, though Maria was confident that the medical staff would not be able to help Paul to the extent that the family could. Piet on the other hand felt that the hospital staff could help Paul much more, since he viewed cancer purely as a medical problem. However, he is very committed to helping his 'Paulie'. It could be hypothesised that Piet was maintaining 'a homeostatic bond' with the medical staff (Selvini-Palazzoli; Boscolo, Cecchin & Prata, 1980, p.3). Moreover, this homeostatic relationship would likely compromise the success of any other treatments that were explored, such as psychotherapy. Lending support to this hypothesis was Piet's claim that he had started to learn to live with the problem and generally managed to 'go on'. As Piet put it:

Cancer is a random part of life it is
evil and unjust... just have
to move on.

Maria endorsed his view, as she saw no way out but to 'move on'. Although both Maria and Piet acknowledged that there was definitely a problem (i.e. with Paul's illness - overt, and with their own relationship - covert) they each had created their own linguistic reality (meaning) about the problem (Anderson et al., 1986).

The Context of the Problem: Emerging Themes

Maria's Story

Family Background

Maria (41) is the youngest of three children. She has two older brothers Jan (44) and Kobus (46). Maria inherited the role of caretaker when her mother died. Her parents

were very close and when her mother died of a heart attack she took on the role of caring for her aging father and her two brothers. This was her first experience of loss. Maria says that her father passed away soon after her mother's death, but he died as a result of a 'broken heart'. It was difficult for her to see someone she loved 'will' himself to die. This had a profound impact on her life both at the time and certainly in later years. This experience empowered Maria with the fighting spirit to help keep her own son alive. Nevertheless her sense of 'hopelessness' would be a thread that would become woven into the fabric of her life. In the context of her family-of-origin she was not exposed to illness, but certainly to the experience of caretaking and loss. Her subsequent profession (clinical psychologist) was influenced by her experiences within her family-of-origin context. Maria described her relationship with her family-of-origin as being disengaged:

We weren't a very close family...
everyone had to fend for themselves.

This was certainly true for her and her siblings (the sibling subsystem). However, her parents were very close and supportive of each other (spouse subsystem). She described herself as 'Cinderella' in her family (this could be due to the fact that she took care of her brothers and father). She grew up in a conservative Afrikaner family in which one's place was clearly defined. Religion also played a fundamental role in this family. Maria described herself as a very 'caring and loving' person who coped quite well with life's little knocks. Maria had to become self-reliant as there was nobody to whom she could turn to for support. She has always been self-confident and has always prided herself on success. This might stem from the fact that she was not allowed to fail in her family. Failure was viewed negatively, especially by her father. Ironically she feels that her father failed her. His failure to succeed in trying to live filled her with rage and anger. She had been a high achiever at school and subsequently was labelled the one most likely to succeed. Maria had always been able to keep herself abreast of any adversity. She learnt how to survive without the help of any family support. Because of her ambition and

tenacity she was awarded a bursary to study at Wits University (her father took credit for this accomplishment - stating that he had given her a good grounding).

Maria's motivation to succeed continued and she passed with distinction every year. However, during her internship year as a Clinical Psychologist the threads that held her together slowly began to fray. This was the loneliest time of her life and also the most ambivalent. If she decided to discontinue with her internship this would be seen as failure. She also lacked the support of her family and the emotional strength to continue. During this time Maria became depressed and began receiving anti-depressants. She has been on anti-depressants ever since. This medication seems to have been her lifeline throughout the years.

Don't anybody dare tell me
that I don't need them (the pills).

Maria meets Piet

It was some time after the internship that Maria met Piet through a mutual friend. Maria said that she was attracted to Piet for several reasons. He was totally her opposite in that he was calm, introverted and seemed very much in control. He was also nine years older than she was. They courted for approximately two years before they decided to get married. On inquiry about the courtship, Maria seemed guarded and did not share too much:

Well, we both came into the relationship
with our own baggage, as do so many couples.

She did however share with me that they were two extremely angry people. This anger emanated from their own life experiences and their experience with each other. During their courtship Maria had a brief affair with a colleague. Piet learnt about the affair

and was very angry and bitter. Maria says that this happened during the time that Piet had asked her to marry him. She says in retrospect there were many reasons for her having had the affair. One of the reasons was that she had never experienced such connection with any one else like she had with Piet (it was frightening). The affair was her way of creating distance between them. Despite this, they still chose to marry. In many ways they were compatible: they were both professionals who were driven by the will to succeed in life. More importantly they had shared beliefs about family and how to raise children. Maria stated that this was an important aspect that connected both of them. Apart from this they had a history together that neither one of them could have ignored. Thus, the theme of involuntary systems is apparent, which might be coupled with the ambivalence that each of them felt with regard to their relationship. Furthermore, they could couple structurally because if anything, they found companionship and friendship in each other.

Maria recalls that she had been extremely lonely for the greater part of her life and Piet shared this feeling of loneliness. This was one contributing factor to their finding 'comfort' in each other. They seemed to have filled a need in each other. Ironically, there had been lots of discomfort. The one contributing factor to their discomfort was that they never resolved the incident of Maria having an affair. It was an issue that was never discussed and was placed into the background. Maria felt that she had betrayed Piet's trust and had taught him to be distrustful of her. In her efforts to build his trust their relationship was subjected to a great deal of pressure. This pattern of not dealing with conflict and issues was one that would be perpetuated in their marriage and subsequently filter down to their children (sibling subsystem). After all Maria and Piet had learnt this in their families-of-origin.

During their marriage, Maria had acquired many friends (this was in contrast to her upbringing where she was isolated from friends). They were 'Houghton Dolls' as she put it and their main concern and worries in life revolved around which colours were in fashion

or which piece of clothing could be bought next. She had many more friends than Piet had. As she put it:

I was not as selective as Piet...
maybe I should have been.
It was a lesson I could have done with.

Paul's illness gave Maria a new lens through which she could view (her) life. One of the things she began to take closer stock of were her friends. She stated that she had a false perception of the meaning of friendship, as she tended to attach a materialistic label to it. Maybe this was her way of connecting with others or even 'fitting in' (i.e. at a material level rather than at an emotional level). When Paul fell ill she lost most of her friends by choice. As she put it:

It was time to sever the umbilical cord
that had been draining me of my life force.
I sat down with my diary and began to
strike each and everyone of the 'friends'
who were not there for Paul and me
and only kept those who truly cared,
for example, those who you could phone
at two o'clock in the morning when Paul wanted
Nando's.... it would be at your door within the hour.

The demands of keeping up socially were beginning to take a toll on Maria and in order for her to gain some perspective she made the decision to review her relationships and friendships. This was her attempt to sever the umbilical cord that was draining her of her life force.

Maria and Piet had been married for approximately two years before she gave birth to Paul. Prior to Maria giving birth to Paul, Piet and her concentrated on establishing successful careers. However, when Paul arrived he was the most perfect thing in her life and nothing else seemed to matter at the time. She had a son and he 'belonged' to her. For a while they were very happy. When Maria spoke of this time in her life, she glowed with pride (like an expectant mother). Her career was in private practice at the time and she decided to give it up so she could spend more time with Paul. Maria once again found herself in a caretaking position (this time by choice): a role that she had experienced in her family-of-origin. It almost seemed as though Piet was excluded from his new family. On inquiry about Piet's involvement at this time, Maria simply stated that he was involved in his career and in supporting the family:

Don't get me wrong Piet was
and is a very good father.

Maria recalls that even though her marriage was not perfect and there was a great deal of the unspoken (for example, they never really discussed divorce, but they both felt the need to be apart from each other). She felt powerless to change anything and was unable to deal with her frustration through confrontation. In avoiding potential conflict she tended to 'bottle' up her feelings since sharing them with close colleagues or Piet usually only compounded her sense of anger, frustration and powerlessness. She viewed this situation as one of the reasons why she and Piet never could have a 'smooth' relationship. Even when there was confrontation it was 'civil' and dignified. As she put it:

Dit was 'n groot gemors...

Nevertheless, it seemed that they had evolved a pattern of communicating in a 'marked' and 'indirect' manner. For instance, while they acknowledged that there was a problem in their marriage, they seemed reluctant to elaborate on how their marital problem

affected both of them and their children. Instead, they got side tracked discussing how they needed to work together to get Paul well. Many families likewise deny the existence of any problems (Minuchin et al., 1978) as they are highly invested in consensus and harmony; constant interruptions and subject changes obfuscate any conflict issues before they are brought to the surface. One example of how Maria and Piet communicated could be through the expression of a symptom. A year and a half before Paul fell ill Maria had developed a brain tumour and was on her death bed. Following intensive brain surgery the tumour was removed and she made a full recovery.

Once again there was nobody to take care of her and Piet was not mentioned as her caretaker. She did however mention that Margaret (the helper) was the only person who really took care of her during this time and the only one with whom she could talk. Her illness did not change her relationship with Piet. It was not as if he did not show concern but she needed more than he offered. He kept himself safe by not getting too involved. He tended to manage Maria's illness by consulting with doctors, getting a full time nurse to take of her, and generally seeing that she had the best care possible. The extended family also expressed their concern but kept their distance. For instance it was noted that Piet's mother would call to find out how Maria was progressing, but she never offered to assist Maria with the managing of the home or the children. Maria's brothers also would send their best wishes and they believed that she was tough enough to get through this ordeal. This belief about their sister could have also been a way to keep their distance but more importantly to keep themselves safe. Maria had to rely heavily on Margaret during this time. Margaret took on the role of mother to Maria, since she (Maria) lacked this figure in her life.

Despite the difficulties in the marital relationship there was a great deal of respect for each other, as spouse and as professional. There was one thing that they were united about, which was that Paul would grow up in a loving close family. They would achieve this by always being there for each other, by supporting each other both in and out of a

crisis. They certainly became a close family in that the boundary around their family unit was closed off to family and friends. This was something that I felt very strongly. They rarely associated with family members and were very selective in choosing their friends. There was strong commitment to conserving the family system, and any intrusion was treated with caution (the intrusion posed a threat to the stability of the system). As Maria stated:

We became a very intense family..
loved intense and fought intense... still do.

Even though the family had become so close their individual limits did not disappear (Minuchin, 1974).

Maria also acknowledged that the intensity became too much to bear at times and she felt like just escaping from the situation. This was exactly what she did. She had decided that she physically needed to get away from the situation. It was important for Maria not to lose her 'objectivity' and in order for this not to happen, she physically had to remove herself. So, she decided to go to France (it was during the time that her and Paul decided to end their marriage) for two weeks to 'clear her head' as she put it:

You become so enmeshed
that you lose objectivity...
I did realise that things had to be sorted
out now, so that the kids could develop into
healthy productive adults....
because if we don't, I am going to send two
unwell people into the world.

The rigidity and overprotectiveness of the family system, combined with the constant mutual impingement characteristic of pathologically enmeshed transactional patterns,

seems to have influenced the family's ability in dealing with conflict (Minuchin et al., 1978). The above statement by Maria can be viewed as her acknowledgment that there was much more at play in this family - as opposed to looking at Paul's illness in isolation.

Maria felt very responsible for the well-being of her children and did not seem to acknowledge Piet too often with regard to this. She reminded me that she was a person who believed in solving problems and solving them fast. The theme of being organised and efficient was also apparent. Being organised was one way in which Maria could be in control of situations and ensure predictability. The irony of this is that cancer provides an unpredictable context in which she is confronted with Paul's illness and cannot solve it. One of the ways in which she knew how to solve this problem was to make Paul happy and make him feel emotionally secure and emotionally well.

On inquiry as to how Piet was involved in Paul's healing, she stated:

It's not about going through this alone or with someone, it's about watching this child possibly dying and the hopelessness around this.

The only other person that Maria could share Paul's illness with was with her helper, Margaret. She spoke very affectionately of Margaret, who has played a very important role in her life. She is mother, helper, nurse, counsellor and confidante:

I don't know how I would have managed if Margaret wasn't in my life.

In searching for a causal attribute to her son's illness (Kelley, 1967) she blamed herself for Paul falling ill. With a great deal of self-blame she admits:

You are consciously thinking about whether I'm

contributing to his wellness or un-wellness.

She feels that her kids are angry with her and blame her for whatever is going on in their lives:

Who else can they blame, you can't blame God because God has a plan for you, so the next best thing to God is the mother.

She also had a great deal of guilt around the fact that she is closer to Paul than she is to Liesel. The relationship that had evolved between Paul and his mother was not a result of his illness, but had been there from the day he was born. Paul's illness certainly made the bond stronger. She acknowledges that her relationship with Paul is an unhealthy one:

Paul and I are far too enmeshed...

What about Liesel?

Liesel is sensitive to this relationship and tries to (over)compensate for her 'exclusion'. She is an overachiever at school and in sport, according to Maria:

She (Liesel) looks at Paul and sees all the things he gets as a consequence of his illness. She is jealous of Paul. Piet and I tend to think that she will be fine – not realising that she needs us just as much if not more.

Liesel is also angry with Paul because she cannot argue with him as other siblings do. Therefore, she oscillates between being close to and then distant from Paul. With the restriction of an ill sibling in the family she is unable to express herself, or rather, her voice

is taken away. The integrity of Liesel's relationship with her brother is therefore affected both directly and indirectly. The opportunity for her to interact with Paul is reduced, as he is physically less able to keep up with her. Furthermore, because of his status he is perceived by Liesel to be receiving all the attention from their parents, thus further heightening the conflict between Liesel and Paul. Despite this perceived differential treatment Maria states:

She challenges everything more than Paul does.

Maria also feels guilty about leaving Liesel out because she is more concerned about Paul and his illness than she is about Liesel. She admits that she is not as close to her daughter as she would like to be.

The theme of loss came out very strongly when Maria shared her story with me. She stated:

You are preparing for loss the whole time. Couldn't just get up and go on holiday. Liesel can't have a 'normal' relationship with her brother. One's marriage is of secondary thought or importance. One seems to lose everything that is dear. The loss is immeasurable. How does one win in a situation that is so complicated?

Piet's Story

Family Background

Like Maria, Piet grew up in a conservative Afrikaner family. Unlike Maria, he grew up in a slightly larger family. Piet has two brothers: Stanley (53), Pretorius (50), and one

sister, Mary (43). Piet described his upbringing as strict. He also stated that they were not, and still are not, a particularly close family:

We grew up relying on our own devices
Some would say that we were independent children.

Even though his relationship with his family was and still is strained he has become closer to Stanley, but this has only occurred as a result of Paul's illness.

Stanley seemed to be the only one that showed
concern.

There has never really been a relationship with his parents and even Paul's illness has not changed this. Piet stated:

My mother is sympathetic to the situation, but
nothing else. Not that more is expected.

When Paul spoke about his parents he was very angry and bitter, but he wore the mask that the situation of 'no support' was acceptable to him.

The Kruger family is a family of few words and therefore finds it difficult to communicate at a verbal level. Piet and his siblings were never really allowed to express themselves. It was difficult to have a voice. It was, however, easier to speak to their mother than to their father. Even when his mother spoke to his father it was as though there were restrictions on when, what, and how to speak. As Piet put it:

We hardly spoke to each other. Everybody just
went about doing his or her own thing, not really

taking note of anyone else.

Paul described his parents as conservative Afrikaners and he was not able to quite fit into that mould:

I was quite rebellious against this system and acted out.

Mr and Mrs Kruger were strict disciplinarians and encouraged their children to be successful. This was a theme that Piet carved into his own life and that of his own family.

Success is an important factor in our lives. Maria strives for success and we have imparted this to both our children.

This was a theme also pointed out by Maria and one that she, too, seemed to have inherited from her family-of-origin. I cannot but wonder then how people/individuals in this family are allowed to fail? Do they get ill, as it is a more acceptable expression of failure and generally warrants sympathy and understanding?

Prior to Paul's illness Piet had no experience of illness though his sister always seemed to be ill (he recalls her constantly having a headache). This might seem like a contradiction, but the meaning that Piet attached or attributed to his sister's headaches was not related to illness, but more to the fact that she was seeking attention. This was a shared family belief and in this respect they did not take much notice of her. Both his parents were fairly healthy, except for his father, who died of a heart attack. Piet says that he had to learn how to be a caregiver as a result of Paul's illness.

On inquiry about his relationship with Maria prior to Paul falling ill, Piet recalls that from the outset of their relationship there was a great deal of anger but over the years they

managed to 'live with it'. As the years progressed it became difficult to get out and leave the marriage. There was always something preventing this move. The children were the deciding factor for Piet's staying in the marriage but for him they could no longer be the excuse. It seemed that he and Maria had evolved a pattern of communicating in a 'masked' and 'indirect' manner.

When Paul first fell ill on the 26th June 1996, Piet took a back seat regarding Paul's illness. According to Piet this worked well. As he put it:

I took on more of a management role... a kind of supportive role ... I saw my role as provider

This position taken by Piet almost seemed pre-determined by the already defined relationship between Paul and Maria. Like Maria there was very little, if any, support for Piet from his family. He recalls:

My mother was very sympathetic. The only real support came from my brother, Stanley.

Paul even lacked a support system from friends:

I don't have many friends and the ones I do have, didn't seem to understand. An external support system was almost non-existent. Maria on the other hand did have more friends to support her. Maria is an extrovert, unlike me, and she finds it easier to make friends and to socialise.

On inquiry as to how the lack of a strong external support system impacted on their relationship (i.e. his relationship with Maria), Piet explained:

In fact we became stronger as a family. We did support each other. We haven't been close as a family for a long time. Paul's illness allowed Maria and I to put aside our differences and work as a unit. But this did not mean that anything had changed between Maria and I.

The more things changed the more they seemed to stay the same (Watzlawick, Weakland & Fisch, 1974). Despite the fact that the family became closer and Maria and Piet having put their differences aside, this did not change the need for Maria and Piet wanting distance from each other (separation/divorce).

In retrospect Piet found recalling any incident/event in their lives specific to the time that Paul had fallen ill, a difficult task. As he explained:

It is very difficult to think of our lives in retrospect except that Maria and I have a long history of anger between the two of us. This has been there prior to Paul being born. It has gotten progressively worse over the years. Our relationship is very strained.

Piet's relationship with Paul has not been particularly close, as he had to work away from home and spent many late nights at the office. However, the overall theme of this family still remained, a tense family that 'loved hard', 'played hard' and 'worked hard'. There were many times that Piet felt guilty for leaving his family. As he recalls:

Maybe if more time was spent at home with Maria and the kids a better relationship could have developed between Maria and myself, but more importantly between the kids and I.

Paul's illness did however encourage a closer relationship with his father. As Piet put it:

Paul and I have become friends, but he is still closer to Maria. This has to be my resolve in life. They have a special bond. Sometimes I feel that there is no space for Liesel or even me for that matter.

Even though Paul's illness was functional in that it brought him and his father closer their individual limits did not disappear. It could be assumed that this was the case because Paul was loyal to his mother.

Piet has a good relationship with his daughter. However, he is aware that she definitely feels left out. He can definitely identify with her position. He describes her as also being very angry with lots of tension between her and Paul. This was there long before Paul fell ill. They compete for their mother's attention, a rivalry which has become worse since Paul's illness. Piet points out a fundamental difference between his two children:

Liesel is more expressive and will let you know how she is feeling or what she is thinking. Paul is more of a gentleman and rarely says anything. He is very conscious of upsetting us.

Piet feels that Liesel is trying to find her own identity in all of this. In this respect

she overcompensates, she is very possessive over friendships and tries extremely hard to conform. Piet says that Liesel is very intelligent but feels that she is an underachiever. This is in contrast to what Maria expresses. She feels that Liesel is an overachiever and Maria wishes that this would change.

Another fundamental difference that Piet pointed out was that Liesel seemed to tolerate much more tension and stress as opposed to Paul. Their levels of intensity and tolerance are very different. Paul is the more intense one, while Liesel is more off-handed, particularly towards her parents. It is clear that both Paul and Liesel have evolved two distinct communicational styles. The one communicates at a verbal level (Liesel) and the other (Paul) communicates at a non-verbal (cell/body) level. Some family cultures lack any language for emotional expression/experience (McDaniel, et al., 1995). This conditions some members in the system to experience any need or problem as merely physical, and physical symptoms become their language for a range of experiences. The problem is then expressed as non-verbal communication in the form of a symptom (McDaniel et al., 1995).

How does Piet give meaning to this experience?

Piet recalls the fear that he experienced when Paul's illness was first diagnosed. This brought issues of his own death to the fore. The fear of losing his son was paralyzing. He recalls:

A sense of overwhelming grief seemed to take hold.
I was in total disbelief... it was as though I had an out
of body experience.

During this time, Maria and Piet began blaming each other for their son's illness. This has since ceased and they have moved beyond the point of blaming. According to Piet this:

... became for too exhausting.

Piet recalls blaming himself for a long time, but finally decided that no one person can cause cancer in another person. He therefore believes that:

Cancer is a random path of life. It can strike without warning. I have certainly not thought of causes in order to make more sense of the healing process. Cancer is evil and unjust, there is no explanation. I don't think of causes any more, just about the healing process.

However, even though Piet coped, believing the above, he further acknowledged that:

It would be much better if my children grew up in two separate happy homes as opposed to one unhappy home.

Piet: This is why Maria and I had to seriously reassess our relationship. We have decided to get a divorce, but will be separating in the mean time. This is best for all concerned.

Researcher: What do you think will happen to Paul?

Piet: I think he will get better and be happier.
We all will.

Exchanging Ideas

Our Communicational Pattern

On meeting Maria I experienced her as polite, co-operative and extroverted. Conducting an unstructured interview with an unfamiliar couple in their home made me feel like an intruder. During the interview with her, it was almost as though she had rehearsed for this interview. Undoubtedly, she had read extensively and used many psychological terms, such as enmeshment, coalition, and so on (given her background). The interview with her was rich with information, but I felt that she did not 'personalise' the conversation. For example, when I inquired about her relationship with Piet, she was guarded and could only mention that he was a very good father. With Maria, I found the interview disjointed because I tried to cover too much territory in the space of two hours.

On meeting Piet, I felt extremely uneasy (as mentioned in Chapter 4). I felt quite incompetent in his presence. As opposed to Maria, he questioned me much more. He inquired about my training, my impressions of leukaemia, and so forth. There was definitely an air of suspicion. To add to this, he did not want the dictaphone near him. Piet also spoke very softly so that he and myself could only hear our conversation. There were very definite rules that governed conversation in the Kruger home. This I had to learn very quickly. For instance, I was requested by Piet not to speak too loudly for fear of being overheard by either Maria or the children. At one point during the interview Paul entered the study to collect a fax. On his entry Piet became silent and changed the topic. This display of behaviour seemed to mirror the manner in which Piet and Maria communicated with each other: quietly and behind closed doors.

An element of secrecy began to take hold. My conversation with Piet took on an even more interesting direction, when he began asking whether or not Paul knew that issues were not so great between Maria and himself. Other questions involved things like

whether or not psychotherapy would help make the divorce easier for Paul. According to Piet, Paul and Liesel had been going for therapy as a gauge to their well-being but according to Piet therapy comprised mainly testing. Furthermore if they had scored well on the tests, then according to the therapist they had been coping with the situation of Paul's illness (as well as other issues). At no point were the parents involved in their childrens' therapy. Piet's faith in this measure of well-being was fading, and he was looking for new answers. Due to Paul's probing I had the uncomfortable feeling that he was looking for the answers from me. Despite this demand, I felt that Piet was more open about his 'problems'/relationship with Maria than she was. This was incongruent because this openness was shrouded by 'secrecy'.

Self-Disclosure

I used self-disclosure as a means of connecting with both Piet and Maria and of establishing an 'ethic of participation' (Kogan & Gale, 1997, p.112). I revealed that I had also been exposed to the context of leukaemia through a nephew who had fallen ill at the tender age of three, but who had subsequently died as a result of the illness. This established a conversational frame: 'despite our differences, we shared common ground', and this helped to position me as an 'insider' to the interaction.

Conclusion

The co-constructed ecology of ideas about Paul's illness can be summarised as follows:

Paul started experiencing his illness when he was nine years old. This was approximately one and a half years after Maria had a brain tumor removed.

When Maria had fully recovered Paul had gotten progressively worse. Wide

ranging medical interventions had only provided short-term relief for Paul. It was also around this time that Maria and Piet were experiencing difficulties in their marriage and were contemplating a divorce (dissolution of the system).

It seems that Paul's illness was embedded in, and an expression, of a series of conflicting discourses within his family system. This can be seen from my different conversations with Maria and Piet. For instance, they 'accepted' Paul's illness and worked together to overcome it, yet they differed strongly in their belief about the nature of the illness. Maria, more than Piet, was ambivalent about their pending divorce (she wanted to hold on). This placed Paul in a position of compromised loyalty. If he got well, would this mean that his parents would stay together, or would the threat of his illness returning keep them together? The theme of ambivalence prevails throughout. For instance, from the beginning of their marriage there was always the threat of separation or divorce, but they evolved so as to accommodate for this threat. Success is an important factor in this family, and this seems to have been passed down through the generations. Therefore, divorce in the early stages of their marriage could be deemed as failure.

Hence, in order to succeed, a consensual domain had evolved between Piet and Maria that they were going to work on their marriage, despite the knowledge of the unresolved and the unsaid. This was done with the exclusion of other systems; for example, they cut off family and most of their friends. When Paul fell ill, the boundaries around the family became even more rigid. In many ways, Paul's illness was functional in that it allowed other systems to 'enter' his rigid family system. Family members became involved (minimally) as well as the hospital system. Even at this level Maria was over-involved, not only with Paul but with those who began to get involved in his life especially the hospital staff. Through his illness, he became a 'celebrity' (he met President Mandela, and appeared on TV etc). When Maria pointed this out to me she also pointed out the fact that there is secondary gain in being ill and Paul tended to 'play' into this.

Paul's illness seemed to be linked to a paradoxical or incompatible discourse. For instance, Maria was organised, efficient and liked to be in control of situations. At the same time she gave Piet the responsibility of managing the family's affairs (a manager's role), thereby putting him in charge. However, she sometimes disagreed with his decisions and wished he were more sensitive to her needs and desires. Yet, coherent with her 'identity' as a dependable and a 'sacrificing' person who put other people's needs first, she found it difficult to express her feelings and tended, instead, to 'bottle' them up.

It seemed that another recursive pattern of interaction that had evolved between the couple over the years both maintained, and was reciprocally maintained, by Paul's illness. The pattern was that Maria and Piet withdrew from one another when Paul seemed to be getting well, and tended to avoid discussing relationship issues and open conflicts. It appeared that many of the rules of their relationship, as well as who would make the rules, had not been clearly defined, including a rule for dealing with conflict/ anger (Haley, 1963). Therefore, Maria would often go to Paul when she felt that she could not communicate with Piet. Paul, therefore, fulfilled a function in his mother's life that Piet was unable to fill: the role of comforter and confidante. Piet was then encouraged to keep his distance from both Paul and Maria (encouraging enmeshment). When Paul gave the indication that he was not feeling well, his parents would rally together for his well-being. His illness would serve the function of reuniting them and defusing conflict. This first-order cybernetics conceptualisation implies that Paul's illness operated like a homeostatic mechanism regulating interpersonal closeness/ distance.

An interlinked network of evolving ideas was co-created and re-created by Maria, Piet and myself into the above case description. However, this is only one of many stories that could have been told about Paul and his family. As such, the themes that emerged from Piet's and Maria's stories flowed out of the researcher's idiosyncratic way of drawing distinctions at a specific time in the research process. Another researcher undoubtedly would have identified different themes. A summary of the interconnected themes that

emerged from the interviews follows:

When Maria and Paul decided to get married they did so without resolving many of their issues. These unresolved issues evolved out of their own life experiences and experience with each other. They had evolved a means of being with each other despite their pent up emotions. In this regard the theme of involuntary systems is apparent. This theme had many implications at various systems levels of the family. It was noted that both Maria and Paul were two angry people. This anger was also perpetuated in their marriage and was therefore another unresolved issue. As the couple were invested in success, they decided to place any threat to their marriage into the background. This meant that they were unable to deal with conflict issues and therefore established a masked and indirect way of dealing with each other. The rules of dealing with each other were not made explicit. However, the trend was not to deal with conflicting issues, as the family was highly invested in maintaining its autonomy (i.e. the family had to conserve its autonomy). When the family was confronted with Paul's illness the boundaries around the family became rigid and closed so as not to allow for any intrusion, this included both friends and families-of-origin. Even though this was the case their individual limits did not disappear. The family experienced a heightened sense of closeness and cohesiveness (this was particularly so when Paul's diagnosis became known). The decision to isolate from the world can be seen in the family's strong sense of loyalty and protectiveness towards each other as well as to the system as a whole. The family's tendency to isolate itself, also had implications within the family. For example, the family's isolation tended to contribute to a strengthening of the enmeshment and alliance between Maria and Paul. However, it should be noted that this interaction was not a direct result of Paul's illness, but his illness contributed to a strengthening of this relationship.

From this interaction there was a tendency for Paul to become triangulated in issues concerning Piet and Maria. Liesel was also subjected to this interaction. With the family facing the many challenges of having an ill child a sense of powerlessness was

experienced. This was due to the fact that they were unable to change the ill child's status, and an overwhelming sense of loss was experienced. There was also a sense of powerlessness around the fact that the couple felt that they could not change anything in their relationship in order to make it 'better'. These emotions were embedded in feelings of guilt as Maria felt responsible for Paul's illness (this later subsided).

With many of the themes and patterns embedded in ambivalence as demonstrated in the case study Paul and Maria were unable to resolve many of their issues and decided that the best recourse would be to divorce (dissolution of the system). It should be noted that Paul's illness did not precipitate this, but was as a result of his parents' own life ecologies, their experience with each other, and their unresolved issues.

In Chapter 6 the second case study (the Loudi family) is furnished.

CHAPTER 6**CO-CONSTRUCTED STORIES ABOUT****THE LOUDI FAMILY**Introduction

This chapter contains a case study description of a family with a leukaemic child.

In presenting the participants' stories, the setting of the interviews will be described as well as the researcher's impressions of the participants. Each participant's history/story will be sketched, followed by a discussion of the context of the problem. Further, a discussion of what evolved from the conversations, as seen from the participants' perspective, will follow. The case descriptions are then summarised in a conclusion. To ensure confidentiality the names and identifying data of the interviewees have been changed.

It must be reiterated that the observations and descriptions presented have been punctuated according to the researcher's particular epistemological frame of reference (see Chapter 4) in interaction with the rest of the system. As such, they do not represent 'objective' statements about the participants or their symptoms. This is consistent with ethnographic research practice (Lincoln & Guba, 1985). As co-constructed scenarios, therefore, the case descriptions not only tell a story about the participants but they also reveal the researcher's value system, way of thinking and of making sense of the world.

It should be noted that the researcher chose to write the case report in the first person, rather than in the third person. This highlighted the collaborative stance she adopted. She also wanted to encourage dialogue between readers and the text and

believed that this style made the stories more engaging or 'reader-friendly'.

The Loudi Family - Case Description

The Conversational Setting

Two two-hour long interviews were conducted with Nazir and Koussa. The interviews were carried out in their home in Sandton. Both the interviews took place in the guestroom at separate times (the reason is mentioned in Chapter 4). Their home was nothing less than magnificent, with a strong Eastern flavour. It was tastefully appointed and seemed quite large.

My Impressions of Nazir and Koussa

At each meeting with Koussa and Nazir I was met by a helper (I later discovered that she was one of several). I was taken through to the guestroom, seated, and then offered a cup of tea. My first interview was with Koussa and she was not punctual in meeting with me, since I waited (anxiously) for approximately ten minutes before she came to meet me. By this time I was a bit more relaxed. She entered the room quietly and timidly as if wanting to be dismissed. She was short and petite and wore her traditional dress (Punjabi). The trimmings in the house complemented her and I definitely felt like the odd one out. Before we began the interview, though, she apologised for her 'bad' English. Despite her accent she was quite articulate in the English vernacular. She had a friendly disposition, although at first she seemed reserved and somewhat guarded.

When I interviewed her husband he was prompt and met me with a friendly handshake - 'Hello Miss Pradhuman what can I do for you?' He was not a very big man: somewhat small in stature. He struck me as a very confident and strongly charactered person (unlike his wife). He seemed easy to get along with as he had a casual and

informal manner about him. This manner allowed me to feel comfortable.

Leukaemia Description

Aziz (13), the older of the two children and his sister Yasmin (11), had always been sickly (asthmatic). Apart from this condition he was a healthy little boy growing up. It was not until he was about nine or ten that something seemed to go wrong. His father (a medical doctor) first noted this. Aziz had lost his zest for life. He experienced symptoms such as headaches, tiredness/fatigue, fever, vomiting and a blotchy complexion. After several tests he was diagnosed with having cancer. This diagnosis was first made by his father ('...every thing inside of me told me that my son had cancer') and was later confirmed by a pediatric oncologist. As the cancer began to take hold of Aziz's body he was unable to perform his daily activities such as going to school. He began treatment (drug therapy/chemotherapy) and was not regarded as a high-risk case because his first remission spanned a six week time period (the normal time period for a first remission).

After the first remission the following months were fraught with relapses/remissions. To date he has been in remission for approximately two years (the longest remission). There have been threats of the illness returning, but these have been nothing more than developmental problems such as the odd cold accompanied by fever and so forth. Even though Aziz was in remission his situation was compounded by the fact that during his illness he also had to contend with and control his asthma. The threat to his life was then two fold.

As with the first case description I was not allowed to speak to Aziz or his sister. Since he was in remission his parents thought that my intrusion might be disruptive for the children. According to them they could not take the risk of something going wrong (i.e. that

my interview could be a perturbation for the children). Both the parents expressed genuine fear and concern.

Kousa described her son's illness as a 'nightmare', a curse that could not be lifted by anybody. Nazir's description was more philosophical. He stated that he has always relied on science (medicine) for explanations to complex problems, but science has failed him in trying to make sense of his son's illness. When Aziz is ill Nazir takes responsibility for administering the medication. This seemed to help Aziz for a time but Nazir also felt guilty about his son's emotional pain. For this there is no 'quick fix'. At times Aziz is in more physical pain than at other times - there does not seem to be consistency in his experience of the pain as mentioned by his father.

Aziz does not have much social activity and during these times (when he is ill) these activities are limited even further. He also has a few friends, as he is very selective when it comes to friendships. When he is really ill he draws on a few friends who understand his illness. This is an attempt to try and normalise his life. They get involved in going to the movies, playing cricket and chess. This involvement with his friends almost, in a way, pushed his illness into the background. It is during these times that Aziz seems to be happiest and healthiest. However, there were times when this did not help as Aziz would experience pain and discomfort for days on end. Therefore, the progression or regression of the disease seemed to be variable.

Nazir confessed that they are a very religious family and it seemed that the obvious thing to do was to turn to religion. The entire family, including Aziz, engaged in prayer (Namaaz) five times a day. According to Nazir:

Our prayer seemed to be more earnest and desperate.

This was the only time that the family really connected around Aziz's illness. The social

system was distinguished by the problem and was constituted by all those who were languaging about the problem - the problem-determined system (Anderson et al., 1986). The family became involved in active communication about the problem (Anderson et al., 1987). It was during this time that the family worked in earnest to get Aziz well. Aziz's well-being lay in the hands of medicine and religion. Even though this was the case Kousa expressed her lack of faith. When Aziz fell ill Kousa recalled feeling 'out of control' and feeling very guilty about her son's illness. She blamed God for this. Apart from her emotional turmoil she also worried that the family would blame her for Aziz's illness. He is the eldest grandchild and this role is very significant in Muslim culture. When something goes wrong with this 'special' child the weight of this issue is cast onto the shoulders of the mother: a heavy yoke to bear by any cultural standard. As already mentioned there was much emphasis on religion and medicine to help this family cope. Nazir developed or established a homeostatic bond with the medical staff (Selvini-Palazzoli et al., 1980) who were responsible for Aziz's health. In this respect any exploration of any other means of treatment would be compromised (at the time of the interview no other means of treatment such as psychotherapy was contemplated).

A closer inspection of the illness/family context will now be explored.

The Context of the Problem: Emerging Themes

Kousa's Story

Family Background:

Kousa (38) grew up in Lahore, in Pakistan. She was the only girl in the family and had two older brothers: Yaseen (40) and Ziaad (42). Kousa recalls her life as very much revolving around the males in her family, that is, her brothers and father. She described these relationships as 'slave and master':

I always had to be serving...
it is tradition to even wash the
feet of the senior male...

Despite this relationship she was fairly close to her brothers and father, but she was closest to her mother. They shared many similar experiences as women in their society. She (like her mother) was bound by the constraints of religion and culture. Her father was a conformist and traditionalist. Despite this 'slave-master relationship' she was obedient to the dictates of her culture, but more importantly to her religious convictions at the time. Her mother led by example and always encouraged Kousa to be 'a good Muslim girl'. This usually meant being obedient and subservient to a male. Kousa continually felt the rumbles of an internal war: that is, wanting to break with tradition but at the same time being in chains (conflict discourse). She was constantly in a double bind and was shrouded by ambivalence. Kousa was determined not to repeat this pattern in her own life the day she got married. However, she was groomed into a caretaking role.

There is a strong learning culture in Pakistan but this is mainly reserved for the males. Kousa recalls that education was always promoted in her family with her father being the main advocate. He encouraged her two brothers to become something in life, but she was merely to find a 'suitable' husband. There is a tradition of arranged marriages in this society but she swore that she would never succumb to this practice. Her two brothers were in alliance with her in this regard and promised her that she would decide whom she wanted to marry. To further ensure that this decision would be a reality she decided to study nursing. Most of the family members supported her decision but her father expressed disappointment. As he put it:

...an educated girl cannot keep a husband...

These words would come back to haunt her in later life.

Kousa had fallen in love with one of her lecturers and he had shown a keen interest in her. They became romantically involved and there was even talk of marriage. This was not to be the case, as a prominent family had approached Kousa's father enquiring about her. The Loudi family had a son (Nazir) who had recently qualified as a medical doctor and who was ready to get married. He had expressed his interest in Kousa, as his preference was an educated girl.

Her father convinced her to get married (nikkaard) and said that if she refused he would disown her. Her brothers also agreed that marriage was the best thing for her. This was the lowest point in her life. She felt betrayed and had a sense of loss for the life she would never have. As Kousa put it:

I couldn't breathe it felt as though I was going to die.
I trusted my brothers to protect me from this -
they betrayed me.

She no longer had her allies.

Kousa meets Nazir

Kousa and Nazir became acquainted and within a month her fate was sealed. Kousa recalls how she resented Nazir because she blamed him for placing her in this position. She said she knew of his family and they had a reputation for being 'lazy'. When they got married she recalled it as the saddest day of her life. She mourned for the life she had lost. Tradition dictated that the wife move into the home of her husband. Kousa had made Nazir promise her that he would not discourage her from continuing with her nursing career. However, her role was predetermined once she entered the home of her in-laws. The 'master-slave' relationship would once again dominate her life. Kousa recalls being constantly angry and ambivalent about everything, even about being educated. There was

no way in which she could express herself. As she recalls:

I wanted to get out but there was nowhere to go.

As a result of this she would 'bottle' up all her anger, as it was considered disrespectful to challenge one's husband. Kousa was expected to feel privileged that she was going to marry a doctor since this profession is highly regarded in the Indian culture.

Placed in this predicament, she vowed that she would never love Nazir. However, in time she began to take Nazir into her heart. A year into the marriage there was pressure for her to have a baby, which came from both Nazir and his family. If Kousa was unable to fall pregnant Nazir was obliged to take a second wife who could bear him children, particularly sons. Within the year she fell pregnant with Aziz. The day Aziz was born Kousa began to live. He became her purpose in life. As she put it:

My son was my world and I gave him all the love I had.

She vowed that she would be a good mother and she says that she has managed to accomplish this despite what others might think.

She now concentrated only on her son and her career. With Aziz she felt that she could bear to be in her marriage as he gave her life purpose and meaning. Kousa had many expectations for her son and one of them was that she would not encourage him to be a stereotypical Muslim man. With Aziz's birth she felt that she became more assertive, she began challenging her husband and slowly became the 'disrespectful' wife.

They began to argue for the first time and this escalated over the months and years. According to Kousa this brought about a significant shift in their relationship as the pretense had been dropped. Very little talking actually took place but this seemed to be

the communicational pattern that developed between Kousa and Nazir: a communication pattern with lots of 'noise'. In this turmoil they decided to come to South Africa in the hope of better job prospects. Nazir had a brother who had already been living in South Africa (also in Sandton). He is a successful businessman and very well-off. Nazir decided that they would live with Mr Islam (this is how he was referred to by both Kousa and Nazir). He was never referred to by his first name. Kousa's position never changed when she moved in with her brother-in-law. This theme in her life is also evident at the level of her family-of-origin. She was literally confined to one room (the bedroom) as her sister-in-law made it known that the house was her home, not Kousa's. This was, yet again, a trying and difficult time for Kousa as she entered into another system that promoted silence. This seemed to be a recurring pattern in her life.

Even though Nazir was on the road to success having had secured a job at the Lenmed Medical Clinic and then subsequently opened up his own medical practice, he became depressed and was treated with anti depressants. At one stage it was thought that he might have 'Bi-polar mood disorder' (i.e. shifts between mania and depression) (American Psychiatric Association, 1994), which were an expression of the opposing discourses that existed in this family system. Kousa was blamed for her husband's illness as she was seen as not helping her husband. The only way that she could lose the label given to her ('bad wife') was to leave the system. But how was this possible, because despite her ambivalence and anger, paradoxically she depended on Nazir for her success as a wife.

Kousa's relationship with Aziz

When Aziz was born he represented a purpose for Kousa and may have given her marriage meaning (as already mentioned). They began to develop a very strong coalition between them. One could say that they became enmeshed with rigid boundaries (closed) but this was also true for the larger system. This relationship proved to be functional for

Kousa as it filled a gap in her life. In short he (Aziz) became the man in her life. Aziz was very in 'tune with his mother'. As Kousa put it:

He knew when I was upset or when something was worrying me... this was so even when he was very young... Uh! I don't know if this is a good or bad thing. I think he used to feel sorry for me.

Kousa recalls never being so connected to her daughter and jokingly puts this down to the fact that she (Kousa) needed a man in her life. Furthermore her daughter was independent and never really bothered about what was going on around her. Kousa recalls:

She seemed to need me less than her brother did.

Nazir's Story

Family Background

Nazir (42) grew up in a traditional Pakistani family where the boy child is revered and groomed for success. Nazir has three older brothers: Islam (44), Ahmed (45) and Ibrahim (47). He was seen as the spoilt one. This was due to the fact that he was born prematurely (almost two months) and doctors thought that he would not survive - but he did against all the odds. The Loudi family is an extremely close family. Nazir attributes this closeness to the family's having common goals that are bound strongly to their religion and culture. There is a definite hierarchy in his family in which a male patriarch (his father) rules. His father's word is rarely if ever challenged. Nazir states that, even though this was the case, his father had a very gentle side to him. He says that although he held his father in high regard he was close to his mother. As he put it:

In many regards I felt sorry for her and took the responsibility of protecting her...

Nazir felt protective towards her because he did not want her to be treated like other Muslim women. His parents were close and extremely loyal to each other. There were times when there was disagreement between his parents but this all took place in secret. To have made their disagreement overt would have meant destabilising the system (Minuchin et al., 1978). Religion was a prescription for living life and any deviation from this was unacceptable. One could say that this system was secretive, rigid, and closed to any change/deviation or perturbation.

Nazir displayed great potential at school and was encouraged to become a doctor by his father. He said that at the time he wanted to become an engineer but he did not want to disappoint his parents. His brothers had gone into the family business, which was the last place that he wanted to be. He finally became a doctor and he recalls the ambivalence that he picked up in his family, that of pride (in his parents) and resentment (in his brothers): a conflicting discourse in his life at the time. In many ways he envied his brothers' freedom, as his father had determined his studies and also who was to be his wife. Nazir was constantly in a double-bind, that is, being allowed to succeed, but this success was contingent on his honouring his parents, his father in particular. He experienced pressure once again, this time not around the choice of a career but that of a marriage partner. Nazir had not shown an interest in anyone at the time, but was pressured into naming a potential wife. He had one of two choices: either he should choose a wife or one would be chosen for him. He opted for the former, but she had to be the right girl.

Nazir meets Kousa

He says that he chose Kousa because she had drive and she was educated, not a trait that one sees too often in a Muslim woman. He admits that they had nothing in

common and Kousa openly displayed her resentment towards him. This was expected and anticipated. In time they would learn to love each other, as did generations before them. Nazir recalls Kousa being more popular than the other girls and much more friendlier as well. This took getting used to and at times was frustrating and angered Nazir, as it made him feel inadequate. Their courtship was short, as this was the way it had to be otherwise people would 'talk'. The social context played an important role in how people conducted their lives. At the same time it represented a rigid influence on various social entities such as the family. The norms that society placed on the family context was also a means of conserving tradition/culture and religion as these norms were dictatorial in nature and ensured the survival of the family as a unit.

When Kousa and Nazir got married he recalls this time being particularly difficult because tradition/culture dictated that the wife live with her in-laws. This meant that Nazir's father would still make the decisions regarding the welfare of the family, including Nazir and Kousa. This caused an internal battle for Nazir.

I wanted to make the decisions regarding my marital affairs, but at the same time I had to respect my father's position as head of the house...it was a matter of loyalty.

When Kousa fell pregnant it was the happiest day of his life.

With the birth of my son I felt liberated...
this is when I made the decision to come to
South Africa to my brother, Mr Islam.

Nazir and Kousa were elated by the birth of their son (Aziz). This seemed to have brought them closer, but not for long as Kousa seemed to take ownership of Aziz and Nazir was

excluded from her affection (more so now).

The birth of my son was wonderful but this was mixed with feelings of rejection from Kousa... I was filled with joy, anger and resentment.

The more Nazir tried to win his wife the more she became closer to her son. This would be a pattern that would be perpetuated throughout the years.

When Aziz became ill Nazir took on the role of medical adviser and provider as Kousa had to stay at home to mind Aziz (a full-time job). She did not have family support because for a time Kousa and Nazir kept Aziz's illness to themselves, until deterioration in his physical appearance indicated that something was terribly wrong. Both Kousa and Nazir viewed their son's illness as their fault and failure. They blamed each other as well as themselves. Nazir felt helpless to help his son, as he felt that medicine was failing Aziz. However he continued to maintain a homeostatic bond with the medical staff (Selvini-Palazzoli et al., 1980, p.3). Moreover, this homeostatic relationship would likely compromise the success of any other treatments that were explored.

Nazir's relationship with Aziz

Aziz was the first born and the first grandson in the family. He would be the one to carry his father's name. As Nazir put it:

My son represented continuation of my name -
this is very important and significant in my culture.

According to this system Aziz's role was predetermined merely by his position in his family

as well as his gender: a heavy load to carry. Nevertheless Nazir was proud that he had a son. He was not very involved in the upbringing of his son, because this was primarily the duty of the mother (a gender stereotype). However, Nazir took the reins when it came to Aziz's religious education. This was where father and son connected, without Koussa. Religion was not only the connecting factor for Nazir and his son but also for the whole family. This is significant because the family did not connect around any other activity.

We do not do much as a family, but there are definite things that we connect around such as our religion and its rituals.

Nazir sees his relationship with his son as being close, but not in the way that Aziz is close to his mother. As Nazir put it:

By virtue of the fact that he is my son makes us close.

Nazir also acknowledged Aziz's closeness with Koussa:

Koussa is everything to Aziz... sometimes he even fights with me over his mother... one time he mentioned that his mother was not my slave... I merely asked why the table had not been set.

Nazir expressed concern about the relationship between Koussa and Aziz:

I don't know how healthy it is to be so close to your child - sometimes Koussa

confides in Aziz whereas she should be confiding in me. He is only twelve but he is much more grown up than that - Kousa gives him too much responsibility...takes my responsibility away...

When Kousa and Nazir argue (which is very often) Aziz comes in to neutralise the situation but more often than not he will side with his mother. As Nazir put it:

...Aziz always made me feel like the bad one...

When Aziz became ill Nazir recalled that he became closer to Aziz than he had ever been. According to Nazir this was partly due to the fact that he feared losing his son to this dreadful disease and also because he was involved in the medical management of his son. Aziz's illness seemed to bring everybody together. Nazir recalls:

When Aziz fell ill, Kousa and I became close
We needed to put our differences aside to make
our son happy...

Shortly before Aziz fell ill Nazir and Kousa had decided to get divorced. This decision had not been discussed with the children (culturally this was not done). However, it was changed and they decided to separate but still live together. The reason for this was that the house was big enough for both families and all their material needs were seen to with the assistance of Mr Islam.

What about Yasmin?

She has been ignored in all of this (the forgotten one). She has definitely been left

out. All the attention is given to Aziz. Despite this Nazir states:

Like her brother she always did well at school;
she is very bright...very competitive and even
competes with her brother at most times...

According to Nazir she is just like her mother; determined and driven. Nazir states that her relationship with Koussa is strained:

They argue about everything...
sometimes I think it is just
to get her mother's attention.

Nazir describes his relationship with his daughter as follows:

...fathers and daughters are close too;
our relationship is no different, we
have a special bond ... sometimes
I think that she is on my side.....
Because when there is disagreement
between Koussa and I she will defend me
even when I'm wrong at times.

Nazir:

It sounds like we are a family that is always fighting;
this could be true...but it is difficult when you trying
to make a marriage work, heal a child and prevent the
other from becoming ill. It is a continuous juggling act.

Researcher:

Have you noticed a significant change in your daughter?

Nazir: Uh! I'm not sure how to answer that - she has become difficult (rebellious). This was around the time Aziz became ill, but she is also at that difficult age....

Aziz and his sister

Aziz has always been protective towards his sister. They are both quite popular at school and amongst their friends; however, as noted above, Aziz is selective in his choice of friends. He feels that his sister should be the same (as already mentioned by his parents). His sister is carefree and Aziz is more serious about life. His parents both agree that he should learn to be more relaxed. Aziz is in a coalition with his mother and his sister is in a coalition with her father. This pattern existed prior to Aziz becoming ill, but his illness certainly contributed to a strengthening of this interaction. These coalitions contributed towards intense sibling rivalry coupled with developmental issues. Aziz is very observant (in his religion) and he encourages his sister to be the same. This is also a point of contention between the two. They are isolated from other family members and with Aziz's illness the boundaries around the family system became even more rigid/closed. Nazir accounts for this in the following way:

...we always preferred not to have many other family members involved in our affairs. This became even more so when Aziz fell ill. We cut off almost all family members...

How does Nazir give meaning to Aziz's illness?

This will be expressed in the form of a quotation, as follows:

... I'm a doctor and I see illness in purely medical terms: this is the only perspective I know especially when it comes to health issues. But I am also a father and this blurs my vision... I don't think I can say that my son's illness is purely medical... many other factors could be contributing... we need to reassess the situation...

Conclusion

The co-constructed ideas about Aziz's illness can be summarised as follows:

Aziz was diagnosed with leukaemia between the ages of nine and ten years of age (prior to the diagnosis his parents had made the decision to divorce). Aziz's parents believed that their son's illness was caused by a biological problem. Apart from the leukaemia he also suffered from asthma; this condition began when he was four years old (the difficulty in breathing is symbolic of how his mother felt when she was forced to marry Nazir). Aziz has been accustomed to taking medication from an early age and this was the system's way of 'solving' the problem. Aziz was born into an 'ill' system, hence one could say that he 'inherited' his illness. In the hope of getting well he was encouraged to take his medication even though to his parents it seemed ineffective in alleviating his illness. His treatment became a matter of routine for his condition.

From the picture that emerged in the interviews Aziz's illness seemed to be an expression/metaphor for long-standing conflicts or ambivalence that existed in the life/interpersonal relationships of his parents. Aziz himself seemed to have an ambivalent relationship with his father: that is, wanting to be close to him, but this meant compromising his position with his mother - a matter of loyalty. Despite Aziz's loyalty to his mother it seemed that he wanted more attention from his father, yet this would

compromise his closeness with his mother, a risk he was not prepared to take. The following information further highlights the ambivalent nature of Aziz's context.

Aziz was the model child/son. He was intelligent, religious and showed potential in other areas such as being a keen cricket player, whilst his sister was labelled as being a 'rebel'. Although Aziz and his father were previously close, Nazir seemed to take Aziz into his confidence more now that he was ill. On the other hand Aziz found it difficult to think badly of his father and he felt grateful to his father for all the sacrifices that he had made for the family. As Kousa put it:

Aziz feels grateful to his father
for giving us a better life in South Africa
and for taking care of his illness...

On the other hand Aziz seemed to resent his father (a conflicting discourse) because of the type of relationship that Nazir had with Kousa (i.e. he did not support or understand her). Kousa never seemed to measure up to Nazir's expectations. Despite her attempts she seemed to fail. For instance, even though Kousa had decided to stop nursing to take care of Aziz she still seemed to be failing in the eyes of her husband. Aziz seemed to pick up on his father's disapproval and he took on the role of 'picking' his mother up and making her feel worthy, especially when it came to taking care of him. As Kousa put it:

...my life would seem worthless if
I didn't have Aziz to take care
of me and even for me to take
care of him... I do worry about
his sister but it is not the same.

Aziz's recurrent hospitalisations were a constant source of frustration for his parents, and were therefore viewed as a sign of their 'failure' as parents.

As noted above, it is interesting that Nazir had been diagnosed with 'Bi-polar mood disorder'. One could go as far as to say that the mood polarities characteristic of this 'disorder' were an isomorphic expression of opposing discourses that existed in this family system.

The conflicting discourses that characterised Nazir's relationship with Kousa are illustrated by the fact that firstly, Kousa was close to Nazir as long as there was distance between them; once in each other's company (without the children) they found each other irritating, and following this irritation an argument would ensue. There was no tolerance for each other's differences. Secondly, in the company of their children they would compete for their attention, especially that of Aziz, and this would subsequently give rise to conflict between the parents and even between the children. The ambivalent relationships in this family were reciprocally and mutually maintained. A complex pattern of interaction had evolved in this family system.

It appeared that one of the ways that Kousa had tried to live up to her husband's expectations (and those of everybody else) was to pretend that she was happy and contented. Nevertheless, her choice to pretend contentment reinforced an already existing ambivalence and may well have introduced other ambivalences. For example, who was she really married to Nazir, Aziz or both? Nazir was both pleased and a little uncomfortable with the closeness between Aziz and Kousa. Although Kousa had done 'right' by her parents in agreeing to marry Nazir this act was not enough. Kousa also had to be grateful for everything that Nazir provided. From her comments Nazir and other family members did not seem to think that Kousa was grateful enough because she challenged her husband from time to time - another conflicting discourse.

It appeared that on one level Kousa's relationship with Aziz helped her to disengage from Nazir and other family members. For instance when Aziz was feeling ill he wanted only Kousa to take care of him. They were then left on their own and Nazir and others were excluded. On another level however, Kousa's relationship with Aziz seemed to maintain the involvement of Nazir in her life, and her relationship with Nazir could be viewed as recursively maintaining Kousa's relationship with Aziz. Thus an interconnected network of interactions had stabilised.

From a second-order cybernetic perspective, Aziz's illness was embedded in, and an expression of, a web of conflicting discourses in which he had participated. From a first-order cybernetic approach, Aziz's illness seemed to serve the function of regulating interpersonal closeness/distance. Aziz's illness enabled his mother to have a purpose, but at the same time it allowed his parents a degree of closeness in working towards a common goal - getting him well.

From the above case description it can be seen that an interlinked network of evolving ideas was co-created and re-created by Kousa, Nazir and myself. However, this was only one of many stories that could have been told about Aziz and his family (relationships). It is also possible that had I interviewed Aziz or even his sister or another member of the family, a different story would have unfolded. The patterns and themes that emerged from this case study flowed out of the researcher's idiosyncratic way of drawing distinctions. Another researcher undoubtedly would have identified different themes and patterns. A summary of the themes that emerged from the interviews follows:

When Nazir and Kousa got married it was not by their own choice. Their marriage was an arranged one (involuntary systems) and one that was culturally acceptable. It must be noted that Kousa was more resentful than Nazir was regarding the arrangement of their marriage (this would have implications for the relationship she forged with Aziz). However,

since there was a strong sense of loyalty to family she (they) conceded to the marriage. This sense of loyalty was a theme that was also seen in their own family. For example, Aziz was extremely loyal to his mother. There was an overall sense of loyalty by each member to the conservation of the family system. In this case there were strong cultural connotations: if the family did not display this sense of loyalty, they would not survive as a family and the parents would have been viewed as failures. In their attempt to succeed as a family they engaged in the family tradition of avoiding conflict issues that would upset the system. Both Nazir and Kousa were powerless to change any aspect of their predicament. This was a theme that came out strongly for Kousa: firstly, she was powerless to change her status in her marriage and secondly, she was powerless to change the status of Aziz (i.e. from being ill). Aziz at some level was in tune with his mother's powerlessness within the system. Despite her status within the system she had to prove her worth and in so doing she had to depend (ironically) on her husband for her success, both as a mother and as a wife. Therefore, she was constantly striving to live up to expectations, but was failing (as defined by the members within the system). Her son was not going to allow this. As a consequence of the powerlessness of the situation, Kousa was extremely angry and resentful and she brought this anger and resentment into her marriage, as she held her father, brothers and Nazir accountable for her predicament. Nazir's anger and resentment on the other hand evolved with their marriage. Since she felt this way towards Nazir she looked to Aziz to fill a void in her life (this was not pre-empted by his illness, but by his birth). The position that Aziz held with his mother was that of a very close, rigid and enmeshed relationship. This had implications for the spousal relationship. However, when Aziz fell ill the entire family system became closed and rigid. Their boundaries were closed off to both family and friends, so as to keep Aziz's illness a secret. It was important to try and keep Aziz's illness a secret because if it was found out that he was ill the parents would be blamed and held accountable. They would have failed as parents. This is how they are judged within the system in which they reside.

Exchanging Ideas

Our Communication Pattern

On meeting Kousa I experienced her as reserved, guarded and introverted. At the same time she was very polite and friendly. She had a warm and gentle disposition about her. As with the Kruger family I felt as though I was intruding.

During the interview Kousa seemed unsure of herself - as though she seemed nervous of making a mistake or saying the incorrect thing. Therefore, in answering or responding to me she was guarded in what she said. This added to the difficulty of the interview as she was extremely conscious of the manner in which she spoke. This made the task of conducting a spontaneous conversation very difficult. I assured her that her English was very good. This confirmation somehow shifted the tone of the conversation - she seemed to relax, allowing the conversation to be less strained. This also allowed the researcher to relax as well. However, Kousa tended to take a more passive role in the conversation. The researcher drew the assumption that Kousa tended to take this position in most situations (this was confirmed during the conversation). In this regard the researcher could identify with Kousa as they share a culture that traditionally promotes silence - particularly amongst the women folk. In this silence there is a sense of entrapment or stuckness and in the light of this the researcher experienced Kousa as vulnerable and 'broken' in a sense.

On meeting Nazir the researcher was definitely taken aback. He was outspoken, no inhibitions, and quite charming. He also appeared to be quite dominant. He made his presence felt. In speaking to Nazir it was clear to note that he held strong traditional beliefs - particularly about women and their roles (ironically these views were not upheld with regards to his own mother). This made the researcher uncomfortable as she has rebelled against these traditional beliefs about women and still does. Nevertheless, the conversation proceeded in a spontaneous manner. The researcher found herself in a

passive role as Nazir seemed to take over the conversation. Our communication style seemed to mirror the manner in which Nazir and Kousa communicated.

Self-disclosure

As with the first case study I used self-disclosure as a means of connecting with both Nazir and Kousa and of establishing an 'ethic of participation' (Kogan & Gale, 1997, p.112). I shared with them my experience of living with a nephew who had leukaemia. This established a conversation from: 'despite our differences, we share common ground', and this helped to position me as an insider to the interaction. It should be noted that our similar cultural backgrounds, I believe, played a significant role as well in positioning me as an 'insider'. The fact that we shared a similar cultural background gave me credibility.

Concluding Remarks

This chapter and the preceding one furnished two case descriptions of families with a child who has leukaemia and the conversations that the researcher engaged in with both of the families.

Chapter 7 contains an overview of the research findings/results.

CHAPTER 7

RESEARCH FINDINGS: AN OVERVIEW

Introduction

In this chapter the researcher constructs a story about how each child's illness co-evolved with his own unique context. The themes identified as common to both of the participant scenarios are then examined, as well as the common patterns that emerged. Finally, comparisons will be drawn from the findings of this dissertation with that of the literature reviewed in Chapters 2 and 3.

From Perturbation to Enduring Pattern

In Chapter 3 several theoretical perspectives were presented. Furthermore it was argued that a symptom initially occurs as a random, destabilising fluctuation which only becomes structurally coupled with its context as it recurs (Bloch, 1987). In the process of structural coupling, a consensual domain or linguistically co-created reality develops about the problem (Anderson & Goolishian, 1987). In essence illness/ symptoms co-evolve with their context to develop an ongoing self-regulating symptomatic pattern (Bloch, 1987).

Viewed from this co-evolutionary perspective, Paul's illness started out as a random phenomenon coinciding with flu-like symptoms such as fatigue, loss of appetite, lack of motivation, withdrawal, tiredness and fever. During a time away from school, however, his illness and life ecology co-evolved, whereby aspects of the condition (leukaemia) became life threatening (chronic) even after the original context no longer existed (Sluzki, 1981). This means that as the problem (leukaemia) and aspects of it (for instance, the conflicting discourses in which family members participated) co-evolved together, changing each other and improving their mutual fit over time so that a self-maintaining pattern (in this

case, leukaemia) formed (Bloch, 1987). As a result symptomatic patterns may endure even though the original context no longer exists. It would be noteworthy to mention that prior to Paul being diagnosed his parents had decided to divorce. This decision was not shared with the children. However, there was concern that Paul had an idea of what was brewing. It was this suspicion that prompted the parents to seek psychological help for Paul and his sister (Liesel) - the parents did not attend therapy. The childrens' wellness was measured in terms of good IQ scores (as long as the IQ scores of both Paul and Liesel remained constant - this meant that they were coping - as far as the parents and therapist were concerned).

Even though the family experienced many problems (both prior to and during the illness), particularly in the area of the spousal relationship, the leukaemia took precedence as the main/primary problem and was maintained as a result of the mutually coordinated linguistic behaviour of the participants involved in Paul's life/illness (i.e. family members, friends and doctors/medical staff) (Anderson & Goolishian, 1987; Griffith et al., 1990). Therefore, Paul's illness was maintained as a result of the coordinated linguistic behaviour of the people involved in his life. Furthermore this in turn maintained the leukaemia as the primary concern or problem and took precedence over all else. This behaviour formed the context of his illness. As Paul's illness accompanied a real medical condition, the consensual domain or shared beliefs about the problem would have mutually qualified the leukaemia as involuntary and deserving of concern and specialised medical treatment.

Somewhere along the way the idea that Paul was strong, confident, grown-up, responsible and sensitive became mutually qualified by the behaviour of his parents (especially his mother) and his peers with whom he interacted. By this definition he took on the role of protector and confidante (to his mother) and adviser (to his friends). It was noted that Maria confided in Paul, but Paul had been unable to share his vulnerability with her or anyone else. Rather than using emotional language to express emotional distress within the system, somatic language is used to describe all difficulties, whether emotional

or physical (McDaniel et al., 1992). As Griffith and Griffith (1992, p.49) state: 'sometimes there can be overt political and cultural prohibitions against speaking about certain dilemmas, leaving only the language of the body for expressing sorrow'. The inability to express one's self was not only evident at the individual level (Paul) but also at the level of the couple (and in their families-of-origin). This pattern seemed to be perpetuated across the generations.

Thus, Paul's illness could be viewed as an expression of his inability to express himself in a different manner from this tradition of silence. Furthermore, his own ambivalence (i.e. wanting closeness and distance between his parents) and the ambivalence at the level of the couple (i.e. having to stay in a marriage but not really wanting to - staying only for the well-being of Paul) could be also seen as an expression of his ambivalence (as well as the conflicting discourses) in the form of a symptom (leukaemia).

In Aziz's case, the leukaemia could be seen as a random destabilising event which occurred after another 'critical moment of stability' (Onnis, 1993, p.142), namely his parents' silent agreement to divorce (this could also be the case with Paul). Again the consensual domain established by those who interacted concerning the problem (i.e. his family) would probably have mutually qualified Aziz's illness as involuntary (biological/physiological), and possibly as a sign of his parents' failure. Interestingly, Kousa reported that her mother-in-law would react angrily towards her stating that she was to blame for Aziz's illness (this seemed to imply that the mother-in-law believed that Kousa should be in control of the problem) and thus, the mother-in-law (alone) possibly qualified Aziz's illness as being the consequence of an external determinant, as opposed to a biological determinant (Kelley, 1967; Rolland, 1987). The mother-in-law could be seen as representing the larger socio-cultural system in which they lived (i.e. an Islamic perspective).

The idea that Aziz was a 'model' child would also have formed part of the family's consensual domain. Indeed this opinion was mutually qualified by the behaviour of Kousa

in particular, who relied on Aziz for support and care. Aziz took on this burden and certainly could not express his own pain and vulnerability. But how could he express these feelings when doing so would have been mutually qualified by the system as an act of rebellion and thus as incompatible with the dominant 'model' child story? He could not. Besides, in his family context to express one's self - meant being disrespectful; this interpretation/perception was a pattern that was perpetuated through the generations. Furthermore, his autonomy as the model child had to be conserved. It is not difficult therefore to understand how Aziz's illness and his context established a mutual fit over time; the language of the body was the only medium through which Aziz could communicate dilemmas concerning his family's relationships (McDaniel et al., 1992). There was a tendency for Aziz to receive attention for his physical pain but not for his emotional pain. This approach conditions members in the system to experience any need or problem as physical, and physical symptoms become their language for a range of experiences (McDaniel et al., 1992). Thus, Aziz's illness could be viewed as an expression of his ambivalence (i.e. simultaneously wanting closeness and distance).

In this regard the fit between the ways of thinking about Aziz and his family system, particularly his mother, is interesting particularly as it is similar to Paul's context: Aziz's illness evoked a closeness between his parents who at the same time were desperate to get away from each other (either to separate or to divorce). This conflicting discourse seems to mirror Aziz's ambivalence - as expressed by the symptom. It is important to note that illness rarely precipitates family disintegration, but rather exacerbates already existing problems or unstable relationships.

Emerging Themes

Avoiding Conflict and Issues

In Paul's family his mother believed that her tendency and Piet's to bottle up

negative feelings had a negative impact on the family. This was a style of communication that both Piet and Maria had learnt from their own families-of-origin. Paul seemed to have learnt and to be continuing this style of communication, but Liesel on the other hand seemed not to want to continue with this pattern of communication (this was perceived by her family as an act of rebellion). It may be that Maria's view of herself as a caring and loving person excluded confrontation from her behavioural repertoire. Paul, being characterised as sensitive and responsible, also seemed to exclude confrontation from his behavioural repertoire. Furthermore, this family's difficulty (with the exception of Liesel) in asserting itself and expressing 'negative' feelings was consistent with the consensus that it behaved appropriately. Because Maria (and Piet) disliked conflict and believed that by asserting herself, particularly in her marriage, would not make a constructive difference, she (and Piet) preferred to go along with, rather than oppose, each other. However, avoiding conflicts and issues often left the family feeling tense and frustrated and this reciprocally perpetuated the pattern of avoidance in that Maria would withdraw from the situation to prevent a potential argument. The consequence of this action was that Maria would seek out Paul thereby strengthening their alliance and an already enmeshed relationship. Furthermore, Maria believed that Piet was not supportive of her. Maria also felt that Piet did not open up enough to her. In this interaction it appeared that the couple had not established a clear rule for dealing with conflict. They tended to communicate in a masked and indirect manner.

In Aziz's case there were clear rules for dealing with conflict. The social/cultural consensus dictated that the role of women was to be quiet and obedient, which generally meant to be submissive. Any deviation from this prescribed role was viewed as disrespectful and in this case as non-Muslim. Kousa certainly found herself being labelled the disrespectful wife. So, her very existence and even that of her husband was forged in ambivalence (i.e. wanting to rebel but being restrained by tradition/culture; wanting an educated, progressive wife but fearing the consequences). Kousa's difficulty in asserting herself, if doing so meant upsetting people or refusing their requests, was consistent with

her definition of herself as a good mother figure, but incompatible with her view of herself as a 'forthright' person. Aziz's leukaemia could be seen as an expression of these conflicting perspectives/discourses and as a means of dealing with the inconsistencies in his family. When Aziz was feeling unwell (this would frequently coincide with his mother feeling the very same way) he would, more often than not want only her to take care of him. Therefore, Aziz's illness was functional in this family in that it gave his mother a purpose (i.e. to take care of him) and it also helped Kousa to be forthright in avoiding meeting Nazir's needs without having to take responsibility for, and face, the consequences of her behaviour. This was because Aziz's illness was mutually qualified by his parents as serious and therefore any request from him was not challenged if it was seen as making him more comfortable/happy (these requests could also be seen as secondary gain for Aziz).

This conflicting discourse seems to mirror Aziz's ambivalence - as expressed by the symptom.

In the light of the above interaction between Aziz and his mother the distinction can be drawn that family patterns of interaction, the individual, and family members' physiological functioning, influence one another (Wood, 1994). This is not only evident in this case study but also in the other case study (the Kruger family) as well.

Loyalty and Protectiveness

Maria's sense of loyalty (as well as Piet's) was underscored by the fact that they had been married for 12 years. However, they had become disenchanted with their marriage and therefore no longer felt 'loyal' to it (more so Paul). Despite this development there was a strong commitment to conserve/protect the family's autonomy. According to a second-order perspective, if a system loses its autonomy it is destroyed as a system. Therefore, it will always strive to conserve its autonomy. From this perspective then, symptoms reflect ideas about the conservation of autonomy. One should remember that

conservation of autonomy is only an idea of the observer and not a concrete reality (Fourie, 1993). Paul's illness was functional in this sense because it allowed his parents to work closely together to get him well, but it also allowed for closeness and distance at both the individual level and the couple level. Because of the threat to the child's survival, the couple may not have been attentive to the evidence or sources of discord and may have evaluated their marriage favourably. Since systems have idiosyncratic ways in which conservation can be attempted, conservation of autonomy manifests itself differently with different families and with different people (as can be seen in both the case studies in this dissertation). Maria's loyalty and protectiveness can be seen in her act of leaving work in order to take on the responsibility of minding Paul (this was a mutual decision between herself and Piet). She would oblige Paul's requests, sometimes against the wishes of Piet, which could have introduced a conflict between loyalties for Maria between her son and her husband - this did not seem to be the case because even though Maria was committed to Piet, however, she was more committed to Paul and his well-being. If Piet was at home, Maria would feel obliged to be there with him; if he made a decision she generally went along with him because to do otherwise would be an act of 'disloyalty' and might upset Piet or create tension/conflict (in an already tense environment) which she wanted to avoid.

The need to protect (conserve) the family was so strong that they decided to cut themselves off from the extended family and even from some friends. The boundary around the family system became rigid/closed. Ironically, even though there was exclusion of family members and friends, Paul's illness encouraged substitutions in the form of doctors and other medical staff as well as parents of other ill children with leukaemia. The parents' overprotection of the ill child introduced an additional dimension of interaction into the system - it induced his isolation from his sister and consequently Liesel found it difficult to express her feelings of rivalry and hostility toward her brother.

The theme of loyalty and protectiveness was also evident in the Loudi family. In their story the theme of loyalty and protectiveness was not only evident at the individual

level, but also at the level of the families-of-origin and was therefore a shared premise (Boscolo et al., 1987). To remain loyal to her parents, Kousa married Nazir, even though this was against her will. Not to have agreed to marry him would have meant being disloyal to her parents. Kousa's loyalties seemed to be divided between loyalty to her own wishes and needs, and loyalty towards others (family/husband), including the dominant cultural discourse. Kousa's mother also shadowed this strong sense of loyalty. So loyal was her mother to the idea of family that her life revolved around her adult children and husband (in particular). Nazir also felt a strong sense of loyalty towards his family, to the extent that he chose 'the right girl' (so as not to disappoint his parents). However, the emphasis on loyalty and protectiveness put some family members in a difficult position whereby loyalty towards one member was often in conflict with another member. This is evident in the relationship between Kousa and her brothers. Hence, their agreement with their father to get Kousa married represented loyalty to their father and disloyalty to their sister.

Kousa also was very loyal to Aziz and he reciprocated this loyalty. Thus, the theme of loyalty is evident across the generations (i.e. three generations). Embedded in his sense of loyalty was his need to protect his mother from a system that did not acknowledge her self worth. His illness was functional in this regard in that it gave her purpose (i.e. to take care of her son) and demonstrated her worth as a good mother. The illness also served to protect her from Nazir to some extent, in that once Kousa was involved in taking care of Aziz she could avoid potential conflict - there was a calming of potentially turbulent waters (the autonomy of the system was conserved/ maintained).

Resentment and Guilt

This theme is inextricably connected to the theme of anger. Maria had questioned whether or not she was contributing to Paul's illness, or had contributed to his illness. She felt guilty with the knowledge that she could be contributing to her son's illness. She also

resented the fact that her ability to help Paul was so limited. Maria also resented the fact that she could not make things right for Paul. She was frustrated that she could not solve this problem. Both Piet and Maria felt guilty about Paul's illness and because there was no medical explanation for his illness they began looking for other causal attributes - themselves and each other. For a time they became entangled in a web of blame. This resentment and guilt seemed to fuel the anger that already existed between Maria and Piet. They had a history of anger between them even before they had married (according to Piet this was never dealt with), which became progressively worse over the years. This theme seemed to play a significant role in the evolution of this family (i.e. both in the spousal subsystem as well as the sibling subsystem): the conflict of feeling guilty of possibly causing Paul's illness and the frustration of not being able to cure him. This 'cure' would mean having to deal with issues that they preferred not to delve into - such as their anger (which in itself was shrouded by secrecy). However, the anger did have some of its roots embedded in the fact that Maria had an affair. The researcher was of the impression that their anger revolved around deeper issues of which the aforementioned was only one of many. The other reason (s) for their anger was not made explicit. The theme of anger was also evident at the sibling level. Maria reported that the children were also angry. This may be seen in Liesel's rebelliousness toward her parents (however, developmental issues should also be considered when drawing such a distinction). Paul's expression of his anger as well as the conflicting discourses (ambivalence) in his family could be in the form of his illness, since he is not as verbally expressive as his sister.

Aziz was also trapped in similar discourses around the theme of resentment/anger and guilt. Like Maria and Piet, Kousa and Nazir also felt guilty about their son's illness. However, since both Nazir and Kousa came from a medical background they believed that there was a biological/physiological causal attribute involved in their son's illness. There was further frustration in terms of medical treatment being so limited in its approach to treatment of the whole person. Nazir in particular felt that he was failing, and had failed, Aziz. He resented the fact that the family was placed in this predicament. Furthermore,

Nazir's and Koussa's resentment and guilt was also fueled by anger. Their relationship also had a history embedded in anger, which likewise seemed to play an important role in the evolution of their family. The anger that they had brought into the marriage was explicit. Koussa was angry that she was forced to marry a man she did not want. Nazir's anger seemed to evolve with the course of the marriage. He felt marginalised by his wife and he resented this.

Koussa seemed to look to Aziz for support, after all, caring for him gave her self-worth while other members in the system including Nazir at times disqualified her. Voicing her resentment would be incompatible with appropriate conduct, and she also lacked the self-confidence to assert herself. Aziz's illness allowed her to achieve this. It seemed as though Aziz was the only one that knew his mother's needs; after all they seemed to connect at a deeper level (for example, when Koussa was under the weather Aziz also seemed to feel the same). Childrens' bodies like our own bodies are tuned to the resonance of family rhythms and when something goes wrong with their bodies, the reverberations penetrate deep into the consciousness of families and health professionals alike (McDaniel et al., 1992).

It is often assumed that people come together out of mutual consent (such as love and commitment). However, some may be influenced by their own life circumstances and come together not because they feel committed but because they may have evolved a mutual fit of coexisting with each other. This seemed to be the case with Maria and Piet. Their relationship was fueled with anger prior to their having made a marriage commitment. They felt that they were no different from any other couple entering into marriage. Though there were many reservations as to whether or not they should get married, it was stated by both Piet and Maria that they were two lonely people and the other person filled the void. Over the years this issue of coming together 'unwillingly' (involuntary systems) was never discussed or dealt with. Also the anger that they both confessed to was not discussed either. It could be stated that this theme in their lives

could have contributed to the many conflict discourses that they experienced in their lives (pile-up phenomenon - McCubbin & Patterson, 1983).

In Nazir and Koussa's case this theme is very explicit. It was clear from the outset that they were not willing to come together, particularly Koussa. For Koussa this was a sentence to a life she did not want. In her resentment and bitterness she chose her son to be the man in her life, as opposed to her husband. In so doing, there were implications for the way Nazir and Aziz communicated and connected. The dance in which Nazir and Koussa engaged around how they communicated and interacted with each other is described in Chapter 6. Since, Aziz was in tune with the rhythms of his family, it is not surprising that Gottman and Katzman (1989) argue that health-related physiological processes in children are shown to be linked to the quality of the parental relationship. In this regard there is mounting evidence for the linkage between certain family interactional processes and childrens' physical well-being as well as psychological well-being (McDaniel et al., 1992).

The theme of resentment and guilt is also evident at the sibling subsystem. Since chronic illness threatens the integrity of the sibling's relationship with the ill child, the opportunity to interact are reduced as the ill child is physically less able to keep up with the healthy sibling (Haversmans & Eiser, 1994). The healthy sibling may perceive that they are treated differently, and as a consequence of this perceived differential treatment there may be heightened conflict and resentment between siblings (Boer, 1990). Furthermore, the healthy sibling may externalize behavioural problems, such as aggression and acting out (Breslau et al., 1991; McCubbin & Patterson et al., 1983). This can be clearly seen in both the case studies whereby the healthy siblings were both labelled as being rebellious. However, in this regard developmental factors should not be ignored.

Closed and Rigid Boundaries/Secrecy

In both the case studies (Chapters 5 & 6) there was a tendency to close off the family from the rest of the world. The closed boundaries and rigidity in both the families can be seen as a means of maintaining the status quo (Minuchin et al., 1978). In periods when change and growth were necessary, the families experienced great difficulty. Their accustomed methods of interaction were retained. When Aziz and Paul fell ill their parents decided that the family would cope with the illness on their own.

In the case of the Loudi family they decided to keep Aziz's illness a secret - until it exposed itself. The cultural discourse in which this family was embedded placed many constraints on their lives. Therefore, to confess that there was a problem would have impacted directly onto the parents (i.e. both families-of-origin and community would have judged them alike as having failed as parents). The Kruger family did not keep Paul's illness a secret but allowed only minimal interference from the extended family. They also cut off many of their friends and in so doing reduced their social support system. A strong support system has been associated with better adjustment in parents of children with a chronic illness (Overholser & Fritz, 1991). Once again it can be assumed that the families' need for conservation was very strong.

Enmeshment/Mother-child alliance

This theme will be discussed as part of the tapestry of the theme of triangulation as they are interwoven themes.

'Enmeshment refers to an extreme form of proximity and intensity in family interactions' (Minuchin et al., 1978, p.112). This interaction was not denied or kept secret by either parent in both the case studies. According to Haley (in Penn, 1983) a different kind of coalition is observed in families with chronic illness. These coalitions cross

generation boundaries and are not denied or kept secret in the usual sense. However, they are frequently fastened to the nuclear family by means of a special set of interactional events around illness in the past which, until the present illness have been folded darkly away.

Maria had openly admitted that Paul and she were far too enmeshed and acknowledged the fact that this was an unhealthy relationship. Kousa also admitted to having this type of relationship with Aziz, but did not acknowledge that it was an unhealthy one. For both families the relationships certainly had implications at all levels (i.e. family subsystems and individual systems). The establishment of this rigid mother-child alliance interfered with their spousal role. In turn the fathers adopted a rigid attitude and became isolated from their wives. The couple therefore found it difficult to communicate their real feelings to one another. The coalition in the nuclear family looks open and adaptational, but is fueled by coalitions in the past, which, though not secret are totally divorced from the family's understanding of their present dilemma.

In the Kruger family's case the enmeshment between Maria and her son further fueled the distance between Piet and herself, contributing to further marital conflict (Minuchin et al., 1978; Wood, 1994) and this in turn maintained the enmeshment between Maria and Paul - a reciprocal pattern of interaction emerged and remained stable over time. In so doing a pattern of triangulation was also maintained (Wood, 1994). Wood (1992) found the pattern of triangulation to be a strong feature in the psychosomatic family.

This pattern of interaction also emerged in the Loudi family. The pattern of triangulation can be seen as far back as their respective families-of-origin. For example, the interaction between Kousa, her brothers and her father, as well as the interaction between Kousa, her mother and her father. This pattern was also perpetuated in Nazir's family. This is evident in the interaction between himself, his mother and his father, as well as his brothers, himself and his father. Aziz and his sister also fell victim to this pattern of

interaction (as described in Chapter 6). Thereby becoming engaged in conflicting issues between their parents.

It is important to note that systems other than the family system should also be considered in the process of triangulation, such as the health-care system. However, this dissertation did not explore this context.

This study, although using a different perspective with which to view childhood leukaemia, has shown some consistent findings with other research attempts, even though the sample size was very small in this study. This dissertation looked at the parents' relationship prior to and during the marriage (with and without children). This is significant because earlier research has not looked at the family as an interactive network of interdependent interactions. More so, earlier research had not looked as far back as the family-of-origin - this dissertation has attempted to do this with a view of providing a historical picture of two families' social contexts and the patterns and themes that were perpetuated in the context of illness. The following findings have been identified:

There was a tendency for the families to experience increased closeness after the diagnosis, but the individual boundaries did not disappear (Minuchin, 1974). The illness had been associated with a strengthening of the family's cohesiveness. This increased closeness is viewed as a positive outcome, only insofar as it remains a balance between enmeshment and disengagement (Minuchin, 1974). This was found in both the case studies in this dissertation as well as other research (Chapter 2). However, the pattern of enmeshment far exceeded the need for disengagement between mother and son in both the case studies. Consistent with other research it was found that since the ill child demands a great deal of attention his/her mother places her duties in relation to the rest of the family on a rather secondary level. As a consequence, a rigid mother-child alliance was established which interfered with her spousal role and the father, in turn, became isolated from his wife. It should be noted that the child's illness further exacerbated the strengthening of the mother-child relationship. The mothers in both the case studies in this

dissertation experienced increased isolation as their involvement with their sons intensified.

Haley (in Penn, 1983) found that coalitions in a family with a chronically ill child cross generation boundaries, but are not kept secret or denied. Penn (1983) has called these interactions around coalitions binding because they are rigidly committed to one course and one outcome. This was found in both the case studies - the fathers acknowledged this and even questioned whether or not this type of relationship (between mother and son) was healthy or unhealthy. The husbands reported feeling alienated from the ill child and worried about their wives' over-involvement with the ill child (Cook, 1984). There was an open transaction for the mother-child alliance - it does not have to become covert since the system is not considered pathological - there is no secrecy, and there is no disqualification of meaning.

As in the case of other research it was found that there was a family tendency to isolate from the rest of the surrounding world, and the family limits became diffused in regards to the family-of-origin (Horwitz & Kazak, 1990). The rigidity and overprotectiveness of a family with a chronically ill child, combined with the constant mutual impingement of pathological enmeshment transactional patterns, makes families' thresholds for conflict very low (Minuchin et al., 1978). This means that the system offers resistance to change beyond a certain range and maintains preferred patterns as long as possible. Many families deny the existence of any problems, as they are highly invested in consensus and harmony (Minuchin et al., 1978). Both the families in the case studies avoided conflict and this was seen as a means of maintaining or conserving the system's autonomy. The patients' symptoms acquired new significance as a regulator in the family system - this seemed to be the pattern in both the case studies. It was found that when Aziz or Paul was ill their illness became a regulator for determining both closeness and distance from other members in the system. It was also noted that the ill child is involved in parental conflict in particular ways as was demonstrated in the case studies (Chapters

5 & 6). During the child's illness a complementary relationship was formed between the marital partners: husbands were high in the instrumental tasks and problem-solving while the wives were high in the expressive and emotional domains (Jackson, 1965). Cook (1984) found that mothers became the caretakers whilst the fathers were the breadwinners. Burke and Weir (1976, 1979) noted that the complementary relationship established between spouses might also extend to their coping behaviour. This seemed to be the case in both the case studies as both families made conscious decisions around who was to take care of the ill child and who was to see to other matters. In both the case studies this did seem as a means of gaining some control over the situation. Parental reactions to their child's illness are influenced by many variables, such as personality, previous experience with illness and caretaking in each spouse. Family-of-origin issues may also be critical, influencing coping styles employed by each spouse and the manner in which the family reorganises itself to meet the needs of the ill child (Kazak & Nachman, 1991).

The following diagnostic pattern seemed to emerge from both case studies: Since the affected child demands a great deal of attention, his or mother places her duties in relation to the rest of the family on a secondary level. As a consequence, a rigid mother-child alliance is established which interferes with her spousal role, and the father, in turn, adopts a rigid attitude, and remains isolated from his wife. In as much as their life as a couple is blocked or compromised they find it difficult to communicate their feelings to one another. On the other hand, the siblings may find it very difficult to express their feelings of rivalry and hostility towards the ill child, the latter becomes the unique centre of attention in the family, and the parents' overprotection induces the ill child's isolation from his or her sisters or brothers. In other words, as soon as the diagnosis is known, the family undergoes a profound crisis that gives rise to a series of adaptive mechanisms.

The results of the case studies suggest that the family of a leukaemic child reorganises its structure in a common diagnostic pattern, in which several changes were

observed. First, there was a family tendency to isolate itself from the rest of the surrounding world, and the family limits became diffused with regard to the families-of-origin. In the process of the reorganisation the ill child is included in the parental subsystem, and acquires authority and a controlling position through his illness. It is important to note that although family members declared the existence of a feeling of togetherness, the individual limits did not disappear. On the contrary these limits became closed and rigid. This could be accounted for by the fact that all members were possibly locked up in their thoughts of sadness, fear, anger, unresolved issues (i.e. in the case of the spouses' relationships), and were unable to express their feelings (a three generation pattern).

It is possible that the observed reorganisation might be present in other types of chronic illness in which there exists a disease representing a serious threat to a child's life. Thus, these changes represent an example of a functional adaptive pattern. However, under various circumstances, this pattern may lose its functionality, become rigid, and consequently symptoms will appear. These circumstances include:

- The existence of a strong mother-child alliance prior to the disease.
- The prolongation of the critical stage of the disease over an extended period of time.
- The overprotection of the patient, promoted by guilt feelings of the parents.

A possible explanation for the families' disintegration in the case studies, secondary to the disease, could be the accentuation of the already present conflicts among the parents as a consequence of the mother-child alliance, which implies an important separation between the parents. On the contrary, the establishment of this adaptive pattern could promote better family functionality when:

- There was an already marked family tendency to disengage prior to the disease.
- The mother or the ill child had a low hierarchical position (this was certainly the case in the second case study where Kousa occupied a very low hierarchical

position).

- The parents had a symbiotic relationship.

Conclusion

The above themes have been drawn as distinctions by the researcher as themes common to both families with an ill child (leukaemia). All of the above themes are interlinked to form a complex web of interactions (between and amongst family members) that are embedded in conflicting discourses of ambivalence, as has been illustrated by the case studies.

The following chapter furnishes the conclusion to this dissertation as well as recommendations for future research.

CHAPTER 8

CONCLUSION AND RECOMMENDATIONS

Introduction

In this concluding chapter, the strengths and limitations of the study will be evaluated. The implications of an ecosystemic psychotherapeutic approach for the treatment of chronic childhood illness (leukaemia) will be noted, as well as recommendations for future research.

General Discussion of the Study

The research aim was to seek a more holistic understanding of the ill child's context and experience, and to furnish a descriptive account of the recursive connections between the illness and the individual sufferer's social context.

The literature reviewed in Chapter 2 indicated that traditional biomedical and psychosocial conceptualisations of leukaemia are limiting inasmuch as they reflect the Cartesian dichotomy between mind and body which has severely restricted the emergence of a comprehensive understanding of the medical condition (Capra, 1983). This in turn has reduced/limited treatment options. By shifting from an emphasis on intrapsychic factors and an explanatory, quantitative methodology, towards a focus on social context and meaning, using a descriptive, qualitative design, this study attempted to address these shortcomings.

In adhering to Maturana's (1975) concept of structural coupling and a constructivist stance, the researcher attempted to describe the problem-determined systems from within these systems, not as if from the outside. Thus, no Cartesian claim to objectivity was postulated. Furthermore, no single perspective was viewed as the perspective; multiple ideas and distinctions evolved throughout the process to co-

create a reality that made sense to, and thus fitted the idiosyncratic system at hand (Anderson & Goolishian, 1988). Consistent with constructivist epistemology, therefore, this study did not dogmatically claim to have found the truth about chronic childhood leukaemia. Rather, truth was defined as heuristic (Auerswald, 1987). The studies and theories discussed in the literature review provide additional perspectives on childhood leukaemia and this study simply adds to the existing body of knowledge about the condition, though from a different perspective.

Rich accounts of two families with a chronically ill child were presented. Their experiences and relationships (as tracked from their respective families-of-origin) gave readers a glimpse of two unique life ecologies. Themes were identified and the common themes that emerged from the stories of the families were delineated. These themes were connected to a pattern of conflicting discourses in which the respective respondents participated. It seemed that the ill child's symptoms (leukaemia) could be viewed as an expression of these conflicting discourses or ambivalences. The themes common to both families included:

- Avoiding conflicts and Issues
- Loyalty and Protectiveness
- Resentment (anger) and Guilt
- Closed and rigid boundaries/secretcy
- Enmeshment/Mother and son alliance
- Triangulation

A summary of the findings follows:

There was a tendency for the families to experience increased closeness after the diagnosis, but their individual boundaries did not disappear (Minuchin, 1974). This finding occurred in both the case studies in this dissertation as well as in other research (Chapter 2). Consistent with other research findings, it was found that since the ill child demands a great deal of attention his/her mother places her duties, in relation to the

rest of the family, on a rather secondary level. As a consequence, a rigid mother-child alliance was established which interfered with her spousal role and the father, in turn, became isolated from his wife.

Haley (in Penn, 1983) found that coalitions in a family with a chronically ill child cross generation boundaries, but are not kept secret or denied. Penn (1983) has called these interactions around coalitions binding because they are rigidly committed to one course and one outcome. This was found in both the case studies: the fathers acknowledged the relationship between mother and son, and even questioned whether this type of relationship (between mother and son) was healthy or unhealthy. The husbands reported feeling alienated from the ill child and worried about their wives' over-involvement with the ill child (Cook, 1984). There was an open transaction for the mother-child alliance: it does not have to become covert since the system is not considered pathological - there is no secrecy - and there is no disqualification of meaning. In the case studies in this dissertation it was found that a strong coalition occurred between the second and third generations (i.e. between the mother and the ill child). No other strong cross-generational coalitions were noted. Though Minuchin (1974) observed that there are strong cross-generational coalitions in a family with a chronically ill child (i.e. between the grandmother and the ill child), on the contrary this dissertation found that the coalitions across the first and second generations were very weak and almost non-existent. This was also true for the first and third generations within the system.

As in the case of other research it was found that there was a family tendency to isolate itself from the rest of the surrounding world, and the family limits became diffused in regards to the family-of-origin (Horwitz & Kazak, 1990). The rigidity and overprotectiveness of a family with a chronically ill child, combined with the constant mutual impingement of pathological enmeshment transactional patterns (as in the case of the case studies), made the families' thresholds of conflict very low (Minuchin et al., 1978). This means that families dealing with the challenges of coping with an ill child have not established effective ways of dealing or coping with interpersonal conflict.

Therefore, to deal with the threat of conflict within the system would threaten the current existence of the family's system. Many families therefore deny the existence of any problems, as they are highly invested in consensus and harmony (Minuchin et al., 1978). Both the families in the case studies avoided conflict and this was seen as a means of maintaining or conserving the systems' autonomy. This means that the families strived to maintain their family systems. The desire to preserve their respective family systems was very strong - given that the threat of illness threatened their existence as a family. The use of symptoms to conserve autonomy can be seen as indicative of a perceived threat to the autonomy of the individual or family. It is a desperate means of self-preservation.

The patients' symptoms acquired new significance as a regulator in the family system - this seemed to be the pattern in both the case studies. It was further noted that the ill child was involved in parental conflict in particular ways, as was demonstrated in the case studies (Chapters 5 & 6). Illness rarely precipitates family disintegration, but rather exacerbates already disintegrating or unstable relationships (Kupst & Schulman, 1988). Therefore, the quality of the marital relationship is significantly related to overall functioning or family coping.

During the child's illness a complementary relationship was formed between the marital partners: husbands were strong in instrumental tasks and problem-solving while the wives were high in the expressive and emotional domains (Jackson, 1965). Cook (1984) found that mothers became the caretakers whilst the fathers were the breadwinners. It was found that there was a tendency for couples in the case studies to either separate or divorce. This was consistent with other research, but also in contradiction to research that has found that the marital relationship is strengthened through the parents' shared experience(s) of having a child with leukaemia (Peck, 1979).

Strengths of the Study

Capra (1983) states that to understand and to deal with pain effectively, it must be viewed in its wider social context. He further calls for a shift in focus from quantity to quality, arguing that 'the art of healing cannot be quantified' (p.141).

This study was founded on a holistic and unifying ecosystemic epistemology. As such, it adopted a 'radically different way of thinking' (Auerswald, 1987, p.325) from the conventional narrow and reductionistic conceptual frameworks underpinning most of the contemporary psychological research into childhood illness (leukaemia). Therefore, one of the strengths of this study was that it took the respective families' contexts (life ecologies) into account, including the attributions of the ill child's parents, belief systems, life circumstances and relationships. Had a quantitative approach been used, idiosyncratic attributions of meaning would have either been lost, or would have assumed statistical importance and the findings would have differed considerably from those of the present study; not necessarily more 'accurate' or 'true' or 'false', but different. In the author's opinion, the researcher, respondents and readers would also have been deprived of an opportunity to make sense 'of a total circumstance' (Fourie, 1996a, p.19).

In contrast to traditional conceptualisations of the problem as a semi-concrete entity (Fourie, 1996a) located within the sufferer, an alternative way of viewing childhood leukaemia was provided. By viewing childhood leukaemia as existing in communication networks, this study transcended the mind-body dichotomy and facilitated the co-creation of different realities. Western adherence to the mind-body dichotomy, on the other hand, has not only resulted in a poor understanding of problems, but also has polarised professionals and thwarted their collaboration, as well as increasing the cost and utilisation of fragmented medical services. Moreover, the cause-effect, symptom-focused approaches of Cartesian dualism confirm the illness theme and therefore frequently escalate the symptoms (Capra, 1983; Engel, 1992; McDaniel et al., 1995)

Another advantage of this research is that because it was informed by a constructivist, as opposed to a realist epistemology, it approximated the clinical situation more closely, and thus may provide clinicians with usable material (Fourie, 1996a).

Trustworthiness of the findings rather than the traditional validity and reliability - was achieved in the study. The researcher disclosed her orientation, was open to the contextual factors that shaped the inquiry, and interacted with the participants until redundancies emerged in the information (Lincoln & Guba, 1985). She formed respectful and trusting relationships with the participants and conducted informal member checks: that is, she tested her interpretations with the participants (Lincoln & Guba, 1985). Member checks were carried out continuously as meanings were co-created through dialogue, which enabled the participants to challenge any misunderstandings immediately (Reason & Rowan, 1981). The researcher engaged in self-reflexive dialogue with the material, which enhanced her understanding of the data. Peer debriefing was used to explore aspects of the study (Lincoln & Guba, 1985) and this helped to enhance the researcher's 'peripheral vision' and thus established credibility. In presenting the case studies, extracts from the interviews were included to substantiate the researcher's re-constructions and to help readers to make sense of or to contextualise the subject.

Shortcomings of the Study

One of the limitations of this study is the application of its stated epistemology. The researcher could have improved the quality of the report and further enhanced its trustworthiness by making the project's observer-dependent nature more explicit (Evans, 1992) (observer-dependent descriptions are coherent with a constructivist, ecosystemic epistemology). The researcher's descriptions represented a reconstruction of the participants' constructions, and reducing the data diluted the richness of the respective stories. Although including transcripts of the interviews would have increased reader access, this was considered impractical. The transcripts

were voluminous, and in this regard it was considered impractical to include them in the dissertation. Pertinent extracts from the interviews were provided instead.

Because this study emphasised personal and unique social and contextual factors - including the researcher's idiosyncratic way of punctuating events - and used a descriptive, qualitative method, the findings cannot be 'proved' or verified by future replication. From a traditional perspective this would be viewed as a serious shortcoming or limitation in terms of reliability. Furthermore, in this perspective replicability is based upon a realist epistemology (Fourie, 1996a; Lincoln & Guba, 1985). However, from a constructivist point of view, research results are co-constructed in social discourse and, therefore, do not reflect an absolute reality, but rather one reality among many possible realities. Thus, an ecosystemic perspective does not aim to 'prove' anything but rather to make sense of the entire inquiry. Consequently, the lack of possible replicability is not regarded as a limitation in this perspective.

One of the limitations of qualitative research is that the human mind tends to select data that fit with working hypotheses and initial impressions (Moon et al., 1990). The implication of this is that the themes and meanings elucidated by the researcher are not the only distinctions that could have been made. Hence, the meanings that readers attribute to the case studies may well differ from the researcher's meanings.

This study could also be criticised for not diagnosing and classifying leukaemia into categories. To have done so, however, would have been coherent with a reductionistic biomedical conceptualisation and, hence, a realist epistemology. Important in terms of this study's constructivist stance, were the participants' idiosyncratic definitions and descriptions of their experience within a leukaemia context. However, the fact that the researcher was unable to interview the ill child or sibling may also be deemed to be a serious limitation.

Another limitation is that member checks were not conducted formally (Lincoln & Guba, 1985), which means that the participants were not provided with the research report for comment. The researcher decided against this, believing that outcomes are negotiated continuously as the participants make inferences from what the researcher asks and the themes and leads she follows during the investigation (Lincoln & Guba, 1985). The researcher believed therefore that informal member checks in a study of this limited scope were adequate for establishing the study's credibility.

Implications for Treatment

McDaniel, Hepworth and Doherty (1993) argue that since all human problems are biopsychosocial in nature, the idea of the mind-body dichotomy is completely incompatible with the needs of people affected by chronic illnesses. As Seaburn (in McDaniel et al., 1993, p.27) states: 'physical conditions become metaphors for other things happening in people's lives'.

One of the important consequences of adopting an ecosystemic approach to the study, diagnosis and treatment of chronic disorders is that the complicated issue of whether the cause of a particular problem is physical, psychological, or a combination of both, is essentially irrelevant (Bassett, 1992; McDaniel et al., 1995). As a unifying holistic conceptual framework, the ecosystemic approach does not separate the emotional and physical domains. Neither is it an 'entity-based' approach focussing on an illness condition deemed to reside within the person. The therapist who operates from a second-order cybernetics perspective works with the problem-determined system's ecology of ideas, facilitating a context in which a new ecology of ideas that fits the client's circumstances, is co-created in conversation (Griffith et al., 1990). A new co-constructed reality may result in or foster better functioning and adaptation to the condition, improve the sufferer's interpersonal relationships, and generally enhance his or her quality of life (McDaniel et al., 1995). An ecosystemic-orientated therapist does not focus on the reductionistic removal of a symptom or impose a solution in a direct, linear manner, as is done from a medical or intrapsychic perspective (Fourie, 1996b).

One other implication of working from an ecosystemic epistemology is that in transcending the traditional Western mind-body dualism, this perspective holds the promise for a sorely needed association between the medical and psychotherapeutic fraternities.

The ecosystemic approach is not another treatment modality but rather an alternative way of thinking about problems (Auerswald, 1987). Therefore, the 'conversational practices' that were used in the study were intended to give readers better access to the research process and the researcher's frame of reference, and not to advocate a specific way of working with families of chronically ill children (leukaemia) or the ill child. Thus various other conversations/techniques from different schools of therapy could have been used to introduce new ideas.

Furthermore, every ecology of ideas is unique and includes the therapist's idiosyncratic perceptions, impressions, and attributions towards the situation at hand. Therefore, as Fourie (1966a, p.15) points out, 'it is unrealistic to expect a particular type of perturbation to have similar and therefore replicable effects in such widely divergent ecologies of ideas'.

Nevertheless, based on her limited experience with childhood leukaemia in this study, the researcher wishes to make a few general therapeutic recommendations. Firstly, it is important that the therapist learn the client's language/frame of reference. This means eliciting a description of his/her symptoms as well as the detailed story about the illness in terms of when it began, perceived causes and possible solutions, the reactions of different family members to the problem, coping behaviours, the situations in which the problem is worse or better, and so on. The therapist may be the first person who has ever listened to a detailed account of the patient's story, and in itself, this may prove to be therapeutic.

In the author's opinion, therefore, the patient's illness story needs to be taken seriously and explored thoroughly before other contextual issues may be addressed (this could be another limitation of the study in that the patient's illness story was not

explored for the reasons mentioned in Chapters 4, 5 and 6).

At the same time, however, it is important to move beyond the illness story towards an exploration of interpersonal dynamics so as to avoid possible entrapment in seeking a treatment solution. Moving beyond the illness story, however, would be likely not to maintain the centrality of the problem theme but also to produce less stuckness, frustration or anxiety in the therapist. One way of avoiding such entrapment could be to 'listen to symptoms for any symbolism or metaphor of emotional pain particularly meaningful to the patient and family' (McDaniel et al., 1995). In this study the author also found it helpful to remind herself that the research/therapy process simply involved two (or more) people exploring the ecology of a problem through conversation (Anderson & Goolishian, 1988). The second-order cybernetics concept of conservation of autonomy was also useful in reminding the author that all systems conserve their autonomy, and symptomatic behaviour is one way in which they may do this (Fourie, 1996b).

Recommendations for Future Research

The literature on childhood chronic illness is replete with studies adhering to a realist epistemology in which contextual factors and researcher values are largely ignored/excluded so that the 'truth' about phenomenon may be 'discovered'. If contextual elements are studied, it is generally done so from a realist stance. Ironically, despite an impressive accumulation of theory and research, childhood leukaemia continues to pose a treatment challenge to researchers and health-care providers alike. Therefore, it is suggested that further research be carried out from an ecosystemic/constructivist perspective in which contextual factors are considered and included. This would facilitate the development of a more holistic and comprehensive understanding of 'health' conditions, and close the gap between the number of studies based on a realist versus a constructivist methodology. It is envisaged that shifting the research focus towards an ecosystemic epistemology would have several ramifications. Firstly, it would provide clinicians with valuable material pertinent to their work in this area. Secondly, it would contribute towards society gaining a different understanding

of the relationship between mind and body. At present the socially accepted understanding by society is that a physical symptom is primarily organic while an emotional problem is primarily psychological (Capra, 1983; McDaniel et al., 1995). Western society only reservedly considers the notion that no division exists between mind and body (McDaniel et al., 1995). Thirdly, a further step can be taken in promoting the view that the manifestation of certain behaviours and illness/disease is a metaphor for a whole network of complex interactions in which the person is embedded. This may have implications for the promotion of and demand for expensive medical procedures. In turn leukaemia and other chronic sufferers would possibly be more willing to accept a mental health referral for their problem as part of a holistic treatment regimen.

Research that investigates the recursive patterns of interaction surrounding chronic illness (leukaemia) sufferers could also consider the relationship/interaction between the physicians and the ill child (and his/her family). This consideration might facilitate the evolution of new consensual domains based on greater mutual understanding and collaboration. As Capra (1983) points out, doctors focus on treating the illness/disease instead of the patient as a whole person and, yet, the patient-physician relationship is 'an important part, perhaps the most important part of every therapy' (p.141).

Conclusion

The ecosystemic perspective represents a 'quantum leap' from an anticontextual and reductionistic epistemology concerned with objectivity and truth, to a worldview which encompasses complexity, contextual patterns of relationships and multiple realities. This radically different conceptualisation of childhood leukaemia may be unfamiliar and disconcertingly abstract and diffuse to most health-care experts working in the field of childhood chronic illnesses. However, it is the researcher's opinion that a unified conceptual framework which views individuals and their problems as an evolving flow of interconnecting ideas and co-ordinated actions (Anderson &

Goolishian, 1987), facilitates a more flexible and aesthetic understanding of the problem, one in which static, piecemeal and reified explanations are avoided.

By furnishing a descriptive account of the contexts of two families with a chronically ill child in this study the researcher hopes that she has provided valuable information that will make a small contribution towards the conceptual shift and public re-education which Capra (1983) calls for - 'To adopt a holistic and ecological concept of health in theory and in practice, will require not only a radical conceptual shift in medical science but also a major public re-education' (Capra, 1983, p.165).

APPENDIX ALetter of Consent

Dear

Your co-operation in my Master's research project is greatly appreciated. I am interested in finding out what effect your child's illness has had on your day-to-day functioning. I would also like to find out how you view the origin of your child's illness, how you cope, and your ideas about possible solution(s) to the problem (if any).

Your participation in my research simply involves a two-hour long interview (maybe longer/shorter) in the forth coming weeks. It is hoped that our conversations will be mutually beneficial and rewarding in shedding new light on the problem of childhood leukaemia.

Please note that:

1. You are under no financial commitment or obligation.
2. All information will be treated with strict confidence. Your name will not be used for any purpose whatsoever nor will it be communicated to any person not directly involved in the study.
3. You are free to withdraw from the study at any time, although please remember that your participation will not only contribute to the body of knowledge on childhood leukaemia but may also help other families.
4. I cannot guarantee that you will derive any benefits (in terms of a 'cure', relief or otherwise) from participating in this project.

Thank you again for agreeing to participate.

NAME: _____

ADDRESS: _____

DATE: _____

SIGNATURE: _____

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