

**EXPLORING STORIES OF COPING
WITH
CHILDHOOD CANCER IN A SUPPORT GROUP FOR PARENTS**

by

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*In loving memory of my father, Nikos Papaikonomou, who
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Dedication

THIS THESIS IS DEDICATED TO THE CHILDREN AND THEIR PARENTS WHO HAVE HAD TO ENDURE THE TRAGEDY OF CHILDHOOD CANCER. IT IS THROUGH THEM THAT WE HAVE LEARNED SO MUCH, BOTH INTELLECTUALLY AND EMOTIONALLY. THEY ENDURE ON A MINUTE-TO-MINUTE AND HOUR-TO-HOUR BASIS THOSE THINGS THAT WE ALL HOPE WE WILL NEVER HAVE TO FACE. WE HAVE NEVER WALKED IN THEIR SHOES NOR HAD TO SIT IN THEIR CHAIRS BUT WE HOPE THAT OUR COLLECTIVE EXPERIENCE IN DEALING WITH CHILDHOOD CANCER WILL HELP THE PARENTS OF CHILDHOOD CANCER PATIENTS ADJUST TO A NEW WAY OF LIFE - AS WELL AS DEAL WITH THE DIFFICULT ISSUES AND CHALLENGES THAT ARISE ON A DAILY BASIS. WE ARE CONSTANTLY AMAZED AT THE ADAPTABILITY OF THE HUMAN SPIRIT AND THE DAY TO DAY STRENGTH THAT IS SHOWN TO US BY THE PARENTS OF OUR CHILDHOOD CANCER SURVIVORS.



Table of contents

	Page number
CHAPTER 1: INTRODUCTION	1
Cancers most common in children	5
The impact of the child's cancer on parents	8
Contextualising the study	13
Objectives	19
CHAPTER 2: RESEARCH METHODOLOGY	21
Qualitative research	21
Methodological unfolding of the study	26
The nature of ethnography	26
Determining a focus for inquiry	27
Determining where and from whom data will be collected	28
Planning data collection	31
Determining instrumentation	32
Data collection procedure	32
Data recording procedure	34
The processing of data or data analysis	34
Summary	37
CHAPTER 3: FROM RESEARCHER TO CO-THERAPIST - AN AUTOETHOGRAPHIC ACCOUNT	38
Impressions of working in a hospital setting	38
My experiences in England	39

Back home	41
The research context	42
Gaining access to a research context	44
Getting started	46
Perceptions of the group process	51
The general methodology of autoethnographic inquiry	52

CHAPTER 4: SOCIAL SUPPORT AND THE PARENT OF THE CHILD WITH CANCER 61

What is social support	61
Models of social support	67
Creation of a social support group: Place, time, size	68
Maintenance of the group	70
Characteristics of social support groups	70
The therapeutic value of social support groups	72
The value of the social support group as related to the parent of the child with cancer	74
The value of story telling in social support groups	77

CHAPTER 5: TESSA’S STORY: LIKE AN ANIMAL IN A CAGE 86

CHAPTER 6: JOAN’S STORY: NEVER TAKE ANYTHING FOR GRANTED 113

CHAPTER 7: VICKY’S STORY: NEEDING TO LET GO AND SUBMIT TO GOD’S PLAN 135

CHAPTER 8: DEBBIE'S STORY: I CAN HELP OTHERS 157

CHAPTER 9: MARIUS AND MARY'S STORY: PATH TO RECOVERY 175

CHAPTER 10: PAT AND CLAY'S STORY: TRYING TO CREATE ORDER OUT OF THE CHAOS 198

CHAPTER 11: CONCLUSION AND RECOMMENDATIONS 218

REFERENCES 237

APPENDIX A: LETTER OF CONSENT 266

List of tables

	Page number
TABLE 1: Traditional and alternative assumptions of inquiry	17
TABLE 2: Demographic and disease related variables of the participants	30

Summary

This study examines through autoethnographic inquiry my research journey in the world of childhood cancer. The unfolding research experience eventually led to the focus of this investigation which is exploring stories of coping with childhood cancer in a support group for parents. Using the principles of ethnographic epistemology this study explores the stories of eight parents whose children were diagnosed with cancer and who decided to join the support group for parents called, TOUCH.

An overview of the existing body of knowledge on childhood cancer and the family is presented as well as the value of a social support group in parenting a child with cancer. The need of a conceptual shift in order to understand the problem of parenting a child with cancer is propagated.

The stories of eight parents within the setting of a social support group are presented. Through the principles of the qualitative method of ethnography the story of the child's cancer is described by means of emerging themes. The coping mechanisms used to cope in this world of uncertainty and ambiguity, follows. Finally the contribution of the support group is discussed in terms of my relationship with the group member, the group members' communication pattern and what was perceived to be helpful to the group member. The eight stories discussed all follow the same pattern.

Four hypotheses emerged from the eight stories described and are presented in the final chapter. The strengths and limitations of the study are discussed as well as recommendations for future research.

Key Terms: autoethnography, childhood cancer, communication pattern, coping mechanisms, diagnosis, ethnography, qualitative paradigm, social support group, recovery, remission.

CHAPTER 1

INTRODUCTION

"Your child has cancer!"

All at once I feel numb

Without my child

I am nothing

want nothing

hope nothing

(From a mother whose child was diagnosed with cancer)

The above quotation captures the essence of the crisis a parent is in once their child is diagnosed with cancer. When a child is diagnosed with cancer parents enter a nightmare world where the terrain is unfamiliar and their basic child rearing tasks are challenged. Life changes for the parent from diagnosis onwards, through to adjustment and then to life beyond the illness. Thus the parent starts one of the periods in their life they will always remember. As will be seen in this study, parents never thought "it could happen to them". Parents feel that it was their right that their child should grow up to be just like them with the occasional illness or broken limb but never do parents anticipate that an illness could take their child's life. In summarising the emotions parents go through the following is important:

- they feel anger at the unfairness of it (Grootenhuis & Last, 1997).
- they grieve that all the dreams they had for their child will come to nothing (Eiser, 1996)
- they try to bargain with God to cure their child (Chesler & Barbarin, 1987)
- they blame themselves for the illness (Sloper, 1996)
- they regret not doing things with their child they intended to do (Sormanti &

August, 1997)

- they feel lost and confused by medical jargon and new words (Faulkner, Peace & O'Keefe, 1995)
- they agonise over what they will tell their children, parents and friends (Snetsinger, 1996)
- they wonder how they will cope with it all (Wittrock, Larson & Sandgren, 1994)

Faulkner, Peace and O' Keefe, (1995) did research on how the impact on parents changed over time by asking parents how they felt after hearing the diagnosis, then while treatment was under way and lastly when treatment was finished. They recorded the number of negative and positive comments per period. However, these researchers found that a positive or negative comment did not relate to the intensity of feeling. For example a mother who had a score of five negative comments during the treatment period and one negative comment during the period after treatment, said that the worst time for her was in dealing with the uncertainty after the treatment period of whether the illness was going to recur in her child or not. However, she went home without any reassurance from the doctor. This is important in the context of this study as I will document the constructions of the parent of the child with cancer thereby capturing the tacit knowledge which remains hidden during traditional research methods.

The emotional and physical disruption that the illness brings about could lead to developmental milestones not being reached. For example Chesler and Barbarin (1987) declare that language is an important sign that indicates a child has progressed from infancy to early childhood whereas when a child has cancer he/she may experience developmental delays in language due to surgery and extended periods of hospitalisation. The child's progress in terms of bowel control, eating habits and social and emotional development is thwarted as a result of the physical effects of treatment and psychological reaction to stress. Parents often experience difficulty in attributing causes to these developmental lags. Parents do not know whether it's as a result of immature behaviour of the child or whether to blame the treatment procedures and psychological impact of the drugs (Comaroff & McGuire, 1981).

A unique dilemma that parents experience is how to tell their child that he or she has cancer. There is no way of mediating the impact it will have on the child when he/she hears the diagnosis.

Chesler and Barbarin (1987) indicate that there are two ways of telling the child namely the *protective approach* where the parents do not fully disclose the illness to their child and the *open approach* where the child has full knowledge of his/her illness and the reality of the diagnosis does not interfere with the family life. The protective approach may be helpful for a short while but at some stage or other, the child will pick up the reluctance of the parents to talk openly and the child may begin to practice mutual pretence (Glaser & Strauss, 1965). Thus, children caught in a silent system may accommodate the parent's need for a charade by concealing their own need to find out the truth about the illness. The study by Chesler and Barbarin (1987) further indicated that catholic parents convey fuller information to their child on the basis that "God will take care of my child".

The sibling structure and peers also play an important role in how the child will be told about his/her disease. Sometimes parents have no control especially as their child interacts with other ill children. (Chesler, Allswede & Barbarin, 1991).

In a newsletter (1998) the Cancer Association of South Africa has a few guidelines for parents of newly diagnosed children. These guidelines have been set by parents who have been through the illness of their child. They are handed out to parents of newly diagnosed children.

- Be honest and open about the illness, to your relations and friends, to the school, your employers, but, most of all to yourselves and your children. Your children know that they are ill; don't make them hide their feelings to try and protect you.
- Your family and friends will not at first know what to say to you, and they will be very uncomfortable with you. The more openly you talk about things, the easier

it will be for them to respond to you and give you the help that you will need so much in the coming months.

- Get used to saying the name of the illness out loud. Words like cancer and leukemia are normally only spoken in hushed voices and never in the presence of someone who has them. It will be with you for a long time, so get used to saying it, and even talk about death. It makes it so much easier for your family and friends to talk openly if you do so.
- Don't be ashamed to show or feel emotions; it just shows that you are human. If you don't feel angry, sad, confused and many other emotions when you learn of the diagnosis, then you are very unusual. Don't forget that your sick child and your other children, will have to cope with many new experiences and emotions. Let them see it is alright to feel afraid, to be unsure and to cry at times.
- Remember that you are in this as a family. Many families who have a good marriage to start with, find that they are strengthened by the experience; but it is not unusual for a marriage to be very stressed by all the extra demands that an illness like this will put upon it.
- Call on the resources that you have. Use your family and friends; if they are true friends they will only be too glad to help you now that you really need them. Use your church; get people to pray for you and your child. You will be surprised how much and how readily people will open up and help you, if only they know how; and that is why you need to make your needs known.
- There are no guarantees. The medical staff will do their best; there may be a very good prognosis for your child; but it is still a life threatening illness and you will live with this for a very long time.
- Don't be afraid to ask the medical staff. You will probably not take in half of what is said to you in the early discussions, and there will be a whole new vocabulary

in your life. Keep notes of the questions you want to ask. There is a lot of literature available, and you will want to get as much knowledge as possible, so ask the staff what they recommend.

- There will be times when all seems very dark and there will also be happy times. The best way to get through the coming weeks and months is to take it one day at a time.

Perhaps it's the enormity of the illness that their child with cancer has to deal with, that makes it unfathomable to parents. The above steps indicate that parents need to deal with and acknowledge existential dilemmas that are generally avoided. Parents cannot protect their children from the illness nor from death, all they can do is help their child to cope one day at a time.

CANCERS MOST COMMON IN CHILDREN

The diagnosis of cancer poses many unique problems and challenges that will affect the child and the family. These problems, unless addressed, can hinder the cognitive, social and emotional as well as the physical growth and development of the child. (Maul-Mellot & Adams, 1987). The reader will now be given a brief overview of the different types of childhood cancers in order to clarify terminology that will be used by the subjects and also to realise what the parents had to cope with. Not all the childhood cancers will be discussed, only those related to the children of the subjects of this study.

Leukemia

Leukemia, the most common childhood cancer, is characterised by uncontrolled proliferation of a certain type of white blood cells that originate in the bone marrow. The rapid growth of these white blood cells in the marrow overwhelms healthy blood cells and infiltrates the blood stream. Leukemia accounts for one-third of all childhood malignancies; it occurs in approximately one out of every 2000 children under fifteen years of age in the United States (Berman & Kliegman, 1990). Two broad

classifications of leukemia exist, acute lymphoblastic leukemia (ALL) and acute myelogenous leukemia (AML). Acute lymphoblastic leukemia (ALL) is by far the most common variety. It accounts for 70% to 90% of the cases and is primarily a disease of childhood, with a peak incidence at four years of age (Lichtman & Siegel, 1983).

Clinical Picture

Clinical manifestations of leukemia result from a decrease or absence of normal marrow elements, organ involvement and metabolic disturbance. Presenting symptoms vary and there is no "typical" presentation. The onset of symptoms may be acute but this form of presentation is uncommon. First symptoms are more often subtle and in retrospect many parents realise that the child has not been well for several months.

The most common presenting complaints are paleness, unusual bleeding, infection, fever of unknown origin, or occasionally joint pain (Behrman & Kliegman, 1990). Fatigue and irritability are often present. Some children will present with abdominal pain. Less common forms of presentation may involve any organ system of the body, such as the cardiorespiratory systems, the kidneys and, occasionally, the nervous system.

Whatever the form of presentation prior to diagnosis, the signs and symptoms of subsequent relapse tend to be very similar if not identical.

Brain tumors

Central nervous system tumors are the second most common childhood malignancies. Childhood brain tumors represent 9% to 20% of all childhood tumors. The most common age for these tumors is between 5 and 10 years of age, but they can occur at any age (Van Eys, 1984). There is no known cause for brain tumors. A developmental origin is suspected in children. In some of these tumors chromosome defects have been demonstrated.

Clinical picture

Most of the symptoms that create the clinical picture of a child with a brain tumor are generalized in nature. It is difficult to assess the condition of a child with a brain tumor because of the lack of communication skills, the vagueness of symptoms, and the commonality of the symptoms. Many young children have visual problems, for example, or are clumsy, have problems at school, and so on. Also, initial symptoms may be associated with other problems such as other childhood diseases, especially cerebral palsy, seizure disorders, and meningitis or head traumas. Psychosocial experience also can produce similar symptoms. It is common in childhood for there to be one or more of the following: a regression or halt in development; deterioration in school performance; irritability; lack of attentiveness; an unusual degree of unpredictability in behaviour and changes in responsiveness; loss of sphincter control; disturbances in previous patterns of sleeping and eating; and other behavioural problems (Behrman & Kliegman, 1990).

The generalised signs and symptoms produced by brain tumors result from increased intracranial pressure and vary according to the age of the patient and the location and growth rate of the tumor (Maul, 1984).

Headaches are the most common sign and symptom of increased intracranial pressure. In very young children and infants, headaches may be expressed as irritability. The headache can be so severe that it awakens the child in the morning. Young children also exhibit head holding, head rolling, rocking and anorexia. Vomiting frequently accompanies the morning headaches and is not preceded by nausea. Impaired vision is another symptom of increased intracranial pressure. Seizures rarely occur early in the course of the disease (Behrman & Kliegman, 1990).

Diagnosis is often difficult due to many possible diagnoses based on these symptoms. Radiological studies are relied upon for diagnosis since many of these tumors are surgically inaccessible.

Retinoblastoma

Retinoblastoma is a tumor that arises from the retina of one or both eyes. Its cause is unknown, and although an infant is born with the malignancy, it is not usually diagnosed until symptoms appear. Unfortunately, by the time that happens, the disease is fairly far advanced. The most common symptom is a white spot in the eye (Berman & Kliegman, 1990).

Metz, Salazar and Rubin (1983) explain that the disease is rare but the treatment is drastic. Although the disease can be cured, it is unlikely that doctors can preserve sight in the affected eye. If the cancer is far advanced the affected eye is removed surgically.

THE IMPACT OF A CHILD'S CANCER ON PARENTS

Hinds, Birenbaum, Clarke-Steffen, Quargnenti, Kreissman, Kazak, Meyer, Mulhern, Pratt and Wilimas (1996) did a study to identify and describe the coping processes used by parents of pediatric oncology patients to deal with the stress of a first cancer recurrence in their child. The grounded theory method was selected because of its usefulness in identifying psychological or social processes that occur in interactions in particular settings or situations. The primary research techniques used were semi-structured interviews and observations of parents interacting with staff. The major claim in this research is that "coming to terms" is a conscious process in which immediate emotional reaction is curbed in order to do what is best for the child. Although this research has its merits to characterise "coming to terms" as a conscious and adaptive process, it clouds individual differences and does not move towards an in depth or holistic understanding of people.

Sloper (1996) investigated parents' responses to the diagnosis of childhood cancer and the early months of treatment; their levels of emotional distress; their perceptions of the effects of the illness on family life; the support available to them and their unmet needs. Semi-structured interviews as well as the Malaise self-report questionnaire were used as methods of investigation. His major claims in this article are:

- childhood cancer presents a crisis for family members
- delay in diagnosis is a considerable concern for parents
- parents also expressed a concern around the process of communication
- despite the high levels of distress found in this study, there was little evidence of support from primary care services in assessing distress or providing counselling.

This article emphasises the wider ramifications and resulting stressors of childhood cancer and it stresses the need for more inclusive professional assistance. The question which remains is whether typical counselling approaches are adequate or do we need something more in order to move towards a closer understanding of the parent of the child with cancer.

In their research on marital adjustment after a child has been diagnosed with cancer Dahlquist, Czyzewski and Jones (1996) were interested in changes in the parents' marital functioning over the course of the child's illness. In contrast to findings obtained two months after diagnosis, marital distress at follow-up was not related to state anxiety. Rather marital distress was significantly related to both depression and trait anxiety, indicating a more chronic state of emotional functioning. Poor child health status predicted a more positive attitude toward the marriage in fathers but not in mothers. Spouses reported feeling more positive toward the marriage when their partners reported higher levels of commitment and/or lower levels of emotional tension. The major claim in this research is that it is important to consider the psychological status of the marital unit as well as the individual parent during the course of the child's illness.

Stuber (1995) suggests in her research that cancer diagnosis, the life threat it poses, and the aggressive treatment that is now employed, are experienced as traumatic by many children and even more so by their parents. She claims that more research is necessary to help us understand which psychological interventions are the most effective to help parents cope with the painful and intrusive procedures their child has to undergo. In her research she found that childhood cancer diagnosis is traumatic to parents rather than merely stressful. She further claims that parents do not put the

experience out of their minds once their child becomes a survivor. The question at this stage is how do they process and make sense of the experience and find meaning in the suffering endured.

Eiser, Havermans and Eiser (1995) did research with the aim of finding out to what extent parents accept that there is no known cause of the disease, or do they search for more tangible explanations. Thirty families took part in the study and the interview included four open-ended questions. They found that fathers were more likely than mothers to accept that there was no generally accepted cause for the disease. Also the incidence of self blame was relatively common especially amongst mothers. Fathers were reluctant to use medical staff as a source of support or information. The major claim in this research is that the unexpectedness of the diagnosis, unpredictability of the outcome and rareness of the disease mean that the situation is one in which we might expect parents to be particularly motivated to search for attributions.

Van Dongen-Melman, Pruyn, De Groot, and Koot (1995) did a study to obtain insight into the late psychosocial sequella of parents of children who survived cancer. Their study demonstrated that after termination of treatment, childhood cancer has late psychosocial effects on parents of survivors and that uncertainty and loneliness are the most frequently reported problems. Their study further provides evidence that religion has a positive effect on negative feelings, including depression, in parents of cancer survivors. It remains unclear why religious belief is associated with fewer problems in parents. Possible explanations are that religious affiliation is associated with social support or that religious affiliation is related to important differences in intrapersonal characteristics. Another possibility is that religion provides extra strategies to cope with childhood cancer. Because childhood cancer is characterised by uncertainty and loneliness, religion may comfort parents and provide a framework to interpret their experiences. All these problems of uncertainty and loneliness indicate that many parents suffer in silence, which may continue over the years after completion of treatment.

Some studies have shown that family members can suffer more psychological distress

than cancer patients themselves. Yet families don't always get the support they need to cope with the crisis, suggests Stuber (1995).

Families coping with their children's diagnosis undergo enormous stress as they struggle to assimilate complex medical information and make treatment decisions. Parents usually have to put their own feelings aside as they help their children fight for their lives. Since children's treatment can last for years, so can the emotional and logistical disruption to their families. Psychologists are just beginning to figure out how to intervene in these cases. What psychologists do know is the importance of understanding the parents' strengths and weaknesses and developing intervention strategies to strengthen the coping skills of those who need it (Kupst & Sculman, 1988).

Research by Dahlquist, Czyzewski and Jones (1996) suggests that the way parents feel and respond to their child's illness will influence the way their child responds to his/her treatment and illness too. Parenting attitudes and parenting behaviours are important and future research should continue to investigate these behaviours to determine ways to help clinicians and parents manage child distress more effectively.

Cohen (1995) generated a substantive theory that begins to explain and predict the emergence, sources, and management of parental uncertainty within the context of chronic, life-threatening, childhood illness. She suggests that the trajectory framework, developed by Strauss and associates for understanding the course of chronic illness, offers insight and understanding into problems like chronicity. 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 retrospectively. The uncertainty of the child's illness trajectory gives rise to sustained parental uncertainty. She further uses the "triggers" to refer to events that predictably intensify parental awareness of uncertainty. These events should be taken into account when making plans to care for the child and family in the future. Although health care professionals might provide the best supportive care, there will always be triggers which are not controllable and which will be a source of stress in parents. Night time fears and the exposure to negative outcomes are two such triggers that Cohen (1995) identified.

Health care professionals should also not assume that because the child has been disease-free for a certain period of time that the parents are no longer stressing about their child's future. The uncertainty of their child's future is a constant source of stress which remains with the parents. It is important, that someone should maintain an ongoing connection with the family, the purpose of which is not simply limited to monitoring the child's illness trajectory or intervening during times of physical crisis. Care of the child must include care of the family and must be provided on a continuing basis. Because childhood cancer affects not only the child but the whole family, insight is also needed into the consequences for parents.

Speechly and Noh (1992) indicate that mothers experience significantly more late psychosocial problems than fathers.

Van Dongen-Melman, Pruyn, De Groot, and Koot (1995) found that uncertainty and loneliness are most often reported by parents. These problems do not decline over time, indicating that many parents suffer in silence over the years after completion of treatment.

Research by Martison and Cohen (1988) as well as Peck (1979), indicates that the impact of childhood cancer on the parents' life have only been examined from their role as parents and subsequently focussed on problems in relation to the survivors' well-being. How cancer affects parents in their personal life has received little attention. Therefore more insight is needed into the whole range of parental experiences not during treatment, but also after it has ended.

The above discussion leads us to the context of this study. I would like to contextualise my study by starting off with a description of why I decided to research this area.

CONTEXTUALISING THE STUDY

When I joined a pediatric oncology unit of a hospital as a volunteer psychologist, I faced a challenge that I had never encountered before. As I began to work with

childhood cancer patients I discovered that there is so much to be learned, so much hidden from the real world. The problem that provided the starting point of my research was the realisation that childhood cancer is the second leading cause of death in children under the age of 15 years old (Faulkner et al., 1995). It is tempting to turn away from thoughts of childhood cancer because it is so sad. Now just imagine what worse blow can fate deal to a parent than the diagnosis of his/her child with cancer? I also came to realise that very little is known about the experience of parents whose child has been diagnosed with cancer. Childhood cancer is a family illness but researchers are always doing surveys and finding out percentages yet in the hospital setting the medical staff and related professions often do not have time to listen to the feelings of the parents' experiences. This leads to parents of childhood cancer patients adopting a culture of silence and oppression.

There are two reasons for this, the first being that the hospital setting, as an organisation, reflects an interest in the patient and his/her family as an organisational participant, (not as an individual with rights and privileges) because he or she is a component of the total organisation i.e. a means by which organisational outcomes are thwarted or achieved. Social support is lacking within a hospital setting and parents need to look for it elsewhere. Therefore the topics of theoretical and research interest that have predominated for a very long time on the treatment of cancer within a hospital setting include discussions on epidemiology, diagnosis, clinical picture of the disease, intervention, finances and so on, but less on the importance of the individual and his/her family (Williams, 1995; Smith, 1996). I realised that much lip service is paid to the parent as an individual, the reason being that we are always engrossed with the problems of the hospital as an organisation and how it can function efficiently that we neglect the needs of the patient's family and we are quite unaware of our neglect.

The second reason according to Capra (1982) for this neglect of the parent as an individual is the established tradition of scientific research. The purpose of scientific inquiry is to test hypotheses in order to generalise the results for the purposes of prediction. Determining the dynamic state of the patient and his/her family in relation to their environment has no place in traditional scientific research. The assumptions

underlying the scientific tradition have guided inquiry for a very long time. Here follow some of these assumptions:

1. There is a single reality which can be known. The finding or the results of the research are considered the truth.
2. The findings are not limited to time and context so they can be generalised.
3. In verifying the above finding a third assumption asserts that causes can be specified which means that the reasons for the finding can be clearly outlined.
4. The researcher is distinctly separate from the object studied. The scientist or researcher is an objective inquirer.
5. The inquiry is value-free. Not only is there no relationship between the researcher and the researched, the total context of the inquiry and the resultant findings are value-free.

These assumptions form a pattern or belief called a positivist paradigm. This movement began as a philosophy in the early nineteenth century and had its major impact not in changing or reforming philosophy, but in defining the "scientific method". This scientific paradigm utilises an established methodology designed to validate findings. Experimental design and statistical treatment and inferences are strategies and technologies to minimize researcher bias and maximize the generalisability of results. This scientific tradition and method have become synonymous with the concepts of objectivity, generalizability and predictability. The majority of research about disease and illness employs this type of inquiry. Capra (1982, p.150) states the following: "The theory of specific disease causation has been successful in a few special cases, such as acute infectious processes.... but the overwhelming majority of illnesses cannot be understood in terms of the reductionist concepts of well-defined entities and single causes".

In the process of reducing illness to a disease, the attention of physicians has moved away from the patient as a whole person and his/her family context. Whereas illness is a condition of the total human being, disease is a condition of a particular part of the body, and rather than treating patients who are ill, doctors have concentrated on treating their disease. Because of the biomedical definition of disease as the basis of illness, medical treatment is directed exclusively at the biological abnormality. These studies have treated the individual atomistically. They have focussed on bits of the individual as a means of studying other variables and have failed to focus on the individual as a whole, as a primary data source from whom much can be learned. Human beings are capable of thought and response and have their own ways of making sense of what happens to them. They determine what has meaning and what that meaning is. Their ability to make sense of things and the resultant sense, or construction of their reality could provide potentially valuable information about understanding an illness such as cancer at a level which has just begun to be explored.

Over the last decade or so, however, a variety of alternative perspectives of illness and specifically cancer has appeared in the literature (Chesney & Chesler, 1996; Webster, 1994). Children with cancer and their parents sometimes feel overwhelmed, drowning in sorrow, rage and despair. Emotional paralysis becomes more than a way of describing feelings; it turns into reality, forcing lives to a virtual halt. As a result the level of analysis of disease and illness is turning toward a micro-level of theory building based on individual sensemaking processes. Attention is turning from the disease or illness to the understanding of the patient who has the illness. At the same time a different set of assumptions about the nature of reality has developed. The assumptions of this new paradigm, called the naturalistic paradigm, directly challenge those of the scientific paradigm. The naturalistic paradigm has a set of assumptions which at first glance are not commonsensical. I use the term naturalistic as it embodies what qualitative research is all about, that is, to capture the character of naturally occurring phenomena (Hammersley, 1998).

Firstly it is asserted that "realities are multiple, constructed, holistic" (Lincoln & Guba, 1985, p.37). Thus one can better understand why different individuals may react

differently to what appears to be the same context. A second assumption hinges on the term context; it is precisely because life situations occur in a particular context that there cannot be universal or generalizable feelings. A third assumption states that what is discovered in context is not the result of patterns of cause and effect, but rather of the “mutual simultaneous shaping” of events (Lincoln & Guba, 1985, p.37). A fourth assumption asserts that the researcher and the object being studied are inexorably linked. The researcher chooses the problem; and both the researcher and the researched are changed by the interaction. The final assumption asserts the value-bound nature of the inquiry. It is now recognised that values, beliefs, past experiences and tacit knowledge are part of and cannot be separated from inquiry.

The assumptions of this alternative perspective of inquiry contradict those of the scientific paradigm as can be seen in Table 1.

Table 1

Traditional and Alternative Assumptions of Inquiry (Lincoln & Guba, 1985)

Traditional Assumptions	Alternative Assumptions
1. There is a single reality,	1. There are multiple, constructed realities,
2. which can be generalised	2. which exist in a particular context
3. and the causes of which can be determined,	3. and are the result of many concurrent interactions.
4. while the researcher maintains an objective stance, and	4. The researcher and the researched are necessarily connected
5. the inquiry itself is value-free.	5. in an <u>inquiry</u> which is <u>bound by values</u> .

The alternative paradigm of inquiry is the methodology which will provide the conceptual integrity of this study. The concept of multiple, constructed realities will give credibility to a study which will propose to document individual constructions of reality. Further the basis of this study, that there is an individual personal reality, will challenge traditional metaphors of illness and disease and utilize qualitative methods within the framework of naturalistic inquiry to meet that challenge. This combination of ideas is made possible by the alternative assumptions of inquiry.

The question then will be : Can there be a science that is not based exclusively on measurement; an understanding of reality that includes quality and experience and yet can be called scientific? Indeed I believe that such an understanding, is possible. Science, need not be restricted to measurements and quantitative analyses. Any approach to knowledge is scientific provided that it satisfies two conditions: all knowledge must be based on systematic observation, and it must be expressed in terms of self-consistent but limited and approximate models (Capra, 1982).

Capra (1982) further says that a true science of consciousness will deal with qualities rather than quantities, and will be based on shared experience rather than verifiable measurements.

According to qualitative inquiry our individual personal reality, the way we think life is and the part we are to play in it, is *self-created*. *We put together our own personal reality*. Therefore making sense of a complex aspect such as cancer is the result of a construction made up of the individual's interpretations and perceptions of the way things are and what has happened to them (Lincoln & Guba, 1985). Yet, *the descriptions, the constructions of sensemaking by individuals who form part of the cancer population as parents does not exist in the literature of health care and humanising illnesses*.

In this research emphasis is placed on the individual (i.e. the parent) and his/her unique experience of the diagnosis of their child with cancer. It is these constructions that will be documented and analysed for tacit meaning and sensemaking of the illness. Rules,

goals, hierarchy of a hospital setting and the causes, etiology, clinical picture and treatment of cancer around which traditional research revolves are not the only reality. The individual's construction or view of all these aspects is as much a reality that needs to be documented. The "what" that coheres in the mind of the individual is as much a reality as any other perceived form or theoretical structure.

Individual constructions of the illness are as much real as are intervention techniques, coping methods and marital adjustment around which traditional research has evolved. Previous research has focussed on bits of the individual (parent) as a means of studying other variables. The studies have failed to focus on the individual as a whole, as a primary data source from whom much can be learned. They have used various scales or questionnaires or projective techniques to analyse the individual, which means studying the individual from the outside, instead of just asking the individual to write down his own story and construct it as he sees it on the entity under study thereby studying the individual holistically. Human beings are capable of thought and response and have their own way of making sense of what happens to them and that is what needs to be documented. Croyle (1999) says that research on communication and communication processes will become a top priority because we need to understand how to help parents and families of cancer survivors adopt a healthy lifestyle. Schover (1999) says that physicians don't always have a good understanding of the gap between what they are saying and what parents understand. In order to move closer to an understanding of the parent of the child with cancer one has to look at the parent's ability to make sense of the illness and how they made sense of it. This is done in this study by analysing the parent's constructions or stories of the illness of their child from the inside out to identify tacit assumptions and to explicate them. By finding out how parents make sense of this illness psychologists can then find out the strengths and weaknesses of parents within this context. Parents' strengths and weaknesses can then be channelled into more useful roles suggests Redd (1999).

Suin (1999) suggests that we need to look at how information is processed by parents and to examine what personal and environmental factors influence decision making. We need to understand and design approaches for parents that will help them pursue

the decision making pathways that are appropriate for their individual situation, personal styles and values. What Suin (1999) is suggesting here is that we need to study the parent of the child with cancer from the inside out in order to move towards an understanding of him/her. Mortality or illness of a child is confronted in a unique way by each parent.

OBJECTIVES

The purpose of the present study is twofold: firstly to explore my journey, through autoethnographic inquiry, during this research process and secondly to give a comprehensive description through story telling of coping with childhood cancer in a support group for parents. I use the qualitative research strategies of autoethnography and ethnography to explore my journey in this research process and the description of the parents' ordeal respectively, because they match well with the specific character of the problem under study: *the complexity of human experience*. Giorgi (1986) suggests that a qualitative approach considers the complexity and richness of human reality and tries to describe this complexity in the most penetrating way. Qualitative analysis uses language as the main mode of obtaining and processing data and results are provided by textual analysis.

In the next chapter I will discuss qualitative research in general and then the qualitative methods of autoethnography and ethnography as applied to this study.

CHAPTER 2

RESEARCH METHODOLOGY

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

QUALITATIVE RESEARCH

Janesick, (in Denzin and Lincoln, 1994, p. 210), equates qualitative research to a dance by declaring : "All dances make a statement and begin with the **question**, What do I want to say in this dance? In much the same way the qualitative researcher begins with a similar question: What do I want to know in this study? This is a critical beginning point". According to Creswell (1998, p. 99) "These questions are open-ended, evolving and non-directional. They start with words such as 'what' or 'how' rather than 'why'".

Strauss and Corbin (1990) refer to qualitative research as a non statistical, non mathematical analytical procedure which is the outcome of data gained through interviews, observations and stories of participants. Quality refers to the nature of the phenomenon under study rather than its quantity. Qualitative researchers concern themselves with issues such as attempts to uncover the nature of peoples' experiences with a phenomenon such as chronic illness for example.

According to Ely (1991) qualitative research has certain fundamental characteristics which will now be discussed and applied to this study:

- Qualitative research is characterised by the researcher's attempts to understand the phenomenon under study. This understanding of the phenomenon is of value not only to the researcher or to the readers but also to the subjects who

participate in the study. When the parents of childhood cancer patients read this study it should make sense to them by being real, valid and reliable.

- In qualitative research the inside perspective of the respondent is important. In the case of this study I attempt to understand what happens to parents of cancer survivors from the subject's own frame of reference once their child is diagnosed with cancer.
- In qualitative research the **researcher** is the primary data collection instrument because it would be virtually impossible to devise *a priori* a non human instrument with sufficient adaptability to encompass and adjust to the variety of realities that will be encountered.

When doing qualitative research one realises that **negotiating entry** into a system requires time, patience and sensitivity to the rhythms and norms of the group (Marshall & Rossman, 1989). The support group from which the participants for this study were selected was a closed access group in a private self-contained setting, one for which permission needed to be granted in order to gain access. The difficulties of gaining access are described by Cassell (1988, pp 94-95):

"One has to keep pushing, and trying, and hoping, and smiling, and pushing some more. For this a researcher needs a thick skin and a certain imperviousness to rejection."

Nobody said that social research is easy. The researcher requires considerable social sensitivity and charm:

"One must fit in, if that seems to be called for; not fit in, if it seems inappropriate. One must dress acceptably, speak acceptably....The [researcher].... should adopt a role or identity that meshes with the values and behaviour of the group being studied, without seriously compromising [his/her] own values and behaviour." (Cassell, 1988, p. 96-97)

Determining the gatekeeper is a very important part of qualitative research. Ely (1991, p 20) states: "Often, qualitative researchers determine their appropriate gatekeepers only after they understand more about the situation that they are studying. But a start must be made." For the purposes of this study it was necessary to get the cooperation of the head social worker of the organisation to whom the support group was affiliated. Usually there is a lot of apprehension around the first interview with the gatekeeper. Ely (1991, p 20) states: "Many a naturalistic researcher, expecting resistance and having a well-rehearsed story at his or her disposal, has found a gatekeeper quite pleased and flattered by the idea of being 'researched'".

I did not have difficulty gaining entrance into this system and as a 'visitor' in the beginning received special treatment. During the first interview I was introduced to the group and acquainted myself with the unwritten social rules. During that interview the members agreed to become potential participants in the study and wanted to engage me in their context. I met with the respondents once every four weeks for interviewing lasting 3 hours. This process lasted for 15 months and resulted in 45 hours of interviews.

In **data collection** there are four basic types of information to collect in qualitative research: (1) observations (ranging from nonparticipant to participant), (2) interviews (ranging from semi-structured to open-ended), (3) documents (ranging from keeping a journal to public documents or autobiographies), (4) and audio-visual materials (which include photographs, and videotapes).

Data analysis is a formidable task for a qualitative researcher. According to Creswell (1998) there is no consensus for the analysis of qualitative data. Here are some strategies according to Miles and Huberman (1994) of analysing data.

- Write margin notes in fieldnotes
- Write reflective passages in notes
- Draft a summary sheet on fieldnotes
- Create metaphors

- Make contrasts and comparisons
- Write codes and memos
- Note patterns and themes
- Count frequency of codes
- Note the relation among variables and build a logical chain of evidence.

During **data representation**, according to Creswell (1998), researchers describe in detail, develop themes or dimensions through some classification system, and provide an interpretation in the light of their own views or views of perspectives in the literature.

When **writing** the qualitative dissertation the researcher engages the reader through a chronological approach as events unfold slowly over time.

Lincoln and Guba (1985) refer to reliability and validity as **establishing trustworthiness** in qualitative research. They further say that all research must respond to the following questions:

1. What is the truthfulness of the findings of a particular study and how can we establish that?
2. What is the applicability of these findings in another context or with other respondents?
3. If the study were to be repeated in the same context with the same participants would the findings be the same?
4. Are the findings a product of the researcher's biases or own motivations, or are they a product of the participants of the study?

Lincoln and Guba (1985) refer to these questions as establishing the "truth value" (p.290) of the study, its applicability, its consistency and its neutrality.

Trustworthiness in this study is based on the five major assumptions of qualitative inquiry as mentioned earlier in this chapter. They are (a) multiple constructed realities, (b) the impact of context, (c) the interrelatedness of action, (d) the connection of the

researcher and that which is researched, (e) the value free nature of the inquiry. These assumptions will now be discussed as applied to this study.

(a) This thesis rests on the assumption that cancer of their child is an individual construction of reality as the parents perceive it. There is more than one way of experiencing this reality.

(b) The context or the setting where the research took place is very significant. It might limit the applicability of the findings but it enriched the content and its significance and contributed towards the interpretation of the data.

(c) Thirdly a linear model of cause and effect is negated in this study and is not seen as conducive to researching a complex issue such as childhood cancer. All actions are interrelated and connected to the context in which they occur.

(d) My connection with the participants of the study is not objective. There is a deep connection between us. In this study I selected a topic which was of interest to me and fitted my belief of the importance of the individual. I also learned a great deal from the respondents as they too learned a lot about their constructions of the illness and how it has shaped their lives.

(e) This particular inquiry is value bound. A respect for and recognition of values adds to an understanding of context.

I will conclude the discussion on qualitative research with Creswell's (1998) view of qualitative studies: Research is not done to gather data but rather to discover answers to questions such as **what is it like for a parent to live through childhood cancer**, by applying systematic procedures such as the naturalistic inquiry in the case of this study. In a qualitative study the research question often starts with a *how* or a *what* which leads to an exploration and description of the topic. The outcome of the study is more a process than a product. The qualitative researcher is therefore interested in what happens to the subjects/parents of childhood cancer patients from the subject's

own frame of reference. How do they make sense of this experience and what meaning do they attach to it. The parent/individual is treated as a primary data source from whom much can be learned. Parents/human beings are capable of thought and response and have their own way of making sense of what happens to them. They/parents determine what has meaning and what that meaning is. This is what this study will explore.

METHODOLOGICAL UNFOLDING OF THE STUDY

This thesis is based on two conceptual frameworks: autoethnography and ethnography. As autoethnographers vascillate in their research process between culture (ethnos) and self (auto) (Ellis &Bochner, 1996a), I have decided to explain briefly in this chapter, the principles of ethnographic inquiry as this was the theoretical and conceptual framework I used to collect, record and analyse my data. I decided to be led by the work of Ellis and Bochner (1996a), Van Maanen (1995) and Denzin (1997) in my quest to produce a thesis based on ethnographic inquiry. The following aspects will be discussed: The nature of ethnography, determining the boundaries for the study, data collection, recording modes, data analysis procedures and trustworthiness.

The nature of ethnography

Ethnographic research, according to Van Maanen (1995), has the following features:

- People's behaviour is studied in everyday contexts, rather than under conditions created by the researcher, such as in experiments.
- Data is gathered from a range of sources, but observation and informal conversations such as interactive interviewing as used in this study, are usually the main ones.
- The approach to data collection is "unstructured", in the sense that it does not involve following a detailed plan set up in the beginning, nor are the categories

used for interpreting what people say and do entirely pre-given or fixed. This does not mean that the research is unsystematic, simply that initially the data is collected in as raw a form and on as wide a front, as is feasible.

- The focus is usually a small number of cases, perhaps a single setting or a group of people, of relatively small scale. It involves life history research which could include the researcher too. This is then termed “autoethnography”.
- The analysis of data involves interpretation of the meanings and functions of human actions and mainly takes the form of developing a story, from which descriptions and explanations are extracted.

Determining a focus for inquiry

In an ethnographic inquiry, it is impossible to specify all the elements of the design in advance. But no inquiry, regardless of the paradigm that guides it, can be conducted without a focus (Lincoln & Guba, 1985). The focus may very well change as the research unfolds but it has to be there in the beginning. Determining the focus of an inquiry serves two purposes: Firstly it establishes the boundaries of the study; it defines the terrain wherein the investigation is to take place. Secondly focusing determines inclusion and exclusion criteria of a study. This is important as in the beginning of an ethnographic inquiry data is collected with a “wide net” and the researcher might land up with information that is not exactly relevant, so focussing helps to discard the information that is not relevant to the inquiry (Hammersley, 1998). It is important to note though that these boundaries are not cast in stone. They can be altered and the naturalist researcher expects such changes. The researcher therefore starts with a particular focus in mind but does not hesitate to alter that focus as new information comes to mind. I use the term naturalistic researcher as naturalism according to ethnographic proponents (Van Maanen, 1995; Hammersley, 1998; Creswell, 1998), is an assumption on which ethnographic inquiry stands. The assumption is that ethnographic research aims to capture the character of naturally occurring human behaviour, and that this can only be achieved by first hand contact

with it, not by inferences from what people do in artificial settings (such as experiments). This is why ethnographers carry out their research in “natural” settings; settings that exist independently of the research process, rather than in those set up specifically for the research purpose.

The focus of this thesis is to investigate what is it like for a *parent* to live through the adversity of his/her child being diagnosed with cancer as well as my journey in researching this topic.

Determining where and from whom data will be collected.

Researchers such as Brink (1991) point out that the intent of the sampling processes in qualitative research is to identify subjects which fit the needs and qualities of a specific study. They should also be able to give a rich and comprehensive description of the problem under study. Whitt (1991, p. 410) further says the following: “ Decisions about whom to interview or what to observe should be based not only on the purposes of the research but also on the potential of the person or event to help the researcher gain insight and understanding about the phenomenon.”

For an ethnographic inquiry, maximum variation sampling is most useful (Hammersley, 1998). The sample should be selected in ways that will provide the broadest range of information possible. Sampling can be expanded until redundancy with respect to information is reached at which point sampling is terminated. This implies that the researcher does not initially know what will comprise the final sample (Creswell, 1998).

The choice of a sample in this particular study was guided by the focus of this study which is to explore what is it like for a parent to live through the adversity of their child being diagnosed with cancer and how a parent deals with such an adversity. In other words how do parents ensure their own “psychological survival” when their child is diagnosed with cancer. This implies that I needed to gain entrance into a system (a natural setting according to ethnographic terminology) where such subjects were available and were willing to give comprehensive and rich descriptions of what it is like

to live with a child with cancer. Although I did not have any rigid criteria for sampling the following applied:

- The subject should be a parent who had a child who was diagnosed with cancer. It did not matter if the child was newly diagnosed, in remission or had passed away.
- The subject should be willing to take part in the research. This is an important consideration in qualitative research as respondents who take part in a study because of some obligation and not because they are really willing to, do not give rich and comprehensive data.
- The subjects should be able to converse in a language familiar to the researcher as using a translator contaminates the flow of the study. Marshall and Rossman (1989, p.49) say: "One cannot understand human behaviour without understanding the framework within which such subjects interpret their thoughts, feelings and actions."

With the above criteria in mind I approached the head social worker of the Cancer Association of Pretoria who was the gatekeeper of a privately run support group for parents of children with cancer. This group called TOUCH was run by the parents themselves and decisions were also made by the parents. This group is affiliated to the Cancer Association and therefore I had to approach the gatekeeper first with a research proposal. After the gatekeeper spoke to the parents, I obtained permission to be part of the support group in August 1998.

The selection of participants initially was not difficult as everyone in the support group was considered a participant. The support group consisted of 12 members. Hammersley (1998) suggests that initially any sample unit will do as well as any other, but as insights and information accumulate and the investigator begins to develop working hypotheses about the situation, the sample may be refined to focus more particularly on those units that seem most relevant.

During 1998 and 1999 when the collection of data took place I realised that not all participants were rich informants, nor did they all want to be tapped for more information. Therefore the final sample was eight parents. Table 2 gives a description of the demographic and disease related variables of the sample.

Table 2

Demographic and disease-related variables of the eight participants at the time of the interview

Parent	Marius	Mary	Clay	Pat	Tessa	Vicky	Joan	Debbie
<u>Demographic characteristics</u>								
Age: Father	35		36					
Mother		32		34	45	40	42	41
Marital status	M	M	M	M	D	M	W	M
<u>Disease related characteristics</u>								
Diagnosis of child	ALL	ALL	R/B	R/B	M/B	L/C	ALL	AML
Age of child at diagnosis	3½ M	3½ M	9 F	9 F	6 M	13 M	7 M	11 F
Length of treatment	2½	2½	1	1	5	2	2	2
Relapse	no	no	no	no	yes	yes	no	no

Abbreviations:

M=married; D=Divorce; W=Widow

ALL=Acute lymphoblastic leukemia; AML=Acute myelogenous leukemia;

R/B=Retinoblastoma; M/B=Medulla Blastoma; L/C=Lung cancer

M=Male; F=Female; Length of treatment is indicated in years

Marius and Mary are a husband and wife team and so are Clay and Pat. Tessa is a single parent. She is divorced. Vicky is married but comes to the group meetings alone as her husband is not interested. Joan's husband passed away from cancer during my research. Debbie is married but like Vicky also comes alone to the group meetings.

Ethnographic sampling is very different to conventional sampling. It is based on informational and not statistical considerations. Its purpose is to maximise information, not facilitate generalisation. Its procedures are very different too, and depends on the

particular ebb and flow of information as the study is carried out rather than on a priori considerations. Finally, the criterion used to stop sampling is informational redundancy and not a statistical confidence level (Creswell, 1998).

Planning data collection

The choice of a data collection method depends on the type of data that the researcher needs (Creswell, 1998). The aim of this study was to give a comprehensive description of what it is like for parents to live through childhood cancer. The result of making sense of this illness is a construction in the individual's mind and it is these constructions that I wanted to document and analyse. As the situation in which qualitative research, and so too for ethnographic inquiry, is done is indeterminate i.e it cannot be controlled like in conventional research methods, the qualitative researcher has to rely on techniques such as interviews, observations, document analysis and non verbal cues (Ellis & Bochner, 1996b). As the design emerges as the researcher progresses with the study in an ethnographic inquiry, I stipulated no formal method of data collection in the beginning (Hammersley, 1998).

As I was not part of each parent's life when their child was diagnosed with cancer, I could give no direct or participatory description or observation as to what the parents experienced. All I could do was conduct interviews and document the parent's stories as to what it was like for them when their child was diagnosed with cancer and the coping methods they used to ensure their psychological survival.

A second reason why interviewing of participants was regarded as an appropriate method for this study was the following as illustrated by Heyink and Tymstra (1993):

- the respondent has the opportunity to address issues which he/she finds appropriate for the study;
- misunderstandings about questions and answers can be eliminated immediately;

- the flexibility and adaptability of the interview situation allows the researcher the opportunity to address new issues immediately;
- the interaction between the researcher and the participant allows for a rapport to develop which can be very therapeutic for both researcher and participant.
- the interview as research design to collect data is considered as an appropriate method when it comes to description of certain feelings, attitudes, intentions and interactions.

Determining instrumentation

Qualitative research, under which ethnographic inquiry as research inquiry resides, demands a human instrument, one fully adaptive to the indeterminate situation that will be encountered (Ellis & Bochner, 1996a; Hammersley, 1998; Denzin, 1997). In the present study the human instrument was myself who collected and analysed the data personally (Whitt 1991). Merriam (1988, p.19) says the following: “The researcher as instrument is responsive to the context; he/she can adapt techniques to the circumstances; the total context can be considered; what is known about the situation can be experienced through sensitivity to non verbal aspects; the human instrument can process data immediately, can clarify and summarize as the study evolves and can explore anomalous responses.”

Data collection procedure

Although logic says that one must know the questions in order to obtain answers this study adopted a different approach. A series of unstructured interviews were the means by which the stories or constructions of parents of childhood cancer patients were acquired. For the purposes of this study a general question was asked, “*What was it like once your child was diagnosed with cancer?*” From that point on, the topics, questions and concerns were generated by the participants and encouraged by me. The interview reports are the result of my interaction with the parents. They developed

through the continual process of data collection-analysis-verification-interpretation which often occurred on the spot as I listened to and thought about what was said. Few probes were necessary as the respondents were communicative.

The qualitative or unstructured interview

The qualitative or unstructured interview implies that the interview as data gathering technique for this study had no rigid rules before hand. This means that there was no fixed preselected number of respondents nor was there any predetermined, comprehensive set of questions which would be used by me in the interview. The interview content was varied from one respondent to another and also from one session to another. Each respondent gave their own information and overall grasp of the subject matter of the study.

The contacts with the gatekeeper are reported in Chapter 3 as her conversations with me formed a very important part of the research and provided me with another meta-position by which to understand the concerns of the parents. Marius, Mary, Clay, Pat, Tessa and Joan were participants from the beginning of the study. Vicky and Debbie came into the support group later. Once the respondents agreed to participate, analysis was ongoing taking the setting, the verbal responses of the participants as well as the researcher's personal reflections into account.

The fact that the qualitative or unstructured interview was used to gather data, meant that there was no interview protocol and that placed more responsibility on me to listen and hear the direction of the respondent. The respondents directed the topics which were covered during the sessions. The interview sessions were not individual interviews per se but group interviews. This meant that all the participants were usually present but often only one person spoke and told his/her story. The other participants took the role of listeners. This was completely spontaneous and I did not know before hand how the interview session was going to proceed. Sometimes every respondent in the group spoke.

In total there were fifteen sessions. These were held on the last Saturday of the month, starting in August 1998 and ending in November 1999. Thus my contact with the respondents lasted a year and three months. The time devoted to each session was three hours.

Data recording procedures

The notebook or journal is an important equipment that a qualitative researcher should have. In this study aside from the notebook which I had with me constantly, I also obtained permission from the group to tape the interviews. The tape recorder enabled me to concentrate on the discussion rather than only jotting down notes. I used the notebook mainly to note down non verbal behaviour. The respondents could at any time ask me to switch off the tape recorder, or they could switch it off themselves. All the tape recordings were transcribed.

The processing of data or data analysis

The data obtained in this study were constructions or stories stemming from the researcher - respondent interaction. The data analysis lead to a reconstruction or re-authoring (White, 1995), of these constructions or stories. In his book entitled *Representation in Ethnography*, Van Maanen (1995) provides several concepts useful in framing the analysis of interviews. He identifies *first order conceptions* which come from the respondent and are his or her point of view about what's going on, and *second order conceptions* which come from the researcher and are his or her point of view about what is going on. The process of interpretation enables a person to make sense of his/her world. However, these ideas are informed by the interpreter's values and therefore the notion of truth or correspondence to an objective reality, are not important issues in this approach which does not adhere to the belief in an objective reality. The data analysis included the following phases:

Phases of data analysis

Phase 1

By the time the data was collected the analysis was well underway. I had a preliminary understanding of the meaning of the data. This understanding was gained by making transcripts and continuously reading through everything repeatedly to immerse myself in the data. This helped me to become more aware and make sense of the respondents' world.

Phase 2

After reading through the transcripts, units of information were grouped under a particular theme. The units were chunks of meaning that came from the data itself (for example *certainty vs uncertainty, control vs lack of control etc.*). Data analysis in ethnographic inquiry is inductive (Creswell, 1998), which means that inductive analysis does not begin with theories or hypotheses but with the data itself, from which theoretical categories and hypotheses may be arrived through inductive reasoning processes. It is thus a bottom-up approach. I tried to move beyond summarising content in my search for themes. Processes and goals were looked at. This was then the phase of inducing themes.

Phase 3

This was the phase of coding the data and it actually blends in with phase 2. During the activity of unitising and developing themes I also coded the data. This entailed marking different sections or units of the data as being relevant to one or more of the identified themes. I used coloured marker pens to highlight pieces of text as suggested by Dey (1993), so that, for example all units in text relating to the theme of "control vs lack of control" was marked in green and all units in the text relating to the theme of "certainty vs uncertainty" was marked in red. These units or bits of coded material were then clustered under the heading of the theme.

Phase 4

The themes were explored once more and headings which overlapped and were

redundant (Hammersley, 1998), were scrapped to arrive at a final list of themes for each respondent.

Phase 5

The final list of themes was negotiated with each respondent for verification of the content. In each case, with minor deletions and additions, the respondents verified the themes and did not see the need for further face to face contact.

Phase 6

The transcripts were read again for finer nuances of meaning not captured under the process of thematising. This is when I became aware of the language used by each respondent. According to Lincoln and Guba (1985, p.333) "the language of the respondent within which the constructions are made and meanings presented also shapes and influences the data". I extracted words and phrases used by the respondents, which depicted what it was like for each parent when his/her child was diagnosed with cancer.

Phase 7

The transcripts were read once more in order to elaborate on the previous phases. I then recounted the story of each participant's story. Each story is based on the transcribed tapes of conversation that occurred during the group sessions. Additional notes taken by myself were also used. Each story consists of an introduction which is followed by the story of the participant's child, which is then discussed in terms of emerging themes. In addition, how each participant coped, as well as emerging processes that were perceived to be helpful from my point of view are discussed. These processes can serve as guidelines for other parents dealing with their child being diagnosed with cancer. My relationship with each respondent is discussed within the context of the support group. The stories are described in Chapters 5 to 10.

Phase 8

Finally the findings are integrated in the form of four hypotheses and conclusions and recommendations are made. Some of these are formulated as hypotheses, which

could lead to further research. Thus, this study generated hypotheses rather than testing hypotheses.

SUMMARY

In this chapter attention is paid to the methodological unfolding of the study, which includes procedures such as sampling, selecting a site and gaining entrance and data analysis.

The next chapter will be devoted to an autoethnographic account of my experiences with researching childhood cancer as well as description of what an autoethnographic account entails.

CHAPTER 3

FROM RESEARCHER TO CO-THERAPIST - AN AUTOETHNOGRAPHIC ACCOUNT

In this chapter I will focus on writing my personal story from when I began my journey into research on coping with childhood cancer. This story will emphasise the complexity of gaining entrance into a system, my experiences during my visiting fellowship stay in England, and lastly how my role changed from being “researcher” to becoming “co-therapist” as I entered TOUCH, (the support group for parents of childhood cancer patients). This account will describe how I realised that autoethnographic inquiry grants me the freedom to include a personal story in an academic dissertation.

IMPRESSIONS OF WORKING IN A HOSPITAL SETTING

I assumed a position of a volunteer in a pediatric oncology unit of a hospital for the first time in 1994. There I faced a culture and challenge that I have never encountered before. I was confronted with a problem I never imagined when doing my literature survey and deciding on the topic of childhood cancer. A major discovery took place: The problems on the surface were only the tip of the iceberg. There was so much to be learned beyond my university knowledge. In spite of these obstacles I felt a compassion for the children and their parents in the oncology ward of this particular hospital.

The pediatrician in the oncology ward was very keen to have me work there. Probably no other research psychologist wanted to take this challenge, and secondly because she seems to be a born server and she wanted to offer more to her patients than her medical services. I was included in the system and did preliminary studies for about

a year.

I struggled to fit into this system for the following reasons: Firstly I was seen as an outsider as I only went there once or twice a week which meant that the patients as well as the other members of the oncology team did not see me often enough and therefore did not regard me as part of the team.

The second and most important reason was that each member of the oncology team had a concrete task to fulfill, the results of which were immediately visible and could be reported back during our oncology team meeting every Friday. For example, the dietician would say she put this child on such and such a diet and the child weighs so much more/less this week. The occupational therapist and physiotherapist would do the same. I had nothing concrete to report on.

The third stressful aspect was the unwillingness of the patients to co-operate. The medical interventions were stressful enough for them and they were unwilling to relate to a student volunteer.

The fourth stressful aspect was the hospital staff and their lack of interest and interaction with the patients. It was very difficult to get any of them to help me with the patients and I got frustrated of asking for help repeatedly.

I persevered in this environment for 12 months until I left for England. I hoped this break would give me time to think about what I was doing as well as gain experience of how the mental health professionals coped at the hospital where I was going to be working overseas.

MY EXPERIENCES IN ENGLAND

In England I was recruited into a psychological therapy programme and assisted the Child and Adolescent Psychologist with psychological evaluation of children included in a psychotherapy outcome study. This study expanded into a support group for the

parents of the children in the psychotherapy programme. Working in this system, and the way we were conversing with each other during the group processes, triggered me into thinking about intimacy and sharing. My conclusion was that a support group should be able to tap into different levels and not become a comfortable interpersonal conversational context where the individual member remains untouched on a personal level. A support group should provide the context for the individual to connect to himself on a more personal level. These thoughts motivated me further to read about psychological intervention programmes for the parent of the child with cancer and to think of how I could apply these insights when I returned to South Africa. I realised that the active involvement of parents brought a more family-oriented approach which encouraged healing in the long run.

While listening to the parents' stories I realised that the instillation and maintenance of hope in the parent is a crucial component in healing the child with cancer. Also, it was remarkable to hear the parents remark at the end of the group session how important it was for them to have observed the improvement of others. This was important as many parents, once their child is diagnosed with cancer, enter a support group with the disquieting thought that they are unique in their wretchedness. There is an element of truth in this, as each person has his/her own constellation of severe life stresses, but I realised that it is the validation and acceptance of others in the group that makes the difference. All the parents, after hearing other members disclose concerns similar to their own, reported feeling more in touch with the world. Simply put, the phenomenon finds expression in the cliché, "We're all in the same boat".

During these interactive group processes I realised that telling as well as listening to stories of others in the group who are, or have been in similar situations has a kind of cohesiveness, an altruism that is therapeutic in itself. Ellis (1997) suggests that our stories impact on us and each other in the group by the fact that we learn from each other in our joint interactions. She further says that one person's disclosures and self probing invites another's disclosure and self probing and this leads to an increasingly intimate and trusting context which makes it possible to reveal more of ourselves and to probe deeper into another's feelings and thoughts. Listening to and asking questions

about another parent's plight leads to greater understanding of one's own and the comparison of experience offers new insight into everyone's lives in the group.

A British Medical Journal editorial (Mott, 1990) suggests that skilled professional support can help to cushion the impact and to sustain and restore family members through this crisis in their lives. This need for support was highlighted in a study by Morrow, Hoagland and Morse (1982) where, in answer to the question "What was most needed that wasn't provided during the illness", 54% of the parents cited emotional support or counselling. This was emphasised in another study by Macaskill and Monach (1989) where the authors observed that there could be no doubting the severity of the distress and personal pain experienced by parents whose child is diagnosed with having cancer. They went on to conclude that their analysis demonstrated that psychological care needs to be offered routinely to the families of children newly diagnosed with cancer and this ought to be an integral part of patient care.

Provision of psychological support for the whole family during the period following primary diagnosis is widely considered essential. However, what form this support should take is unclear (Pearce, O'Keefe, Faulkner & Clarke, 1992). Given the existing evidence on psychological morbidity and the increasingly good medical prognosis for pediatric oncology patients, it is remarkable that studies relating to the value of specific psychological intervention are extremely rare and that no clear guidelines regarding models of care exist. Maguire (1993) has pointed out that a number of centres have tried to tackle the problem of adverse psychological sequelae in children with cancer and their families by establishing a specialist nurse or social worker.

BACK HOME

When I arrived back in South Africa I reflected further on how I would go about moving towards an understanding of the parent of the child with cancer as well as integrating my past experiences. My realisation was that any situation (or activity) that one is involved in can become a researchable project. The process links talking, writing,

researching and doing into a never-ending flow of interconnections. Anything and everything can be the focus of the research process. I also realised that I needed either to create or get entrance into a support group of parents who had to deal with childhood cancer, similar to the one in England, in order to apply what I experienced. I also needed to find a theoretical orientation, a window, through which I could describe my research journey.

Initially I prepared a research proposal which corresponded with the requirements for a controlled experimental study. After discussions with various possible supervisors and remembering my experiences in England, the said proposal somehow lost its appeal. It was only after I had been introduced to some basic literature on "autoethnographic inquiry" that I recaptured my motivation for continuing this research process.

THE RESEARCH CONTEXT

According to Ellis (1998) autoethnographers are drawn to experiences of loss (either their own or others) out of which such existential crises arise. The loss that a parent experiences when his/her child is diagnosed with cancer shatters the meaningful world he/she has assembled for him/herself (Sawyer, Streiner, Antoniou, Toogood & Rice, 1998).

At this point I wish to make a brief personal statement. I chose a career in psychology because I find meaning in working with people on a personal level. Although I am not a parent nor have I experienced the loss of a child, I can identify with people in pain. Although my painful experiences are not necessarily the same as those of my subjects, I have a strong desire to understand, manage and recover by creating an account that makes sense of pain and puts the pieces back together as suggested by Frank (1995). My research journey thus starts with a story of my personal experiences as a researcher and moves on to the stories of my participants. According to Behar (1996) in autoethnographic inquiry the researcher's story is integrated with, or told alongside the participants' stories. My personal story continues in the form of dialogue or

personal reflections and is told within the process of gaining entrance into a new system and its culture. The inner workings of myself, while grappling with issues surrounding this type of research, will be documented and presented in concrete actions, thoughts and feelings as suggested by Ellis, (1998).

According to Ellis and Bochner, (1996b) autoethnographic work is about interaction between the researcher and the participants. "Investigators are a part of the world they investigate and the ways in which they make it and change it, thus breaking away from the epistemology of depiction that privileges modes for inscribing a preexisting and stable social world" (Ellis & Bochner, 1996b, p. 4). Thus the interactive researcher cannot unilaterally determine the direction of the research, it is a co-evolved process. Autoethnographic inquiry is embedded in relationships and the research is dependent on the setting up of an interpersonal context where trust and respect are essential ingredients. The process demands intimacy from the participants, a honesty and openness in the issues that one is grappling with. One should always be sensitive to what the other participants are grappling with and be prepared to explore their concerns and not hold on to what one wants to do (Ellis, 1998). In my writing I show interaction so that the reader might participate more fully in the emotional process. I will try and be true to the feelings that emerge from each story told by the participants of the study (Frank, 1995).

When looking at how I should formally go about my research journey I was confronted with a number of difficulties.

- Researching emotional experiences and documenting them means having to make sense out of personal and others' emotional experiences that have no objective value in the traditional sense.
- Do I trust my own abilities to think, relate, connect, resift, reconsider or change?
- What ethical issues will be embedded in the sharing of intense and life threatening emotions?

- Will I be able to separate myself from the context as I am the research instrument?
- Whose expectations am I to meet?

In examining these difficulties of doing a qualitative research project, Meloy (1994, p. 12) states:

“Qualitative researchers in their writing illuminate the sense of not knowing what will happen until you get there. A major sensemaking strategy is reducing ambiguity. Qualitative researchers continuously make more and more, rather than fewer and fewer, decisions. It is only at the point of closure to a qualitative research experience (and even then there is most likely no singular billboard or flashing sign) that the complex, layered experience in which we engage begins to take shape as a sensible whole that can be - and indeed has been - organised, interpreted, and, perhaps, understood. Theses do not emerge all at once; if the thesis is qualitative, chances are it will not arrive head first. Understanding follows doing.”

GAINING ACCESS TO A RESEARCH CONTEXT

My next step, after returning from England and reflecting on what had happened there, was to gain entrance into a local system in order to carry out my research. Finding such a system and gaining entrance did not prove to be a problem as I became aware of TOUCH and realised that this organisation was exactly where I wanted to be.

Before I phoned the gatekeeper of TOUCH, the head social worker in charge of the future respondents for the study, a whole lot of questions went through my mind:

- How do I approach her?
- What do I say?
- What would I like to know?

- What will the focus of the conversation be?

During conversations with other experts in the field the following suggestions seemed to be important to remember when making contact for the first time.

- My attitude should be one of “not knowing and wanting to learn”.
- I should not introduce myself as “the psychologist” thereby implying any expert position.
- I would outline some of my concerns which arose during my volunteer work in an oncology ward and ask if it would be possible to be part of a group where I could share these concerns.
- I would share the idea that I am interested in health issues and that I have a sense that in a hospital setting medical staff often leave patients in the dark. How could we break this culture of silence on the part of the patient?
- I would emphasise that I could not get answers on my own and needed to collaborate with others.

With the above advice in mind, I phoned the social worker, Petra, to set up a meeting. I knew nothing about her, except that she is a social worker working in the field of childhood cancer and counselling parents.

The first contact with the social worker (June 1998)

Petra, was very approachable and also compassionate. I told her I was busy with my doctoral thesis and that I was looking for a group within which I could exchange ideas. She informed me about the parent support group which she runs once a month. I asked to meet the support group. She replied she would ask the group members if this could be done.

I left Petra's office feeling very positive. From what she had said I understood that this was a newly formed support group running for about six months and that they needed advice and counselling. I also got the feeling, that she wanted me in the group.

Second contact with the social worker (July 1998)

Petra did not call me for about three weeks so I decided to call her. Being very anxious that she might have bad news, I stalled calling her for another week, after which I picked up the phone and dialled. She apologised for not having called me as she had been ill and also had to take over somebody else's responsibilities at work. She said the group was enthusiastic to meet me.

Towards the middle of August, as the time drew nearer to meeting the group, I was getting quite nervous. However I decided to allow the process to flow on its own without too much structure and planning. The main thing for me was to remain co-operative with Petra, the gatekeeper. I did not know where this would lead me but for the moment I was pleased that I had a context in which I could engage with a parent support group, and hopefully conduct my research on the impact of such a group on helping parents cope with the ordeal of having a child diagnosed with cancer, or having lost a child to cancer.

GETTING STARTED

What was evident at this early stage was that I knew nothing about the group except the little Petra told me at our first meeting. She was the connection between myself and the group. The start would be slow as we would have to get to know each other. Openness and trust would be two aspects that would guide my interaction with her and the group members.

Session one (30 August 1998)

Before the session started Petra told me that she was quite anxious as the parents had

never spoken intimately about their experiences. The sessions have always been very structured with a speaker to inform the group about certain issues. They have also been busy with practicalities such as deciding on the ground rules for the group.

When I walked into the conference room and met the group I intuitively had a good feeling about this session. The chairperson of the group, I heard then, had also been diagnosed with cancer himself and would not be able to make all the future sessions. The whole group was not present due to unforeseen circumstances. I had a tape recorder and, with the permission of the group, taped our first session.

Once I was introduced to the group, they asked me to say something about myself. I told them I was doing a qualitative research study. They wanted to know what I meant by qualitative research. I told them I was interested in the multiple meanings of their individual experiences of their child being diagnosed with cancer. I further explained that I would report the information in an interpretative and narrative style as is done in qualitative research (Ely, 1991). They asked me to explain "multiple meanings". I answered that it referred to the different perspectives each one of them had about childhood cancer. As they wanted to know about my past experiences in the field, I shared my experiences with them at the Royal Marsden Hospital in England in a spontaneous way. It seemed as if that gave me more credibility.

I will now present the transcription of parts of the conversation. Bochner (1994, p. 4) calls this *interactive ethnography* where the "ability to converse intimately" refuses to close off further discussion or quiet the voices of the other.

Marius: "Did you work more with parents or with children?"

I interpreted this as a question testing my ability to work with him as a parent so I assured them that I worked with parents.

Marius: "Did you find a lot of anger in them?"

Me: "To a certain extent yes."

Marius: "Was there a difference between men and women?"

Me: "Yes, women showed more emotion than men."

At this point I decided to change the direction of the conversation as I felt the respondents should be talking.

Me: "How do you feel? Do men and women respond differently?"

Mary: "Yes."

Pat: "Yes, I am the one who does all the talking, my husband says very little."

Tessa: "I also do all the talking."

At this point I decided to ask a open-ended question without any cues.

Me: "Is there anything you would like to talk about?"

They spoke and shared their feelings with one another, something they had not done for a long time.

Marius: "I can write a book on all my experiences. No-one and I mean no-one can tell me they know how we feel."

Me: "Tell us how you feel."

Marius: "It is something I wouldn't wish on anyone - the hospital, the doctors, the nurses - what they did to us and our child."

Pat: "They did not even tell us it was cancer."

Mary: "The first time I heard my child had cancer I fell off my chair, I was hyperventilating, they had to inject me."

Marius: "It was like a bad dream."

Tessa: "And you wake up the next day and the dream is still there."

Marius: "I slept with my child in the ward. I insisted on a bed next to his. The nurses did not do their job. They took his temperature and said he had no temperature. I stretched out my hand and he was very hot. I told her to put the thermometer again. She did, and found a high temperature."

- Mary:** "The wards are cold with no pictures."
- Marius:** "They sweep the floors and gather all the dirt next to the intensive care unit. The pathologists who did the bone-marrow transplant were callous. They held my child down forcefully. My baby was screaming and I could do nothing. I wish I could get hold of them now and..." (The respondent shows his fists as a demonstration of anger).
- Pat:** "After the diagnosis of our daughter with retinoblastoma we lost all our friends."
- Clay:** "It was as if we committed one or other kind of sin and this was our punishment."
- Mary:** "Everybody stays away, it's like leprosy."
- Marius:** "I will always support anybody who is ill after my experience because that is when one needs others. This is why this support group is so important to us."

In the silence that followed I decided to pursue the theme of confiding in people and asked the respondents who they confide in. The women were crying by this time. They all said they confided in their parents and in one another.

- Me:** "How did your child react when you told him or her about being ill?"
- Marius:** "It rained with tears the day we were told our child had cancer. I still cry in church every time we sing. I also cry in the shower."
- Pat:** "My child's belief was incredible and she told me that she gives her life over to God. She has become a stronger person."
- Mary:** "I see the opposite with my son. His self esteem has dropped and he always walks around with a stick in his hand. I don't know if he sees it as a weapon."

We concluded the session on a calm note. I asked them to write me a story on their ordeal from the point of diagnosis of their child, up until the present time. My intention with this was to obtain more information about the feelings which they found difficult to

express during this session.

The session lasted for about three hours.

It was clear to me that the group members felt angry and aggressive. They experienced that life has been unfair and they were given a blow by their child being terminally ill. They needed to blame someone or something as they did not know how to get rid of this anger. They wanted to get rid of it for their ill child's sake, as well as for their other children that were not ill. Men and women differed in the display of feelings. The men kept their feelings to themselves but as a result suffered more on their own. The women cried a lot and talked a lot about this wherever they went. Both parents felt the unexpectedness of this whole event was the most traumatic aspect.

One parent, Clay, presented the theme of isolation. He said it almost felt as though he committed some kind of sin and has lost all his friends too. Then everyone joined in and said its like leprosy, everyone stays away because they don't know what to say. They felt people phoned, because they are inquisitive and once they are up to date they never call again. They felt the need to talk to an outsider, someone who would not judge them in any way. They felt somehow inferior to others and they did not know how to get rid of this. They said that they felt scarred for life and they would like to know how to get rid of these scars. Perhaps by improving things in the hospital environment and making conditions better for others, they felt they might be able to feel that this whole ordeal of theirs contributed somehow to something good.

Another aspect that came out strongly was their disappointment about the emotional handling of this illness by the medical profession. Many of them said that they were ill informed or informed late about their child's condition. One parent was highly upset about his child's treatment in the ward. They felt the wards are not friendly, having no decorations and also there were no special programmes for the children that are ill.

The issue of confiding in people also seemed to be something the parents were disturbed about: "You always need to be strong for your child because your child

confides in you but you also need someone other than your spouse to confide in. There are so many issues that come up, so many unresolved conflicts that pop up and it is difficult to communicate.”

PERCEPTIONS OF THE GROUP PROCESS

Although the first meeting was an emotionally difficult one for me, I managed to stay in control and keep the process flowing. I realised that although the group did not know me they trusted me to such an extent that it was quite frightening. I did tell them that everything they said was confidential but their honesty and openness was unbelievable. I wondered, to what extent would they feel they had said too much when they got home? What if they started feeling unsafe and did not talk again?

Two weeks after the first session I had a peer mentoring session with Petra. During this meeting she told me that she would like me to extend my role from researcher to her co-therapist. My original intention on entering this system was to do qualitative research on the parent of the child with cancer. By accepting her offer my identity had now changed from researcher to that of co-therapist.

I went through a period of questioning everything - from the reasons why I wanted to embark on the doctoral research, to personal concerns about the work that I was doing, to the meaning of life in general. It felt as if I was dealing with an existential crisis (Frankl, 1962). My supervisor responded to this by directing me to some fundamental research philosophies. I decided to review some of the well known publications that specifically focussed on connecting the personal to the cultural (Van Maanen, 1995). In this way I could integrate my personal struggle with this doctoral thesis and the research focus on the parent of the child with cancer.

Bateson (1980, p. 32) states that “science probes and does not prove”. He argues that science is nothing more than a way of perceiving and making sense of one’s own perceptions. He further advocates that one should not assume that one can predict certain responses or reactions from an intervention. In an open system (like the one

I was in) there are random events that usually shatter one's perceived notions of any causal relationship that was thought to exist.

Martin (1993, p. 368) also states that "when natural scientists move from the closed systems of idealised, laboratory setting to open, real-world systems, their causal laws suffer suppression and interference through interaction with other, unknown and unpredictable, laws and regularities".

I came to realise that the particular type of research design a researcher uses, has an impact on the nature of the research process which ultimately determines the types of conclusions that are drawn.

With this shift in focus from being a researcher to becoming a co-therapist, I realised, that I had tried, initially, by defining myself solely as a researcher, to create a research context that would keep me separate from that which I was intending to research. According to Dell (1985), a system is autonomous and its structure (mental and physical) will specify how it will react under certain conditions. With this shift in my identity from researcher to co-therapist I needed to look more closely at how I was constructing my understanding of the work that I was doing.

A significant turning point occurred when my supervisor introduced me to the field of "ethnographic research" and in particular to autoethnographic inquiry.

THE GENERAL METHODOLOGY OF AUTOETHNOGRAPHIC INQUIRY

Autoethnography according to Ellis (1997, p. 9) is an "autobiographical genre of writing and research that displays multiple layers of consciousness, connecting the personal to the cultural. Back and forth autoethnographers gaze, first through an ethnographic wide angle lens, focusing outwardly on social and cultural aspects of their personal experience; then they look inwardly, exposing a vulnerable self that is moved by and may move through, refract and resist cultural interpretations. As they zoom backward and forward, inward and outward, distinctions between the personal and cultural

become blurred, sometimes beyond recognition”.

Usually written in the first person voice, as is this thesis, autoethnographic texts can appear in the form of stories or personal essays or journal writing, be it fragmented or whole. The personal narrative of the researcher is important in autoethnographic inquiry. In this type of research the participants are encouraged to participate in the research or therapeutic process and take an active role in what happens. In becoming a co-therapist as opposed to a researcher only, I would now be given the licence to be personally engaged in exploring the feelings and emotions of each session in myself and in the participants of this study. According to Ellis (1997, p. 12) “Autoethnographers vary in their emphasis on the research process (graphy), on culture (ethnos) or on self(auto)”. In this thesis there will be an interplay between myself and the culture of the support group which will be documented in the form of narratives or stories.

Why personal stories matter

Understanding is one of the central assumptions in autoethnographic inquiry (Ellis, 1997). Central here is the argument that human action does not consist simply of fixed responses or even of learned responses to stimuli but involves interpretation and construction of responses. If we are to explain human actions effectively we must gain an understanding of the cultural perspectives on which they are based. Ethnographers argue that it is necessary to learn the culture of the group one is studying before one can produce valid explanations for the behaviour of its members (Hammersley, 1998). This is the reason for the centrality of participant observation and interactional interviewing to ethnography and autoethnography since these methods promise to provide in-depth understanding of cultural perspectives.

For this study I decided to use interactive interviewing (as stated previously) since my role had changed from researcher to co-therapist thereby changing the boundaries of the study to include both research and psychotherapy (Lieblich, 1996; Miller, 1996). The research would consist of a narrative mode of interviewing in which the members

of the support group would each be given the opportunity to tell about their experience once their child was diagnosed with cancer. The telling of the experience (i.e. each parents' story) or in other words the performance of a personal narrative (Reissman, 1993), was considered to be an appropriate method of gathering data for this study for the following reasons:

- stories determine which aspects of our experiences get expressed as well as the shape of that experience
- people live by the stories they have about their lives and for the purposes of this study it is these stories or constructions that parents have about their child's diagnosis which shaped the way they managed the illness.
- stories provide the frames that make it possible for us to interpret our experiences and I shared my interpretations of the parents' stories with them. These acts of interpretation were achievements that I and the participants took an active part in and this contributed to the trustworthiness of the study.
- stories bring a researcher or therapist closer to an understanding of the people they work with, be it in therapy or research. Attempting to understand people you work with and wanting them to know that you are moving towards an understanding of their dilemma, is a way of gaining confidence between the two parties, which leads to the gathering of information as well as new possibilities. This is an important assumption on which autoethnography is based.

A story according to White (1995, p. 80), "can be defined as a unit of meaning that provides a frame for lived experience. It is through these stories that lived experience is interpreted". It is the stories of each parent whose child has been diagnosed with cancer which provided me with a sense of the unfolding of events when the parent was going through the ordeal of diagnosis, treatment, remission or death. In this way I moved towards an understanding of the parent of the child with cancer.

I refer to these personal stories of the respondents as *evocative narratives* (Ellis, 1997). An evocative narrative is a story filled with meaning (Reissman, 1993). The meaning takes a different form depending on who the listener is. These stories were interpreted or transcribed by me as I experienced the respondent. Meaning is ambiguous because it arises out of a process of interaction between people: self, teller, listener and recorder, analyst and reader. Although the goal may be to tell the whole truth, our narratives about others' narratives are our worldly creations. Meaning is fluid and contextual, not fixed and universal (Denzin, 1997). According to Bochner (1997), the mode of storytelling is similar to a novel or biography and has the following characteristics:

- It fractures the boundaries that normally separate social science from literature
- When the reader encounters the written report or text he/she becomes a co-participant in dialogue instead of being a passive recipient, therefore the traditional view of the reader as a passive participant is rejected
- Secrets or hidden details of private life are disclosed which stresses the importance of emotional experience thereby challenging the orthodox view of rationality
- Narrative texts do not try to explain, they rather stress journey over destination and thus overshadow the scientific illusion of control and mastery
- The lives of the researcher and participants are connected across the curve of time therefore the conventional mode of portraying social life and relationships as a snapshot is resisted
- Evocative stories activate subjectivity and evoke emotional responses, they are used rather than analysed, they are told and retold rather than theorised and settled, they offer lessons rather than truths, therefore are a good substitute for the empty and lonely facts of conventional data gathering techniques.

The question I will be asked is, "How can stories represent truth?" It is as if critics see stories or narratives as fictionalising life, something that is so overly broad, it can include everything and anything (Shotter, 1997). Narrativisation tells about past actions and not the past itself. A second question I could be asked is that stories reflect a

“romantic construction of the self” (Atkinson, 1997, p. 335), and are not worthy of being classified as part of social science. Atkinson believes that a text that acts as an agent of self-discovery or self-creation (precisely the narrative challenge one faces when an expected life story is interrupted by illness, violence or accident), cannot be an academic text.

So what then is the point of a storied life?

To find meaning in our lives involves a struggle. We have to find the meaning of our suffering in the face of fear and threat, in deep anxiety and shock evoked by certain life events. We have to exercise courage. We need to make sense of our lives, that is from the tensions constituted by our memories of the past and anticipations of the future. Life and narrative are inextricably connected (Reissman, 1993). Life both anticipates telling and draws meaning from it. Narrative is both about living and part of it (Hacking, 1995). Personal narrative, the project of telling a life, is a means of taking control and making sense of events over the course of our lives (White, 1995). We all have a desire for continuity (Denzin, 1989; Crawford, 1996; Van Maanen, 1995), to make sense of our lives as a whole. The success of our personal identity depends on how well we bridge the memories of the past with the expectations of the future. The work of self-narration is to produce this sense of continuity, to make a life that sometimes seems to be falling apart come together again, re-telling and re-storying the events of our life. Our vulnerability is revealed in our narrative attempt to achieve a coherent sense of ourselves (White, 1995), so in the final analysis, the self is indistinguishable from the life story it constructs for itself out of what is inherited, what is experienced and what is desired (Kirby, 1991). Rich (1978, p. 34), says “the story of our lives becomes our lives.” It is part of our existential struggle to move forward.

So the question should rather be *what are the consequences of this story of mine? How has it shaped me, or changed me? What new possibilities has it introduced me to?* Storytelling is a process. It is never in neat steps (Deck, 1990; Neumann, 1996).

I realised that my work with the parent support group could have a therapeutic impact.

This, however, does not mean that it would not be of value as a research project. It should not be difficult to understand that stories entail moral work and ethical practice. As a researcher I would still be asking questions such as what would be the right thing to do as suggested by Ellis and Bochner, (1992).

Doing autoethnography

The problem I was facing now was how would I go about gathering data? How would I make sure the data was valid? Behar (1996) says that if you are not willing to become a vulnerable observer, then maybe you ought to reconsider doing autoethnography. By living the experience, by becoming part of the pain you will be able to form a story about each participant that will break the reader's heart, suggests Behar (1996). In autoethnography, the important aspect about the data is how it affects the reader. Denzin (1997), indicates that just like a good novel, the reader should be "grabbed" by your story, should identify with some special character. In writing autoethnography one needs to construct the event or story as close to the experience as you can remember it.

As I was thinking about the participants I realised how therapeutic it would be for them to tell their story to each other. Then I would go through each story and share with them certain themes I picked up in their story. Lather (1993), suggests that to increase reliability in autoethnography when other people are involved, you take your work back to them and give them a chance to comment, add materials, change their minds, and offer their interpretations.

Formalising ideas on method and form of autoethnography

After my first session with the support group I decided to formalise some ideas about how I would go about my study.

I elected to carry out the research in a **natural setting**. Thus conversations and interviews with the participants (the parents of the child with cancer) would be held at

the venue where they met as a support group. Sharing the same concerns and difficulties in the presence of each other and in their natural venue would make the participants feel more comfortable and also contribute to trustworthiness of the data as cross checking would be made possible. Reflecting about the conversation afterwards would make tacit knowledge explicit. The responses of the participants would explicate the complexity of the task of understanding and describing their experiences.

I would be **the data-gathering instrument**. Although the information itself would be recorded on tape or in my journal, it would also be filtered, sorted, edited and interpreted by me. The interaction between myself and the participants is the most vital connection in the collection of information. My ability to conduct an interview, gain the respondent's trust and interest, will influence the amount and type of data gathered. Autoethnographic inquiry is not value-free (Ellis, 1997) therefore the researcher's previous experiences, assumptions and his/her realities will also influence data gathering and interpretation. Every researcher is unique and every inquiry is unique, therefore the study cannot be replicated by another researcher. In my contact with the participants I also respected the fact that each participant viewed their experience from their own reality.

The purpose of the research was clearly stated at the first meeting as the participants and the social worker were informed that I was conducting research on the experiences of the parent of the child with cancer from the parents' point of view. They were also informed that usually research in this field is done in a quantitative manner using prediction as the main frame of reference whereas this study is all about understanding the realities of the participants. The participants would be given the opportunity to tell their stories as they experienced the entity under study first hand. This would expand our body of knowledge. The aim of the research is to tell the story of their experience after their child was diagnosed with cancer and this understanding of the individual participants and the documentation of their experiences could alleviate the pain experienced by other parents whose fate is to also go down this path.

The explication of **tacit knowledge** is an important characteristic in autoethnography (Denzin, 1997; Reissman, 1993). This tacit knowledge shapes the participants' view of illness and in order to understand how the participants experience the illness of their child the tacit knowledge needs to be extracted from the stories and shared with the participants. This would help the participants in understanding and in finding meaning in their struggle. Therefore I needed to use my senses, intuition, creativity and past experiences as well as present awareness to get the most information from the inquiry.

A prolonged engagement with the respondents over a series of respondent directed conversations and interviews is imperative. The assumption in this thesis is that the individual constructs the illness in his/her head therefore **qualitative methods**, in particular, the unstructured interview and story telling were used because they enable the construction to emerge from the creator.

In ethnography and autoethnography participants are selected on the basis that they are able to provide rich descriptions of the entity under study rather than being random or representative (Creswell, 1998; Ellis & Bochner, 1996a; Van Maanen, 1995). This means maximising diversity of perspectives. Samples are usually small as researchers prefer to look at a few cases with intensity. The importance is always to get off to a good start. In this study my aim was to get the respondents to feel at ease but in order to do that I had to ensure that I was also at ease, comfortable with the study and interested in the participants.

In this study sampling was **purposive** and convenience selection was used. The richest informants were selected as participants. The sample comprised of eight individuals selected from the support group consisting of twelve parents who had a child diagnosed with cancer and who wanted to share their experiences in the form of conversation. I obtained the consent of participants to use the data collected for the purposes of this research.

The categories by which the data were analysed developed as a result of working with the data rather than being derived from previous hypotheses. This type of **inductive**

analysis enables possibilities to emerge and understandings to develop. The researcher can be creative with the data rather than confined. This does not mean drawing conclusions that are not grounded on the data but allows for some mental freedom.

The stories presented later in this study are samples of **negotiated outcomes** as I discussed with the participants the meaning that was derived after analysing the content of the conversations. On a second level I reflected on the data as part of the process of making sense of things. The purpose of this study was not to question each participant's construction of reality but to document those constructions, therefore these negotiations were done in a limited sense.

In order to be of help as a co-therapist I needed to get clarity in my mind about what "philosophy" I would follow and how conversations would be of help to the participants. For a conversation to be therapeutic you have to create the space to talk about the "unsaid" (Bateson, 1980). Another important aspect, especially in a group process, as ours was, is that, in social support there is a need for reciprocity (Sarason, Sarason & Pierce, 1990). In the next chapter I will look at the impact of social support and the need for reciprocity.

CHAPTER 4

SOCIAL SUPPORT AND THE PARENT OF THE CHILD WITH CANCER

WHAT IS SOCIAL SUPPORT?

Social support is a complex and multidimensional construct. It has been studied in a myriad of ways to determine types of support provided, categories of support providers, mechanisms by which support protects people against the negative effects of stress and even what the best definition is for support.

Social support does not occur as an isolated entity, but rather is derived from relations with members of one's social network. Social networks are a series of ties or social connections between individuals that vary in terms of structure and function (Chelser & Barbarin, 1987).

An often used definition of social support notes that it consists of interpersonal transactions that contains three components, namely social shemata, supportive relationships and supportive transactions (Pierce, Sarason & Sarason, 1996). These elements are interrelated and mutually influence each other in various significant ways. As these components constitute social support, I will discuss each one separately.

Supportive schemata

Each person has a mental map (shema) of past experience in his/her mind. The way each individual perceives the availability of others upon which they can rely for support has proved to be one of the strongest predictors of personal adjustment (Lakey & Cassady, 1990).

Supportive schemata involve the expectations of a person of the support the environment will provide should he/she need it. According to research findings (Fiske & Taylor, 1984; Markus & Zajonc, 1985) people develop *schemata* about others that include *expectations* for their future behaviour and *assumptions* about their motivations and intentions. These schemata are usually formed from childhood. If interactions with parents were supportive, sensitive and well matched to the child's needs, children and later as adults, develop positive expectations about the willingness of others in general to provide support, whereas children whose needs for support were not met develop a generalised view that others are not willing to help them when in need. This schema has further implications in that it is linked to one's self concept. Children grow up with a negative self image if they do not get support from their parents and as adults give themselves negative attributes, and believe that they are not worthy of getting support (Lakey & Cassady, 1990; Sarason, Pierce, Bannerman & Sarason, 1993).

Support schemata also influence the responses of potential support providers. Studies have shown that those high in perceived social support are more interpersonally sensitive and more strongly desired as potential sources of social support (Sarason, Sarason, Hacker & Basham, 1985).

Supportive interactions with parents provide children with an opportunity to acquire coping skills that enable them to meet the challenges posed by stressful situations. Parental support also reduces children's distress by increasing their coping resources, thereby reducing the threat posed by stressful situations.

Supportive relationships

Pierce, Sarason and Sarason (1991), suggest that aside from the supportive schemata that people have about how others in general will respond to them, they also have expectations about how specific others will respond to them should they require their assistance.

Research on social support according to Pierce, Sarason and Sarason (1996), involves

studying supportive relationships in such a way that one person is identified as the support provider and the other as the support recipient. Although this approach has its merits especially when it comes to a parent-child relationship it also has its flaws. It does not take into account that a person is in any relationship both a source and a recipient of social support. We cannot isolate or separate specific supportive transactions from the everyday fabric of relationships in which people mutually support each other as they cope with challenges that impact on themselves and others. People who provide support at a certain moment in time do not simply let go of their own need for support; instead they continue to deal with their own concerns. So in effect, by giving support to others they also receive support from those very people they are currently giving support.

In the social support literature giving support is seen as a “cost” and receiving social support as a “benefit” (Pierce, Sarason and Sarason, 1996). This not true says Weiss (1974). He suggests that the very opportunity that one has to provide social support to someone else contributes to self esteem and healthy functioning. He refers to it as *opportunity for nurturance*. Studies have shown that individuals who provide as well as receive social support experience higher levels of satisfaction (Cutrona & Russel, 1987). Even young children have a need to be helpful to others in their family (Bowlby, 1980), which suggests that reciprocity is important throughout the lifespan.

Supportive relationships are based on a set of supportive transactions initiated by both participants as they seek to cope with a range of life events that require personal and social resources. The pattern of supportive or unsupportive transactions exchanged between the participants serves to shape the relationship specific schemata each person forms regarding the nature of support.

Supportive transactions

Supportive transactions involve behavioural exchanges between at least two individuals and are composed of the following: Supportive behaviour, support seeking, support provision, support receipt. Although not all supportive transactions involve all of these

elements most transactions include efforts on the part of the potential support recipient to elicit support from another person, the enactment of supportive behaviour on the part of the provider and consequently the receipt of supportive behaviour by the individual who attempted to elicit support (Pierce, Sarason & Sarason, 1996). Let us look at each of these supportive transactions briefly:

Supportive behaviour

Supportive behaviour can be divided into *emotional support* (behaviours that communicate to an individual that he/she is loved and cared for) and *instrumental support* (behaviours that provide assistance in a task directed way) (Pierce, Sarason & Sarason, 1991). Many researchers (Cutrona & Suhr, 1994; Caruso, 1992), have indicated the difficulties of developing measuring instruments for social support behaviour. They found that one cannot really break supportive behaviour down into compartments. For example when a man who has just lost his job receives money (instrumental support) from a support provider, he could conclude that he is valued and loved (emotional support) by the provider of such assistance.

A resolution to the problem of categorisation can be achieved, according to Pierce, Sarason and Sarason (1996), by defining supportive behaviour in such a way that it attends to the appraisals of both potential support providers and potential support recipients. Furthermore these authors suggest that definitions of supportive behaviour should look at those interactions that are either intended by the provider to be supportive or are perceived by the recipient as supportive. Supportive behaviour has the potential to facilitate (1) coping with respect to a particular life event (short term) and (2) adaptive personal functioning (long term). Definitions of supportive behaviour need to take into account the intentions of the support provider as well as the appraisals made by those who are receiving supportive behaviour.

Of course individuals seeking supportive behaviour are likely to react according to the schemata they have formed on previous experiences with particular supportive networks. Let us now look at support seeking.

Support seeking

According to research by Milgram and Palti (1993), individuals who seek support in life fare better than those who are unable to seek assistance when they need it. Low levels of support seeking is also associated with lower levels of support receipt according to Searcy and Eisenberg (1992). Williams (1995) suggests that social skills also underlie support seeking because he found that individuals with a certain ability to negotiate supportive transactions was a contributing factor to social support. He further argues that the acquisition of these skills begins with the family and the early interactions between the parents and children. These skills are then generalised to peers and other non family members. Another important factor contributing to the seeking of support is trust (Grace & Schill, 1986).

According to Pierce, Sarason & Sarason (1996), support seeking attempts can either be *direct* or *indirect*. Direct attempts are when an individual makes an explicit request for help. This has the advantage that there is no doubt in the mind of the potential provider of support, that help is needed. Indirect support seeking involves greater risk in the sense that there is no clarity of communication.

The decision to seek support from a family member or peer begins with the recognition that some form of assistance is needed. This process begins when the individual assesses his/her available resources with which to confront a specific stressor that has already occurred (Lazarus & Folkman, 1984).

Support provision

Giving support is not always as easy as it might seem. Several important steps are involved in this part of the social support process. Firstly the potential support provider needs to perceive that the other person needs support. During this part of the equation the support provider usually evaluates the support recipient's resources for dealing with the crisis. This means that the support provider assesses the support recipient's personal coping repertoire as well as the person's network of support. Thus the

support provider might fail to give support if he/she fails to perceive the need for support (Dakof & Taylor, 1990).

Part of the decision concerning the type of support to be provided involves the provider's assessment of his/her willingness to provide support. If the support provider is going through a crisis then he/she might fail to provide support, not because he/she cannot perceive the need for support but because he/she is unable to provide the assistance.

Having determined the course of action the support provider will take there are also other issues which need to be considered. For example the support provider should give support without damaging the self concept of the support recipient (Tessler & Schwartz, 1972). Timing is also important in the supportive transaction. Supportive behaviour that is given too early in the coping process may prevent the individual from developing personal coping skills that might reduce the person's need for assistance in the future. On the other hand support provided too late in the coping process cannot prevent the person in need from experiencing personal failure. The act of giving assistance provides an individual with an opportunity to enhance self-esteem and to increase a sense of reciprocity in the relationship.

Support receipt

Supportive behaviour occurs in an interpersonal context and this context strongly influences the recipients' perceptions of the supportive behaviour (Pierce, Sarason & Sarason, 1992). Once the support recipient has recognised that his/her network of support is in action, his/her coping skills will be facilitated (Nadler & Fisher, 1986). A recipient may be especially likely to recognise supportive efforts on the part of a provider when the recipient has requested assistance from that person or when he/she has received aid from that person in the past.

Mismatched support is an issue which needs careful attention as it can be problematic rather than helpful. Provision of mismatched support (i.e. support that differs from the

type of support desired by the recipient) may be especially problematic when the recipient feels ambivalent about the obligations he/she might have towards the provider if the recipient makes use of the provider's support.

Also receiving support from family members might be difficult for the following reasons. Firstly, although family relationships carry with them strong societal prescriptions about providing support, a family member may still elect not to receive assistance from family members because of concerns of obligation, secondly because the potential recipient may want to maintain independence from the family, and thirdly because the recipient may be concerned about being stigmatised as taking advantage of family members to provide support (Martin & Martin, 1978).

In conclusion to the discussion on supportive transactions it is evident that these transactions have an important influence on coping with a specific life event. The discussion on supportive schemata and supportive relationships indicates that these transactions have important implications for personality development. Supportive transactions over one's life, especially the transactions that took place in one's childhood with one's parents, contribute to support schemata that incorporate expectations about the supportiveness of the social environment. These transactions with others also lead to relationship specific schemata about the supportiveness of particular others (Pierce et al., 1992).

MODELS OF SOCIAL SUPPORT

Rapmund (1996) suggests that various researchers have proposed a number of models of social support. Let us look at two of these:

Newcomb (1990) suggests that social support is a process that evolves throughout the entire lifespan of an individual. It is shaped in a reciprocal, bi-directional way between the characteristics of the individual and those of other people in his/her social world. He further proposes that social support can be viewed from a macro level which is across the life span or on a micro level which is more in terms of immediate

transactions. Social support is an aspect of human connectedness.

Vaux (1990) views social support in the same vein as the models discussed previously. He also proposes an ecological approach and suggests that social support is a process which occurs within an ecological context. Support resources, behaviours, and appraisals are three distinct conceptual components of social support which occur in the context of relationship transactions between individuals and social networks. There are two parts to these transactions. The first is to establish the interconnections between resources, behaviour and appraisals, and, secondly, to understand how person and ecological factors affect the support process (Vaux, 1990).

Now that I have considered what social support is, it is time to turn to social support groups as a therapeutic measure for parents whose child has been diagnosed with cancer. Firstly, though, let us look at social support groups and how they are created.

CREATION OF A SOCIAL SUPPORT GROUP:

PLACE, TIME, SIZE

Before a group is convened, according to Pierce, Sarason and Sarason (1996) there are certain decisions to be made about its functioning. The gatekeeper (therapist, convener, researcher etc.), must secure an appropriate meeting place and establish policy about the life span of the group, the admission of new members, the frequency of meetings, the duration of each session and the size of the group.

The physical setting

Group meetings may be held in any setting, provided that the room affords privacy, freedom from distraction and the opportunity to sit in a circle. Some therapists prefer the members to be seated around a circular table. There should be no central obstruction, each member should be able to observe the entire body of the other member and, thus, be able to observe non verbal behaviours.

Open and closed groups

According to Chesler and Barbarin (1987), when the group is formed it is usually designated by its gatekeeper as an open or closed group. A closed group, once begun, shuts its gates, accepts no new members, and meets for a predetermined number of sessions. An open group maintains a consistent size by replacing members as they leave the group. Generally, open groups continue indefinitely.

Duration and frequency of meetings

Most group therapists agree that at least sixty minutes is required for the warm up and for the unfolding and working through of the major themes of the session. A group session can continue for two hours after which a point of diminishing is reached. The group becomes weary, repetitious and insufficient after two hours. Furthermore the leader of the group (therapist, researcher etc.) functions best in segments of eighty to ninety minutes, longer sessions render the leader less effective. Closed groups have fixed times of meeting but open groups arrange the frequency of the meetings as the group members want to. It can be once weekly or once monthly. The ideal would be once every two weeks as such groups have an increased intensity, the members continue to work through issues raised in the previous sessions, and the entire process takes on the character of a continuous meeting (Zarle & Willis, 1975).

Size of the group

Consensus of the literature (Chesler & Barbarin, 1987; Faulkner, Peace & O'Keefe, 1995; Budman, Demby, Feldstein & Gold, 1988), suggests that the ideal size of an interactional group is approximately seven or eight, with an acceptable range of five to ten members. The lower limit of the group is determined by the fact that a critical mass is required for a group of individuals to become an interacting group. When a group is reduced to four or three members, it often ceases to operate as a group and therapists often find themselves engaged in individual therapy within the group. The upper limit of the group is determined by sheer economical principles. As the group

increases in size, less and less time is available for the working through of any individual problems. Since it is likely that one or possibly two patients will drop out of the group in the course of the initial meetings, it is advisable to start with a group slightly larger than the preferred size; thus to obtain a group of seven to eight members one should start with a group of nine to ten members.

MAINTENANCE OF THE GROUP

The leader or gatekeeper of the group is solely responsible for creating and convening the group (Chesler & Barbarin, 1987). His/her offer of social support and help is the group's reason for being there. The maintenance of the group depends to a large extent on the leader. Initially, the patients are strangers to each other and know only the leader who serves as a transitional object. He/she is the group's primary unifying force. The members of the group relate to one another at first through their common relationship with the leader of the group. The leader must recognise and deter any forces that might threaten group cohesion. Continued absences, disruptive socialisation, slowness and scapegoating all threaten the integrity of the group and demand the attention of the group leader. The group leader is responsible for maintaining physical entity in the group even if it means removing a member from the group for the good of the other members. Once the group is a physical reality the leader of the group must direct his/her energy towards shaping it into a social support system (Chesler & Barbarin, 1987).

CHARACTERISTICS OF SOCIAL SUPPORT GROUPS

Social support groups are the only component of the delivery system whose sanction for existence comes from its immediate beneficiaries, rather than from the socio-political structure (Katz & Bender, 1976). Because social support groups are for the most part under the control of their members themselves, participation in these groups should enhance the members' sense of empowerment, which may itself have positive mental health consequences (Rappaport, 1987).

Caplan (1974) clearly captured many of the essential characteristics of social support groups. He defined support systems as “continuing social aggregates that provide individuals with opportunities for feedback about themselves and for validation of their expectations about others, which may offset deficiencies in these communications within the larger community context” (p. 4-5). He went on to note that within these social aggregates, “the person is dealt with as a unique individual. The other people are interested in him in a personalised way. They speak his language. They tell him what is expected of him and guide him in what to do. They are sensitive to his personal needs, which they deem worthy of respect and satisfaction” (pp. 5-6).

Caplan (1974) considered social support groups to be support systems, referring to them as “mutual-help groups of people in the same boat” (p. 23). Thus, they have also been characterised as ready-made social support systems in domains of problems (Shumaker & Brownell, 1984). However, while it is true that social support groups are formed around particular problems or afflictions shared by all members, there are other, more specific characteristics that should also be noted that distinguish them from other support systems and from the other components of the health care system.

Unlike other social support systems, such as family and friends, because all the members of social support groups share the same problem, they relate to each other as peers within the context of their group, each acting as provider and recipient of help, focussed on their common problem or condition. These three characteristics of social support groups, namely commonality of problem, members relating to each other as peers and members playing dual roles as both providers and recipients of help, are often cited as keys to understanding the unique effectiveness of social support groups (Gartner & Riessman, 1977; Levine & Perkins, 1987).

Social support groups also differ from naturally occurring social support systems in that they are intentional, and their activities are guided, in varying degrees, by particular ideologies concerning the nature of their members' affliction and how it can be effectively dealt with (Levine & Perkins, 1987). These ideologies vary in their elaborateness and in how clearly they are articulated, but they usually provide members

with a new way of viewing their problem (Humphreys, 1996; Kennedy, Humphreys & Borkman, 1994), infusing them with a sense of purpose and direction, much as the theories of health professionals do so for them.

The final defining characteristic of social support groups is that their origin, sanction for existence and the control over their mode of operation rest with the members of the group themselves; they are autonomous. This autonomy has a number of consequences. It frees them from the dogma under which establishment health care professionals labour, thus allowing them to take a more pragmatic approach to dealing with their members' problems. It places greater responsibility upon the shoulders of the members for both the successes and the failures of the group, which can be therapeutically beneficial (Roberts, Luke, Rappaport, Seidman, Toro & Reischl, 1991).

THE THERAPEUTIC VALUE OF SOCIAL SUPPORT GROUPS

Lieberman (1979) suggests that following reasons as to why social support groups could have a therapeutic value:

- *Differential mortality in membership.* As compared with a matched comparison or control group, at any given time, or over any specified time period, social support groups will contain more individuals who are benefiting from their membership than who are not, since those who are not benefiting are more likely to have dropped out due to the relative ease of doing so.
- *Differential competence and adjustment.* Participation in a social support group requires a certain level of social competence and interest in social relationships. Thus, as compared with any matched group of comparably distressed individuals, social support group members are likely to have higher levels of interest and competence in social relationships, and to the extent that these are factors in personal adjustment and in the ability to benefit from interpersonally mediated therapeutic interventions, social support group members, on the average, should be better able than non members to benefit from social support

group participation.

- *Differential motivation.* In joining a social support group, members make a commitment, at some level, to changing and to taking an active role in changing, which may not be present, or as strong, in non members. Thus, as compared with any matched group of comparably distressed individuals, social support groups are likely to be composed of members with higher levels of motivation to work on their problems.

In contrast to any other intervention, a social support group does not exist as an intervention apart from its members who are both the instrumentality and the object of the intervention, as proposed by Levy (1984). Change the characteristic of its membership and the intervention is changed as well. The very fact, proposes Rappaport (1987), that individuals are members of a social support group long enough to contribute data to any evaluation of their effectiveness suggests that they find this mode of intervention effective, and that it probably represents a good match with their beliefs, attitudes, and personalities. This cannot be said of any mode of intervention, since in no other mode are individuals so free to become engaged and disengaged.

Based upon the observations of Levy and his colleagues (Levy, 1979; Wollert, Levy & Knight, 1982), members of social support groups reported the frequent use of supportive (empathy, instillation of hope, mutual affirmation, justification, normalisation), expressive (catharsis, sharing, self disclosure) and insight orientated (explanations, functional analysis, discrimination training) activities. They were also consistent in reporting infrequent use of confrontive interpersonal behaviours (confrontation, seeking feedback, offering feedback) and certain types of behaviourally oriented activities (modelling, imitation, behavioural rehearsal). These findings suggests that social support groups take a relatively broad approach to helping their members, not only in dealing with their members' identified personal problems, but also in attempting to meet their needs for empathic understanding, a sense of meaning and an opportunity to express their feelings and share their experiences with one another. This will be seen in the present study too.

THE VALUE OF THE SOCIAL SUPPORT GROUP AS RELATED TO THE PARENT OF THE CHILD WITH CANCER

Support groups represent another avenue of help that can be used to great advantage by those facing the crisis of childhood cancer. The support group concept was developed two or three decades ago and has proved so successful that there now seems to be a group for every possible life situation (Pierce, Sarason & Sarason, 1996). Groups of families who have a child with cancer meet regularly to share their experiences. Such groups provide the freedom to express emotion such as feelings of guilt, anger, grief and fear with others who have had similar experiences (Chesler & Barbarin, 1987). Support groups work because no one can understand what the family of the child with cancer is going through like another family member that has experienced the same thing. But groups are not for everyone, some people do better if they remain isolated. Some can't share their feelings in a group and some can't even say the word "cancer" (Faulkner et al., 1995).

Support groups not only allow one to be angry but also provide coping strategies and suggest practical ways to get through the experience. The group provides a safe place to "fall apart" for a time, to break down and cry, and to not have to maintain a brave exterior for the outside world.

Wallace and Vaux (1993) suggests that support groups can start and evolve into more "businesslike" endeavours or can be purely valuable in terms of psychological factors.

"Businesslike" endeavours

- Providing information and education to the public and to other families
- Offering practical help and services to members e.g. transportation
- Raising funds for projects
- Organising volunteer activities

Psychological endeavours

How do social support groups help people who need support? Discussed below are some factors which contribute towards healing according to Lieberman and Borman, (1979) as well as Yalom (1995).

Hope

People who have been through the same trauma and have survived can be of great inspiration to others. Groups invariably contain individuals who are at different points along a coping-collapse continuum. Each member thus has considerable contact with others, with similar problems, who have improved. The instillation and maintenance of hope is a crucial part of support groups. Not only is hope required to keep people going during a crisis but it can also lead to healing and a positive outlook. If one thinks of faith healing and placebo treatments one realises that therapy can take place through hope and conviction. The patient's belief in himself has to be increased and a group always has more power to reinforce positive expectations, remove negative preconceptions and present powerful explanations about events in one's life.

Universality

Before entering into a social support group many people feel they are alone and unique in their misery and that they alone have frightening or unacceptable problems or thoughts. Of course, there is an element of truth to this as each individual has a unique constellation of life stressors but people with social isolation have a heightened sense of uniqueness. In support groups disconfirmation of a patient's feelings of uniqueness is a powerful source of relief. There is no human deed that is fully outside the experience of other people. After hearing other members disclose similar concerns people report feeling in touch again hence the expression, "We're all in the same boat".

Altruism and the need to reciprocate

In support groups people receive through giving, not only as part of the reciprocal giving-receiving sequence but also from the intrinsic act of giving. The experience of being important to others boosts self-esteem. It is only, as Victor Frankl said, when we transcend ourselves and become absorbed in others that a sense of life meaning ensues.

Another issue regarding the need to reciprocate is that support, however much needed also creates uncomfortable feelings for many of the people. In my group many people said that they felt they wanted to return the favour as soon as possible because otherwise they felt a sense of dependency which they did not like. One father said to me: *"I never had to have outside help before. But this cancer is too much. Travelling to Cape Town and having to find accommodation there was just impossible to budget for."* A mother said to me the following: *"You feel a need to reciprocate. You always think and jot down how you spend the money given to you"*. These feelings of both needing and wanting to reciprocate do not go away after the child's illness but stay with the parent for a long time suggests McCubbin (1990). My years of experience in working with pediatric oncology patients and their parents tell me that parents continue to feel obligated for years after the child is well, or after the child's death. This was also confirmed in the clinic and hospital settings during informal discussions with parents whose children had been in treatment for years.

In a situation such as childhood cancer, social support, is for the most part, given freely and without expectations of return suggest Last and Grootenhuis (1998). There are practical reasons for this type of social exchange. One reason is that altruism for those less fortunate is a cultural value in our society proposes Hammersley (1998). More specifically, giving and receiving assistance are implicit in the family and friendship social roles. This type of communal giving is often expected, regardless of whether the recipient can repay the donor in the short term.

A support group can always carry the implicit assumption that the people forming that

group can no longer solve their own problems. From my observations and interviews with these parents it was obvious that these parents did not want pity but understanding (Yamagishi & Cook, 1993). Always wanting to reciprocate could be a sign of wanting to regain control and diminish the sense of dependency and promote psychological outcome (Chesler & Barbarin, 1984). I feel that this feeling the parents had of wanting to reciprocate is a healthy one. The support group is there for the parent's needs, for looking after each other. The dilemma for these parents is that there really is no way to balance the exchanges in this situation, therefore the situation of the parents falls somewhere between generalised reciprocity and balanced reciprocity according to Williams (1995).

Insight

Insight is a process which encompasses clarification and explanation. Insight occurs when one discovers something important about oneself. In social support groups people obtain insight on at least four different levels according to Lieberman, Yalom and Miles (1973):

- Patients gain a more objective perspective on their interpersonal presentation i.e. on how other people perceive them. Are they arrogant, warm, tense or bitter?
- Patients gain understanding into more complex interactional patterns such as if they relate only to the therapist or only to men or women in the group, or if they exploit others
- Patients also gain motivational insight
- Patients also gain genetic insight which an understanding of how they got to be the way they are.

THE VALUE OF STORY TELLING IN SOCIAL SUPPORT GROUPS

Like walls that bear the weight of a building, personal stories depend on certain structures to hold them together suggest Epston and White, (1992). Stories told in a

Harry Stack Sullivan and his interpersonal theory of psychiatry (Sullivan, 1953), is very helpful in understanding support groups and the therapeutic effect they have. Sullivan proposes that the personality is entirely the product of interaction with significant other human beings. The need to be closely related starts from infancy and develops through the lifespan. The developing child has a quest for security and tends to stress those aspects of the self that meet with approval from its primary caregiver and deny those that meet with disapproval. Grenebaum and Solomon (1987) state that satisfying relationships are important during the adolescent years as well as important in forming intimate relationships during adulthood.

This brings us to Sullivan's view of the therapeutic process involved in interpersonal relationships. He suggests that the proper focus of research should be on the processes involved when people relate to each other. "One achieves mental health to the extent that one becomes aware of one's interpersonal relationships" (Sullivan, 1938, p. 121). These ideas that therapy or support is interpersonal is very relevant to group therapy. When you enter a support group you by implication look for approval, belonging, understanding and support by other people. People need people for survival, for socialisation, for the pursuit of satisfaction. No one transcends the need for human contact.

When one is faced with a terminal illness either of oneself or child or a close family member, one is struck that, in the face of death, we dread the utter loneliness (Kübler-Ross, 1977). People faced with this kind of dilemma are often haunted by the thought of being abandoned by the world of the living. What people need in a time of despair is to make contact, to be able to touch others, to voice their concerns and to be made to feel *part of* (Weiner, 1987).

Many of the issues that I have raised on interpersonal relationships have a vital bearing on therapy within a social support group. According to Sullivan (1953), the role of consensual validation, as well as the meeting of a human being's social needs are important aspects of interpersonal relationships. Let us now look at the importance of emotional experiences within social support groups.

Emotional experience

When considering the emotional experience of an individual within a support group the views of Carl Rogers and his person-centered theory are exceedingly helpful. Implicit in person-centered theory is the view that *people are essentially good* (Rogers, 1961). According to Rogers (1987) man is fundamentally a *social* being who, when given positive regard and respect which is due to him as *a person*, can be trusted to be a normal, self controlled and socialised individual. Change and learning can be brought about by simply listening to the individual's story without passing any judgements (Rogers, 1980). The individual, within a support group, should be allowed to express his/her emotions freely be they negative or positive without fearing a catastrophic outcome. The group should be supportive enough to permit this risk taking. The individual should then be allowed to examine this incident with the aid of consensual validation from the other members. This ultimately leads to the facilitation of the individual's ability to interact with others more deeply and honestly. The group members must experience one another with as much spontaneity and honesty as possible and they must also reflect back upon that experience. This reflecting back, this self reflective loop, is crucial if an emotional experience is to be transformed into a therapeutic one. The role of the therapist would then be to trust the individuals in the group to develop an agenda on which they wish to work and then to keep on directing the group toward the self reflective aspect of that process. The goals of person-centered theory concern the client as a person and not his/her problem (Rogers, 1977).

Finding meaning

When interviewing individuals after they have completed group therapy one of the critical outcomes which they stress is that the most helpful single event during the therapy is how meaningful the people in the group were to them. Through that they opened up to share their lived experience(s) that is to tell their stories and found meaning in that too. Let us look at what is meant by *meaning*.

Dimensions of meaning according to Frankl

Meaning is experienced as something that is found and not something that is created or invented (Frankl, 1967). This means that meaning is more than a mere self-expression, or a projection of the self into the world.

Shantall (1996) suggests that phenomenologists, through the analysis of man's consciousness, have pointed out to its intentional nature. The same author further proposes that consciousness intends something, points towards something outside itself. Consciousness never exists in a vacuum, one is always conscious of something. Consciousness, therefore, can never be separated from the objective world the person is busy experiencing (May, 1965). Frankl (1970) takes this phenomenological position regarding the experience of meaning. We are meaning orientated. We want to find meaning in our lives. Yet there is no way meaning can be found except through an experience of meaning. We subjectively experience the objective reality or real existence of meaning. Shantall (1996) proposes that meaning is not something concrete that can be pointed to and observed. We cannot demonstrate or prove its existence in a tangible way. We can only testify to its existence through our personal experience of meaning. Because meanings are subjectively experienced as existing on an intangible level beyond the concrete, it appears as if meaning is just something we ascribe to or project into the things around ourselves, things which in themselves are neutral. In the light of this neutrality, Frankl (1970) concedes that reality may well seem to be just a screen upon which we are projecting our wishful thinking. If that were so, meaning would be no more than a mere means of self-expression, and thus something profoundly subjective. *The only thing which is subjective, however, is the perspective through which we approach reality*, and this subjectiveness does not in the least detract from the objectiveness of reality itself. What is seen *through* the perspective, however subjective may be, is the objective world, also the objective world of meaning.

It follows from the above discussion that meaning can only be experienced by being open and receptive to its existence.

The value of story telling

The idea that it is the meaning which persons attribute to their experience that is constitutive of those persons' lives has encouraged social scientists to explore the nature of the frames that facilitate the interpretation of experience. Many of these social scientists (Reissman, 1993; Bruner, 1990) have proposed that it is the narrative or story that provides the primary frame for this interpretation, for the activity of meaning-making. It is through the stories that persons have about their own lives and the lives of others that they make sense of their experience. Not only do these stories determine the meaning that persons give to experience, but these stories also largely determine which aspects of experience persons select out for expression.

This perspective should not be confused with that which proposes that stories function as a reflection of life or as a mirror for life. Bruner (1990) proposes that people live their lives by stories - that these stories are the shaping of life, and that they have real, not imagined, effects - and that these stories provide the structure of life. Let us now look at some further thoughts on what stories are all about.

The structure of a story

Bruner (1986) proposed that stories are composed of dual landscapes - a landscape of action (experience) and a landscape of consciousness (meaning). The landscape of action is constituted of (a) events that are linked together in (b) particular sequences through the (c) past present and future and according to (d) specific plots. In a text, the landscape of action provides the reader with a perspective on the thematic unfolding of events across time. The landscape of consciousness is constituted by the interpretations of the story given by the readers as they enter the writer's world. The landscape of consciousness features the meanings derived by the readers through reflection on the events and plots as they unfold through the landscape of action. Perceptions, thoughts, speculation, realisations and conclusions of the characters in the story dominate this landscape.

The origin of stories

What is the origin of these stories that are constitutive of persons' lives? The stories, according to Bruner (1990), that people live by are rarely, if ever, radically constructed - in other words, it is not a matter of them being "made up", "out of the blue", so to speak. Each person's culture and beliefs about people and relationships influences his/her construction of his/her story. Each story is historically constructed and negotiated in communities of persons and within the context of social structures and institutions. Thus, stories are inevitably framed by our dominant cultural knowledge. This knowledge is not about discoveries regarding the nature of persons and of relationships, but is constructed knowledge, that is, specifying of a particular strain of personhood and of relationship.

Stories that persons have about their lives circumscribe the meanings that they give to experience, as well as the aspects of experience that they select out for expression. However, stories do not always handle all the contingencies that arise in "life as lived" in a very accomplished way. Just as with texts, in reference to life as lived, the stories that persons live by are full of gaps and inconsistencies and, also, these stories constantly run up against contradictions. The resolution of these gaps, inconsistencies and contradictions comprises the therapeutic aspect which can be achieved within support groups or group therapy (Gilligan, 1982). The affective sharing of one's inner world of lived experiences and then the re-storying of that within an accepting environment is of paramount importance in group therapy (Gladding, 1995).

The therapeutic effects of telling stories within a support group setting

In several studies (Grunebaum & Solomon, 1987; Bunch, Lund, & Wiggins, 1983; Powell, 1985), researchers transcribed and categorised support group patients' explanations of the therapeutic factors in their support group and found that more than half indicated that the primary mode of help in their group had been the listening of their lived experiences by the members of the group. Those patients who felt validated by the other members of the group, in other words, those individuals whose stories were

listened to and talked about, attended more sessions, experienced more social contact with other members and judged the group as having a therapeutic mode.

The therapeutic effect of a story lies in the re-authoring (White, 1995). When a story is re-authored it is divided into clusters of meaning and the individual is free to accept or reject these alternative meanings. It is a form of what White (1995) calls *externalising the problem*. As persons become engaged in these externalising conversations, their private stories cease to speak to them of their identity and of the truth of their relationships - these private stories are no longer transfixing of their lives. Persons experience a separation from, and an alienation in relation to, these stories. In the space established by this separation, persons are free to explore alternative knowledges of who they might be, alternative and preferred knowledges into which they might enter their lives. The support and acceptance of the group during this process is of paramount importance. Group membership, acceptance and approval are of the utmost importance in the individual's developmental sequence. The more authentic the care in the group, the quicker alternative knowledges will be generated by the individual (White & Epston, 1989).

Conclusion

From the discussion in this chapter we see that it is essential that the members perceive their support group as safe and supportive. Ultimately, it is within this framework that many uncomfortable issues must be broached and explored. The therapeutic process of story telling assists in establishing a sense of agency (White, 1995). Finding meaning in one's lived experiences or stories is in itself an experience of escaping passengerhood in life and being able to play an active role in the shaping of one's own life - of possessing the capacity to influence developments in one's own life according to one's purposes and to the extent of bringing about preferred outcomes. According to Frankl (1970), this sense of personal agency is established through the development of some awareness of the degree to which certain modes of life and thought shape our existence, and through the experience of some choice in relation to the modes of life and thought that we might live by.

CHAPTER 5

TESSA'S STORY: LIKE AN ANIMAL IN CAGE

INTRODUCTION

Participant: Tessa

Age: 45 years old

Children: One son, Peter, 13 years old and diagnosed with Medulla Blastoma
(more common known as brain cancer)

Occupation: Consultant in a computer company

Marital status: Divorced

My impression of Tessa is that she is a very sensitive person who keeps herself isolated as far as possible. She always dressed very simply in a track suit pants and a T-Shirt. When she initially joined the support group it was because she could not remain alone in this crisis anymore. She was very quiet and only spoke when she was given a chance. She struck me as a very obedient person doing all the exercises the group was given after each session. Being very reserved and withdrawn and alone as her husband deserted her after the diagnosis of her child, she needed to connect with people. I felt she needed to build a type of relationship with somebody who could guide her through the darkness she experienced. I felt she needed empathy, that is why she joined the support group. Rogers (1961) describes empathy as the ability to "enter the client's phenomenal world - to experience the client's world as if it were your own without ever losing the 'as if' quality" (p. 284).

She told me that she does not tell new friends about her child's cancer diagnosis because she is not sure of what the reaction will be. She says that even in a job application she did not mention it because she was afraid of discrimination. She says

she told her supervisor later and up to now there have been no repercussions.

Peter was often present during the group sessions. When he became restless Tessa told him to go and play outside. Peter is a dark haired little boy who has the typical physical symptoms of mild neurological brain damage due to the brain tumour. He has a slight squint in his one eye and walks with a slight slant. He has a hard time articulating words because the muscles needed to produce speech have become weak. He gets tired very quickly so Tessa has worked out a rest schedule for him.

Tessa struck me as a mature person, open to experience and wanting to find some direction in her life. She seemed like a caged animal wanting to break free but did not know how. She had a friendly disposition but masked bitterness and anger behind that. She also seemed to have a negative sense of self worth. The depth of her despair touched me.

THE STORY OF THE PETER'S CANCER

Peter was a very sickly child and whenever Tessa took him to the doctor he was diagnosed with an allergy. After being very sick with a stomach virus he was hospitalised for ten days. His physical symptoms included continual vomiting, terrible headaches and tiredness. After several examinations during this first hospitalisation in 1991 he was diagnosed with brain cancer (Medulla Blastoma). This was a terrible shock to Tessa. As she put it: *"Shock no.1 - a 4,5 cm tumour at the base of the brain"*. Because of the mass of the tumour there was extensive pressure on the brain and the brain pulled away from the skull causing many problems. At that time Peter was six years old.

After the tumour was operated on, the diagnosis confirmed that it was cancerous. This period felt like an eternity to Tessa as she was divorced and had to deal with it alone. Her mom was with her though. As she states: *"This period felt like an eternity I was totally shocked, it felt as though someone threw a bucket of ice water over me. I stood at his (her son) bedside crying and crying, my mother doing the same."*

Tessa described her son's cancer as suffering and hell. She was angry as she states: *"I hated everything, I hated my son's father and his family, I hated God for doing this to us. At that stage I wished a bus would run over me so that I could be removed from this earth, this hell."* Ekert (1989) suggests that it is entirely normal for parents to be angry, even wildly furious, when their child is diagnosed with cancer. What greater unfairness is there?

After the operation there were severe complications and bleeding in the brain. Every couple of days he was back in theatre. Tessa was at her wits' end but she said that she had to devise many ways to accept her son's illness. These will be discussed later.

During her son's frequent visits to the hospital for radiation therapy, Tessa had her fair share of difficulty with the medical care providers. Eventually she got to a pediatric oncologist she could relate to which made things easier. Tessa felt that there was honesty and clarity between her and this doctor and serious issues were not avoided. Overholser and Fritz (1990) indicate that many parents feel more at ease when they realise that the health care workers are collaborating with them to provide the best care for their child. They go on to say that the most positive and encouraging aspect of the relationship between parents and health care providers, be they doctors, nurses etc, is that everyone has the same goal, and that is trying to cure the cancer.

Tessa's son vascillated between getting better and deteriorating which made Tessa want to give up at times but then she fought back again. Through her religion she found meaning and took one awful day at a time. Heath (1996) propose that such vascillations are typical of children with cancer and depend on the age of the child, the relationship between the ill child and the family, the stage at which the cancer is diagnosed and the amount of disruption to their everyday life.

The context of Tessa's story will now be discussed in terms of emerging themes.

EMERGING THEMES

BAD NEWS VS GOOD NEWS

Tessa directed her efforts mainly at talking about the horror of the news. *"Shock no.1 - a 4,5 cm tumour at the base of the brain. This was only the start of our long suffering"*. The full meaning of this did not sink in immediately. *"I was totally shocked, it felt as though someone threw a bucket of ice water over me"*. One definition of bad news which is useful in practical terms is any news that drastically and negatively alters the person's view of his/her future (Buckman, 1984). It seems as if the bad news that the tumour was cancerous created a feeling that was so frightening that Tessa did not know how to protect herself against it. She did not know who to turn to, to mediate the impact of the news. The medical professionals did not give her enough information and her family *"only contacted her because they were inquisitive, not to help"*. When she accepted the news she started questioning the fairness of it all. *"Why me, why us?"* When she realised how bad this bad news was she *"stood at her child's bedside crying"*. She also did not share the bad news with her son fearing that he might not get well if he knew what was really wrong with him. She reached a stage on the one hand of superficial carelessness where *"she started giving his clothes away"* and enormous emotional shock deep inside on the other hand. *"I tried to separate myself from reality by starting to talk about him as not being there anymore"*. Culling (1988) suggests that from the time of diagnosis parents enter a type of grieving process over the potential loss of their child. Barbor (1983) describes the grieving as anticipatory grief and indicates that, although in many cases the child will recover, the threat of death is always present. This anticipatory grief involves various acting out of emotions like giving the child's clothes away as Tessa did.

The treatment also lead to bad news all the time. *"After 3 monthly, then 6 monthly brain scans the tumours started growing again. We were back for the check up and were referred to an oncologist with a note closed in an envelope. Obviously he did not say a word just said things don't look good. No explanation no nothing"*. The bad news without any support or compassion perpetuated her suffering and pain. She had no

one to speak to in order to examine her negative state of mind and who could engage with her, until she was referred to a pediatric oncologist, Dr Anne. This was the best news she had so far. *"She was absolutely super. I asked questions and she chatted to me like a friend. She was a friend to my son too. It was lovely knowing her and she made this session a dream. The chemotherapy went well and my son wasn't very ill with it"*. It seems at this stage Tessa started to eliminate the negative emotions and placed her faith in Dr Anne. Although *"the tumours regrew again"* and they *"started chemotherapy again"* she was more at peace with the whole process as things *"went well"*.

The next piece of bad news she received was that Dr Anne was leaving, which put her in a predicament again. *"My best medical friend. I thought I would cry. I was panic stricken because there would be no-one else to help my son"*. But then *"Dr Kate took over Dr Anne's patients and what a lovely doctor she also was, willing to help in whatever way she could. Things went well for a while"*.

This was followed by the bad news that *"the scan showed that the tumours had formed a cap on the brain and that nothing could be done for him anymore and that it was just a matter of time"*. At this stage the doctor said she would try one more chemotherapy treatment. This gave Tessa a ray of hope. But she was still told that they *"could not do chemotherapy indefinitely for years"*. It was at this stage that she adopted emergency measures to cope. *"Because he wasn't at school anymore I gave his school clothes, bags and things away. The day he passed away I did not want to do that then, it would be so final"*. The uncertainty of whether the next piece of news would be good or bad made Tessa weary. *"At this stage we were just waiting for the next 6 to 8 months. I started arranging time off work and tried to get my mind ready for it"*. The existential challenge of childhood cancer threatens one's understanding of the natural order of life and death. It therefore becomes important to find different ways to cope and make sense of the chaos of the illness suggest Horwitz and Kazak, (1990). Tessa started preparing herself for the worst news and her dominant mindset of how things were going to happen directed her behaviour. Her ideas about her son's death created a reality which she acted upon.

"After about 4 months he started moving around a little". For the first time in this ordeal could she say she saw her son improving. This was good news. *"Amazingly he grew stronger and stronger by the month".* These personal shifts from good news to bad news had a draining effect on Tessa. Eventually she did not know how to respond to any news. *"I actually don't know how I feel at this stage. I am happy to have him here for longer but dread the deterioration again because this time I know it's final".* Cincotta (1993) suggests that when parents have a child diagnosed with cancer they have to face the reality that they are powerless over their child's destiny. This feeling of not knowing increases their own distress.

ISOLATION VS SUPPORT

The first time Tessa says something about her relationships is *"I was divorced at that stage and his father was not at all involved".* The words *"not at all"* emphasise her isolation in this dilemma. She had to cope alone vacillating between good and bad news. This is why *"this period felt like an eternity".* Her isolation is also stressed by the personal *I* level she uses in interactive situations. *"I was totally shocked, I don't think I spoke to someone in specific, I spoke to anyone and everyone who could listen".* Tessa offers an explanation of her isolation and in this way probably makes sense of her experience as been isolated by saying *"my experience was that most people did not know what to do or say".* Tessa's interpretation of how people reacted was that *"they were interested to know what happened and why and then it ended there because they did not know how to handle the situation".* As she did not have an open communication with family and friends she could not share her pain so her grief was directed inwards and she *"became depressed".* She describes it as a sense of powerlessness (Horwitz, 1992). There was no support, acceptance or encouragement from friends nor family. *"At that stage friends and family only contacted me because they were inquisitive, not to help. As soon as they were up to date I would not hear from them for a while. In this period I realised who my friends were out of my circle of friends. I was left with a few".*

Tessa's support came in the form of a colleague and friend who as she says *"was old*

enough to be her mother". She *"used to confide in her often"*. Here Tessa seems to have found someone who supported her on three levels: (1) a mother, (2) a friend, and (3) a confidant. As the illness is risky and unpredictable "the mother" was unconditionally accepting and as *"her mother-in-law also had cancer and passed away as a result thereof she was clued up with everything involving chemotherapy and radiation"*. As "a friend" this person was someone Tessa could identify with and open up and to relate and talk and get rid of all the negative feelings. As "a confidant" this person was someone Tessa could rely on implicitly.

As time went by Tessa gained support from the medical staff too. *"My friend who was working for a pediatrician helped me where he could and also my GP"*. But they too could support her only up to a point as she says because *"the situation was so specialised"*. Tessa seems to have received the most support from the two pediatric oncologists that treated her son. *"Dr Anne was absolutely super. It was lovely knowing her"*. Then she heard Dr Anne was leaving. *"My best medical friend. I thought I would cry"*. Then *"Dr Kate took over Dr Anne's patients and what a lovely doctor she also is pouring questions over her too and she was quite willing to help in whatever ways she could"*. In the literature (Kazak & Nachman, 1991) it is known that the proliferation of single parent families has made hospital personnel more understanding of and sympathetic toward the problem of single parent families.

As a single parent, especially one who does not have an adequate support network, Tessa faced a true emergency when her child was diagnosed with cancer. Few people have a network that can support a major crisis for a sustained amount of time. So Tessa had to do everything and experienced a task overload, as the literature calls it (Kazak & Nachman, 1991). She says *"eventually when my son was sent home, I took 6 weeks leave from work to look after him. He was like a new-born baby. Then I started panicking. What would I do? Where do I go? I was the sole breadwinner, I was not financially well off"*. Single parents have a difficult time coping, as is stressed here by Tessa, because they also feel isolated in terms of the financial aspects of childhood cancer suggests Williams (1995). When Tessa realised that this crisis will make her work attendance sporadic for a period of time, she felt threatened as to what

will happen if she loses her job. Her sense of despair is expressed in the sentence *"I often wished something would happen and that God could take my son and myself off this earth"*. Tessa's mom supported her in the form of staying at the hospital with her grandson *"during the day"* while she had to go to work. After work Tessa would go to the hospital and stay there until 20h00 and then leave.

Tessa's isolation and loneliness is also stressed when she describes that *"when friends came over to visit they were shocked to see that lifeless body just lying there, but did not know what to do or say"*. This made it difficult for her as her present boyfriend treats her the same way as her friends. He does not set time aside for her as she says *"because my son is not his own child things are different"*. When Tessa joined the support group she felt a sense of belonging and support in comparison to the isolation she felt before. She could share her pain and find a caring nobody else could give her as they did not understand.

UNCERTAINTY VS CERTAINTY

In Tessa's story the only certainty was that her son was ill and that she was isolated. This she expressed in her opening sentence *"I have a son who was diagnosed with brain cancer (medulla blastoma) in 1991 and have been battling with this horrible disease ever since. She continued to say that her son was a very sickly child and whenever she had him at the doctors he was diagnosed with an allergy"*. The uncertainty of his condition is expressed here. *"Eventually he was so ill with a stomach virus that he was admitted to hospital for 10 days"*. The signs and symptoms of cancer vary so much and are usually so insidious at first as in Tessa's son's case allergies, vomiting, terrible headaches and deadly tired (Van Eys, 1988). The disease therefore may develop for some time before parents realize that something is wrong, and before it is recognised and diagnosed by a physician. For the uncertainty of the diagnosis to become a certainty takes time as Tessa says: *"After many visits to the doctors and after been told continually that he was suffering from bad allergies, I insisted on further tests and he was eventually sent for a brain scan to see what the cause of the headaches were"*. What followed were certainties that shocked Tessa but she just had to put her

feelings of uncertainty behind and deal with the practical aspects of her child's diagnosis which were:

- *“at 6 o'clock in the evening he was diagnosed with a tumour at the base of the brain”*
- *“he had to be taken to hospital X at 6 o'clock the next morning to put in a 'pump' from the brain down to the stomach to aid the drainage of the fluids which were the cause of the headaches and vomiting”*
- *“because of the massive pressure in the brain caused by the tumour, which formed a type of plug, the brain pulled away from the skull which caused many problems”*
- *“they would operate”*
- *“after the four hour operation the doctor walked up to Tessa and said that the tumour is cancerous and he hoped he removed everything”*
- *“eventually her son was sent home and she took six weeks leave from work to look after him”*

These certainties created a realm of uncertainty for Tessa where she says: *“I was totally shocked, it felt as though someone threw a bucket of ice over me”*. It is obvious that the natural energy flow in Tessa's environment was blocked due to her child's illness. According to systems theory being aware of the nature of the conditions that surround one is important, since meaningful and effective decisions or interventions can be made in a situation only if the dynamic pattern of energy flow is considered (Bloch, 1984). How Tessa relates or connects to these conditions will determine whether she will work with the energy flow of the illness of her child or against it. It seems as if Tessa's intention was that her son must get well and in order to try and achieve this she *“took six weeks leave from work to look after him when he was sent home”*. Her physical and mental activities were working overtime as she tried to cope with all the uncertainties of the illness. Would the tumours come back or not? *“In 1993 the tumours regrew again”* and her son was referred to a pediatric oncologist, Dr Anne. The chemotherapy, which is often unpredictable, *“went well and her son was not very ill with it”*. Tessa started believing in Dr Anne as *“she made the chemotherapy sessions a dream”*. In 1994 the following certainties occurred:

- *“the tumours regrew again”*
- *“they started chemo, a more intensive course this time”*
- *“this would be the last session of chemo as there were so many complications every time it was given”*

These realities plunged Tessa once again in despair, as she says *“I was devastated asking why us”*. She started questioning the fairness of life once again but realised that illness is a very powerful force which one has to work with and not against it as she said, *“life had to continue and every time my son would be cross and miserable about it, and later just get up and carry on again”*. The next event that plunged Tessa once again into uncertainty was when she heard that Dr Anne was leaving. *“My best medical friend I thought I would cry”*. Fortunately this uncertainty did not last long as *“Dr Kate took over Dr Anne’s patients and what a lovely doctor she was willing to help in whatever way she could. Things went well for a while again”*.

Upon reflection of Tessa’s descriptions I realised man’s yearn for intimacy and connectedness with others. Tessa’s connectedness with Dr Anne and Dr Kate gave her peace of mind, as she felt that these doctors cared for her and her son in a very special way. This attitude of doctors usually helps to make the uncertainties of the illness and treatment more bearable, suggests Cohen (1993). These two doctors in essence were not making Tessa feel like a refugee in the world of hospitalisation, treatment and illness. Woolley, Stein, Forrest and Baum (1989) found that parents need to elicit and talk about their feelings and be reassured about the normality of them and work through their anger, guilt and fear. They need permission to express them. The doctor’s ability to sit and listen to the upset and anger without taking it as a personal attack helps to set up a working relationship.

In 1996 though the following events occurred which left Tessa very uncertain:

- she could see her son visibly deteriorating
- his left eye twitched and started to pull to the left
- a scan showed that the tumours had formed a cap on the brain
- Dr Kate decided to do one more chemotherapy treatment

- chemotherapy could not be done indefinitely for years
- for three months she could see her son going backwards
- he was bedridden
- all she could do was wait for the next six to eight months

Tessa was certain that her son would die. She says: *"I started arranging time off at work and tried to get my mind ready for it"*. Then things turned around dramatically:

- *"after about four months he started to move around a little"*
- *"amazingly he grew stronger and stronger by the month"*
- *"amazingly after a couple of weeks he started to get up and move around"*

The unpredictability of this illness is once again depicted in the above descriptions. It is a continuous fluctuation between hope and despair (Cohen, 1995). The theme of certainty vs uncertainty is clearly depicted in the following description of Tessa: *"If things go well as they have been going the last year I should have him for another couple of years. I actually don't know how I feel at this stage. I am happy to have him here for longer but dread the deterioration again because this time I know it's final. No more chemotherapy will be given again and no doctor can do anything for him anymore, so now it's a period of waiting, wondering and hoping. I suppose God knows the reason for all this but we will never know"*.

TO TREAT OR NOT TO TREAT

Treatment is a time of enormous emotional and physical stress for a child with cancer and for the parent (Culling, 1988). The goal of all treatment for childhood cancer is to damage the cancerous cells, but to do as little damage to the normal cells as possible. This chemical balancing act causes the side effects. During this process parents often have to see others (medical professionals) making decisions about their child and they have little control or say over what happens to their child when it comes to treatment. However ultimately it is the parent who grapples emotionally with the quandary of whether to treat or not to treat (Van Eys, 1988).

chemotherapy instead of radiation seemed to work well with the child and this made Tessa happy. Mother and doctor were working well together. *"In 1994 the tumours regrew again and a more intensive course of chemotherapy was started. Fortunately in 1994 a medical breakthrough was made against nausea caused by chemotherapy. This went well"*. The physical and emotional pain Tessa had to endure seemed to be alleviated by the fact that her child is responding to the treatment without bad side effects. During this period though she was told that this would be the last chemotherapy treatment. This frightened her as she says: *"I was devastated"*. After the last course of chemotherapy her son started deteriorating. The physician had to decide whether to treat once more or not to treat. She *"decided to give one more chemotherapy treatment. She said she'd do three months treatment, as in the past and should he be worse after that we would have to stop completely. We couldn't do chemotherapy indefinitely for years"*. Stopping treatment scared Tessa as the end of treatment is almost as bad as starting. Medical support that the patient is dependent on is cut and it seems to the parent that there is no protection, now, against the cancer. The treatment becomes familiar after a while and leaving is like leaving home for the first time to go to college (Van Eys, 1988).

This last session of chemotherapy went well and even if Tessa knows as she says that *"according to medical research in this type of cancer the child does not grow older than 18 years old"* she is happy to have him for a couple of years longer. She is aware that if her son starts deteriorating *"no more chemotherapy will be given again and no doctor can do anything for him anymore, so now it's a period of waiting, wondering and hoping"*.

ACCEPTING SUFFERING VS FIGHTING SUFFERING

Throughout Tessa's story we encounter her suffering continuously. Although pain and suffering are universal phenomena, humans struggle to accept this fact (Tillich, 1961). Suffering is expressed by parents of childhood cancer patients in a variety of emotions (Culling, 1988). The first one I will explore in Tessa's story is anger. It is entirely normal for parents to be angry, even wildly furious, when their child is diagnosed with

cancer (Culling, 1988). What greater unfairness could life hurl at one's face? As Tessa says: *"The only thing I saw and realised at that stage was suffering and hell, and that it was. I hated everything, I hated my son's father and his family, I hated God for doing this to us. It felt like every move I tried to make, I was like an animal in a cage and could not escape. At that stage I wished a bus would run over me so that I could be removed from this earth, this hell"*. Parents are angry at a number of things. Tessa is angry at the disease itself, for causing pain, for frightening her, for its very existence. She is also angry at Peter's father for not being there, for not taking care of the child. She is also angry at Peter for being sick, for causing so much heartache and anguish, for costing money that she can't afford. She says: *"He was like a new-born baby. He couldn't lift his arms, move his head or anything. Then I started panicking. What do I do? Where do I go? I was the sole breadwinner. I was not financially well off. I often wished something would happen and that God could take my son and myself off this earth"*. She is also angry at family and friends who do not understand, and who cannot face the fact of the cancer and have abandoned her. *"At that stage friends and family only contacted me because they were inquisitive not to help. As soon as they were up to date I would not hear from them for a while. In this period I realised who my friends were out of my circle of friends. I was left with a few"*.

The second emotion connected to Tessa's struggle of whether to fight or accept suffering is premature despair. We see that she caved in immediately after hearing her son's diagnosis and started giving his clothes away. Hinds, Birenbaum, Clarke-Steffen, Quargnenti, Kreissman, Kazak, Meyer, Mulhern, Pratt and Williams (1996) suggest that the hospital environment forces parents to contemplate the possibility of the death of their child. In hospital, they meet other children with cancer and their families, and will inevitably get to know children who subsequently die. This acts as a constant powerful reminder of what could happen to them, making them consider the possibility of death even when treatment is going well for their child. Parents have to learn to live with this constant threat in their lives.

Thirdly Tessa also uses denial mechanisms, as Peck (1979) calls them, to protect herself and her son from the pain and fear of cancer. She did not tell her son the truth

about his diagnosis as she says: *"I never explained to him what cancer is and that he had a terminal disease and that he could get taken away any day. How could I tell him that he would probably not reach 18 years old? A child has such a fear of death that I never explained it to him. I feel it's a little unfair to do that to him"*.

In her story Tessa seems to direct her anger and grief inwards as she says: *"I am a very reserved person and don't easily speak about my feelings"*. This turned into energy sapping depression. Not only was this not helpful, but it was debilitating. Crying and sadness diminished her physical energy, and left her to anguish *"Why me? why us?"* But eventually she realised that she could not allow herself to get to a point where she ceased to function as her son needed her and depended upon her. Thus she started to resolve the issue of accepting suffering rather than fighting it.

Tessa shared these experiences in the support group and in doing so, also, heard how other parents coped and dealt with this disease and thus felt the healing influence of the support group according to Pierce, Sarason & Sarason (1996). Thereby she started to accept that suffering is inevitable in peoples' lives and it helps us to become stronger as she says: *"I must admit it has made me a stronger person but I continually ask why us? Life is so unfair and there is nothing one can do about it"*. Tessa's belief has also helped her to cope as she says: *"God alone knows how long he still will be with us. God knows the reason for all this but we will never know"*. Finding meaning and making sense of this terrible illness was not easy for Tessa. Suffering often seems to occur at random, senseless and indiscriminately with no meaning at all, let alone a purposeful or positive meaning states Shantall (1996). And while Tessa was in the midst of her pain and suffering it was impossible for her to reflect on any possible meaning behind it. There was very little she could do except endure it. It was natural that she should view her suffering as senseless and unfair and wonder, *"Why me?"* Despite the unpleasantness, her suffering did strengthen her and deepen her experience of life. Her belief in God gave Tessa some relief. The vulnerability she experienced in the midst of her suffering opened her up to join a support group and to deepen her connection with others. This helped her to accept Peter's illness and to work through it with him and to understand that accepting suffering is a powerful

method of helping us even during the most trying times in our lives.

HOW TESSA TRIED TO COPE

An important factor determining whether the experience of childhood cancer is ultimately destructive or growth producing for family life may be the coping styles each parent employs to deal with the stress. According to Lazarus and Folkman (1984), most research on stress and coping focusses on the immediate responses of the individual and fails to recognise that coping is a process and involves time. Coping is a complex process and not always fully understood.

A single parent, especially one who does not have an adequate support network, faces a true emergency when a child is diagnosed with cancer, propose Manne, Miller, Meyers and Wollner (1996). Probably the most important source of stress, which must be alleviated as soon as possible if the parent is to cope, is task overload.

Tessa tried to cope by seeking assurances, preparing for loss, fighting to a point and assuming meaning.

Seeking assurances is an action taking response which corresponds to Lazarus and Folkman's (1984) problem focussed strategies. One of the best ways to establish control over any situation is to learn as much as one can about it. The expression "knowledge is power" has great relevance in childhood cancer. Finding out that one's child has cancer will automatically trigger fears and fantasies of the blackest kind, but information about the disease will bring about the necessary assurance a parent needs to shade those fears into a manageable pale gray says Hinds et al., (1996). For this reason Tessa became actively involved in her child's treatment and tried to take control by focussing her fears into practical tasks. The more actively she was involved in caring for her child, the less time she had to worry about the ultimate effects of the illness.

According to Hinds et al. (1996) parents feel helped by learning of treatment options,

by the comforting familiarity of the health care team and by receiving clear guidance from the treating physician. It is quite clear that Tessa felt very comfortable with “Dr Kate” as she and her child were treated with warmth, kindness and gentleness. The theme of isolation versus support wove its way throughout her story. She had to cope on her own with the good and bad news. Tessa’s isolation is also stressed by her language usage. She uses the personal “I” level. *“I was totally shocked, I don’t think I spoke to someone specifically, I spoke to anyone and everyone who could listen”.*

A second process which Tessa used to come to terms with this illness was vacillating between preparing for her child’s death or fighting to cure him. Hinds et al. (1996) suggest that continuous cognitive shifts between two possibilities - the cure or the death of their child - is a component parents use to come to terms with this uncomfortable experience. Knowing that they are doing their best to help their child survive (fighting) allows parents to simultaneously consider the possibility of treatment failure and the child’s death (preparing). This is an alternating adaptive pattern which parents use to manage tensions as they adapt to the uncertainty of the situation. As Tessa noted:

“For three months I could see things going backwards. I knew he was busy dying and I could not do a thing about it. I didn’t talk about it, I couldn’t cry anymore, I felt dead inside. I started giving away his clothes he wasn’t wearing anymore and also clothes that were still too big. Because he wasn’t at school any more I gave his school clothes, bags and things away. The day he passed away I did not want to do that then, it would be so final. Maybe I was nuts to do that but I was so scared for the future, scared of how I would handle things.

Dr Kate eventually decided to give one more chemotherapy treatment. She said she’d do 3 months treatment, as in the past, and should he be worse after that we would have to stop completely. We couldn’t do chemotherapy indefinitely for years, but we had to fight this illness to its end.”

Parents reported that the intent of preparing for loss was to avoid being taken by surprise (Hinds et al., 1996). Thus, the adaptive function of preparing may involve

some feeling of mastery or control over emotional reactions. Worden (1991) observed similar behaviours in adults experiencing anticipatory grief over an imminent death. The parents in this study were not facing an imminent death. Yet, their thoughts frequently anticipated that possibility. A few parents had problems discussing the topic because they feared that actively preparing for the child's death could be interpreted as a lack of faith in God's ability to perform miracles. Factors that influenced these alternating realisations included the clear sense that a greater being would decide the outcome of the child's treatment and the knowledge that support from family, church members, and friends was available. Such values of spiritual beliefs and social support are common findings in coping studies (Gurklis & Menke, 1988; Perry, 1990; Sodestrom & Martinson, 1987).

After exhausting herself with the fruitless questions of why her child, Tessa saw that there were no answers to these questions. She then chose to assume meaning, that is, to conclude that there was a greater purpose, most likely spiritual, underlying the illness of her child. As Tessa noted: *"God knows the reason for all this but we will never know."* Perry (1990) suggests that despite this pattern of adapting by believing that God has a plan with all of us, all parents usually express a desire for predictable care routines for their children. The parents' desire for predictability and their need for mental rest and relief was also found in a study done by Futterman and Hoffman (1973). Familiar routines and social support was something parents searched for in order to find an equilibrium. The theme of accepting suffering versus fighting suffering indicates that by accepting that, behind this suffering and pain, there is some sort of meaning, it is easier to endure it all.

Kalnins, Churchill and Terry (1980) suggest that a number of over-arching factors contribute to instability within the family system when they are hit with cancer especially when one is a single parent like Tessa. Single parents have difficulty coping with the financial aspects of childhood cancer. Most often the single parent is the mother, as in Tessa's case. According to the same authors, when a woman suddenly experiences a crisis and her job attendance is sporadic, she has the additional fear of losing her job as Tessa did. As Tessa said: *"...I took six weeks leave to look after him. He was like*

a new born baby. He couldn't lift his arms..... Then I started panicking. What do I do? Where do I go? I was the sole bread winner, what if I lost my job? I was not financially well off'.

In order to help her cope Tessa decided to join a support group.

THE CONTRIBUTION OF THE SUPPORT GROUP

Introduction

Social support is a very complex phenomenon as it involves interpersonal relationships which mutually influence each other all the time (Pierce, Sarason & Sarason, 1996). Each person gives their own meaning to a supportive experience and this meaning is very often based on a mental map formed by the individual of past experiences (Fiske & Taylor, 1984). Kazak and Nachman (1991) also found that parental reactions to childhood cancer are influenced by many variables, including personality and previous experience with illness. According to Tessa, the support group was very helpful in the beginning. Aside from the group sessions there were also talk sessions where experts in various fields (for example dieticians, medical doctors, psychologists etc.) were called in to give information pertaining to their field of expertise. Parents were given the opportunity to ask questions afterwards which Tessa found very useful as parents in a situation like this "are always hungry for information".

The social worker, Petra, was very helpful in giving practical advice such as places to contact for help. Tessa felt that both Petra and I asked the group stimulating questions and she found the answers that came from the group, very helpful as she says "*...in the long run one learns to just accept things as they are and you continue building your life on that*". Tessa said that she "*actually felt quite special to have been blessed with a child*" like she has. Seeing other children getting better was inspiring to her. Knowing and seeing that others had problems similar to hers and having solved them gave her hope. The existential factors which gave this whole experience some meaning were:

- recognising that life is unjust at times
- realising that ultimately there is no escape from some of life's pain and from death
- realising that no matter how much support one gets from people ultimately one has to face the problem alone
- learning that ultimately one has to take responsibility for your own life

The group also had a cathartic effect (Lieberman & Bornman, 1979) on Tessa. She felt that she could get things off her chest and was able to say what was bothering her without holding back.

Also a very important aspect of the support group for Tessa was an altruistic factor (Figley & McCubbin, 1983). She said that being able to forget about herself when others were sharing their story, and putting their needs ahead of hers gave her self respect. Lynam (1992) suggests that helping others in the group and being important in their lives can give one a lot of satisfaction as it did with Tessa.

After a couple of months she felt strong enough to go on without the support group. She felt that the activities of the group changed to more "business like" ventures, that is collecting money and arranging fund raising projects, and she felt she could not really contribute nor gain anything from these ventures.

Tessa was therefore able to detach herself from the group as she had overcome the initial fear and bitterness that lead to anger and depression. She stopped hiding herself and shifted from a defensive perspective to a more incorporating and accepting position. She did not feel "like an animal in a cage anymore". Tessa was able to let go and trust, to let go of the past and to let go of the future. This allowed her to open herself to the present moment and to live each day at a time.

My relationship with Tessa

When I met Tessa I experienced her as polite and co-operative and an instant rapport

developed between us. She was a very agreeable person. Within the group context she did not say much except when asked or given a chance to speak. It was initially difficult to get information from Tessa as she was very reserved and, yes, one could say afraid of the others in the group. Nevertheless, I realised she was in the group because she needed a deep interpersonal bond with other individuals sharing her pain (Bowlby, 1980). Harry Stack Sullivan (1953) proposes that during therapy within a support group one should look at the process involved when people relate to each other. When Tessa entered the support group she was looking for approval, belonging and understanding. She experienced a type of relief to talk to people who would listen, unlike her ex-husband and many of her friends who disappeared when she needed them. She externalised (White, 1995) what she was feeling and my reflection of what she was trying to verbalise helped her to see things differently or perhaps more clearly.

Tessa's communication pattern

During the group process Tessa directed her efforts at the question I asked in the beginning which was the following: "What happened once your child was diagnosed with cancer?" Her conversation centred around a personal "I" level. As said previously she is a single parent so she had to go through it alone which was emphasised by the continuous use of the pronoun "I". Examples are "*I had him at the doctors*". "*I insisted on further tests*". "*I was divorced at that stage and the father was not at all involved*". "*I was totally shocked ...*" "*I have been suffering from depression ever since*".

Tessa used evocative and emotive language such as "*The only thing I saw and realised at that stage was hell and that it was. I actually tried to separate myself from reality by starting to talk about him as not being there anymore*". The language that Tessa uses is mainly emotive because it contains many subjective words such as "*it was hell*". These are words or phrases that carry more than factual information. They carry opinions. These words bring about an emotional energy which swept the group into identifying with Tessa. I chose the following statements as underlying how she as a parent felt towards the diagnosis of her child with cancer. "*The period felt like eternity to me*"; "*It felt like every move I tried to make, I was like an animal in a cage and could*

not escape"; *"I felt as though life was draining out of me"*; *"...I felt dead inside"*; *"Life is so unfair to some and there is nothing we can do about it"*. The illness of her child was like an endless struggle for Tessa. She felt deserted, uncared for and very very lonely. The simile she uses "like an animal in a cage" to make a comparison between herself and the animal and the illness and the cage is a very emotive and powerful way to describe the power of her son's illness to restrain her and force her in a situation she did not want to be in and could not get away. She, like the animal, had to be with her son and feel the fear and grief and pain without being able to escape. She could not help her son nor herself as she says "I knew he was busy dying and I could do nothing about it". "I actually tried to separate myself from reality ..."

Tessa's feeling was one of being caged by the illness and she could do nothing except feel all the negative emotions that went with the illness of her son such as suffering and depression, grief, fear and pain.

During the group sessions Tessa also made several statements indicating her negative emotional state of mind. I am listing the statements I found to be emotional assertions about herself according to Rogers' (1972) person centred theory.

1. *"I was divorced at that stage and his father was not at all involved."*
2. *"This period felt like an eternity."*
3. *"They were interested to know what happened and why and then it ended there because they did not know how to handle the situation."*
4. *"The only thing I saw and realised at that stage was suffering and hell, and that it was."*
5. *"I was like an animal in a cage and could not escape."*
6. *"The doctors treated the whole situation so casually as though nothing was"*

wrong.”

7. *“I just knew things were going to turn horrible and I was too scared to take him for a scan but I had to.”*
8. *“I actually tried to separate myself from reality by starting to talk about him as not being there anymore.”*
9. *“I knew he was busy dying and I could not do anything about it.”*
10. *“I was so scared of the future.”*
11. *“This has made me a stronger person.”*
12. *“Life is so unfair to some, and there is nothing we can do about it.”*

Tessa's own sense of negative self worth can be found in assertions (5), (8), (10) and (12). This seems to be one of her biggest mental blocks. The list of emotional assertions as Tessa creates and feels them generates a probable governing assumption of bitterness and anger leading to depression. It is this bitterness and anger towards the diagnosis of cancer of her child which has become an enemy that has caged her (assertion 5) and has made her try to separate herself from reality (assertion 8). Anger and bitterness are a great obstacle to compassion as we see in assertions (3), (5), (6), and (10) and they destroy one's virtue and calmness of mind as we see in assertions (2), (9), (10), and (12). Assertion (11) is the only positive assertion which makes me think that perhaps her anger was a kind of protector and brought Tessa a kind of blind energy as we see in assertion (7) to help her son.

What was helpful to Tessa

During the group sessions I tried to steer the group away from discussions “about the weather” and tried to focus their energy on one another as Rogers (1972) suggests.

I felt that if the group members were to open up I needed to open up first (Keeney, 1983). I used self-disclosure as a means of connecting with the group participants (Kogan & Gale, 1997). When Tessa heard about my experiences in England, as well as my personal pain which I shared with her she felt she could be herself. She opened herself up to the group (Rogers, 1972) and was able to listen to herself, to experience what was going on inside of her and thereby understand herself better. This was a dramatic personal shift for Tessa as she was always closed up. This personal shift threw her into another level as she started responding differently to her son's illness. As her son got better she started to live each moment with him to its fullest potential. With Tessa specifically I followed Rogers' person-centred approach (Rogers, 1972), looking at Tessa as a person and not as much at her isolation and despair. I felt she needed assistance to cope and she found it in the support group. What was helpful to her was my focus on the here and now (Piper, McCallum & Hassam, 1992) in the support group. Gradually this helped Tessa to "forget" about the suffering and hell of her son's treatment and to value the process that was taking place "here -and - now" and this encouraged her fellow members to do the same. This was a openness to each unique moment.

By being able to concentrate on the "here - and-now" in the group and opening herself to each unique moment of life, a process of *illumination* according to Yalom (1995), took place for Tessa. She was willing to change her fixed ideas about certain issues such as the medical professionals and the despair she felt about all the uncertainties that surrounded the illness.

Tessa said that the group offered her an interpersonal playground to expand herself, it was an opportunity to actively engage with people and grapple with her own unique issues surrounding the illness of her son in her own unique way in an accepting context, that is the group context.

Within the group Tessa also learnt different ways of relating to people. She could express her anger in the group and by being listened to (which did not happen in the hospital setting), she did not feel isolated anymore and she could move beyond the

“stuckness” of relating to people in an angry or attacking manner.

The group members, Petra and I showed Tessa empathy which was something she was not used to from health care professionals. By being understood she started to become empowered and this helped her out of her despair. This sense of empowerment was further augmented as I respected Tessa and also acknowledged her as an expert in the field of parenting an ill child. I further did not impose strict norms on the group so if Tessa did not want to attend a meeting she did not have to. She had a choice, something she did not experience with her son's illness. I never coerced her into telling me or the group anything she did not want to.

At last she could move from denial to acceptance of everything that happened: *“God alone will know how long he will still be with us, because according to medical research and experience in this type of cancer the child does not grow older than about 18 years old. Life is so unfair to some, and there is nothing we can do about it. All I can do is trust that all will go well and enjoy my son for the period left. I actually feel blessed to have him.”*

CONCLUSION

When Tessa's son was diagnosed with cancer she was like an animal in a cage. She was milling around suffering and hell and could not escape. She wished a bus would run over her to end her suffering. She kept on wondering why her, why she being punished. She tried to separate her self from reality, talking about her son as if he is not there. Eventually she could not cry anymore, she felt dead inside. She was caught in a no win situation because of being a single parent and lacking the skills and support.

Forming a relationship with Tessa afforded me the opportunity to get to know her and share my meanings with her. Listening to each other and in affiliation with the other members in the group we were able to co-create new meanings. In as much as Tessa learnt from me and the group we learnt a lot from her.

In summary the following themes emerged from Tessa's story:

- The theme of bad news versus good news
- The theme of isolation versus support
- The theme of uncertainty versus certainty
- The theme of treatment versus no treatment
- The theme of accepting suffering versus fighting suffering

Tessa's coping mechanisms were discussed. They are:

- Tessa tried to cope by seeking assurances, that is looking for information
- Tessa tried to cope by preparing herself for loss before it happened
- Tessa tried to cope by fighting to a point
- Tessa tried to cope by finding meaning in this whole ordeal

The contribution of the support group is discussed in terms of the following factors:

- The information it provided and allowed Tessa to find the assurance she was seeking for
- The cathartic effect it had helping Tessa to get rid of her feeling of anger and despair and to continue fighting
- The existential effect of giving meaning to illness in life
- The altruistic effect helped Tessa to prepare for loss

My relationship with Tessa within the support group is discussed. Tessa's communication pattern is described in terms of the language she used as well as what my perspective of what was helpful to Tessa. This discussion focussed on the following factors regarded as helpful:

- Looking at the "here and now" in the group
- The group became a playground in which Tessa could expand herself
- Tessa modelled a different way of relating to people within the group

- The group offered Tessa empathy, respect and freedom of choice, something she did not experience before

This allowed Tessa to escape from her cage and feel free at last and also blessed to have her son.

CHAPTER 6

JOAN'S STORY: NEVER TAKE ANYTHING FOR GRANTED

INTRODUCTION

Participant: Joan

Age: 42 years old

Children: A son, Alan 9 years old and diagnosed with ALL(Acute lymphoblastic leukemia) and a daughter, Hester 14 years old.

Occupation: Pre-school teacher

Marital status: Widowed

When I first saw Joan she seemed everything but a pre-school teacher. She is big in stature and comes across as a very forceful character. She always dressed in tent-like clothing perhaps to camouflage her weight but also metaphorically her real self. Joan lives in a rural area outside Pretoria together with her two children. Her husband who initially accompanied her to the support group passed away due to cancer too. Joan and her husband, Ivan, joined the support group as they felt "stigmatised" in this rural area where they lived. Their children Alan and Hester were avoided. Gallo, Breitman, Knalf and Zoeller (1991) suggest that when a child is diagnosed with cancer the family immediately undergoes a very stressful and significant change that makes them "different" from other families. They say that when people encounter sick children it creates a sense of anxiety and apprehension which reminds us of our own vulnerability, thus families with sick children are avoided. Consequently Joan and Ivan needed empathy, understanding and a sense of belonging. I did not see enough of Ivan to be

able to recount his story therefore this story is based on Joan's participation in the group. Shortly after they joined the support group in 1998 Ivan was diagnosed with cancer which metastasized very quickly and he was bedridden. He died soon after that.

Joan was a dedicated participant in the group, not missing any sessions especially once her husband died. She had a kind of presence that no one could ignore. She always carried with her a file containing articles she came across or little verses of encouragement which she shared with the group. She also always took notes. There was a kind of purposefulness that embraced her. Her message to the group was, "Never to take anything in life for granted". Petra and I always felt we could sit back, when Joan was there, as she "ran" the group (perhaps her teaching qualities manifested in this way).

THE STORY OF ALAN'S CANCER

It was March 10th 1995, Joan says, a typical late summer's day. Her dear, sweet, gentle Alan, as she describes him, who had started school six weeks ago was dreadfully ill. At that time Alan was 6 years old. Many trips to the doctor over the past month had failed to pinpoint the reason for his uncharacteristic lassitude and ghastly pallor. Joan tried in her own mind to find a reason for her son's malaise. Alan's grandfather, whom he was very close to, had died three months ago, but Joan felt that her son's symptoms were too severe to be seen as grief. Also the "virus" the doctor thought responsible should have started to work its way out of his system by now.

At 7:41 that morning Joan's worst fears were confirmed by the pediatrician. "*Your child has Acute Lymphoblastic Leukemia*". To Joan these were blunt cold words spoken with no gentleness. Pinkerton, Cushing and Sepion (1994) suggest that confirming the diagnosis of cancer to a child's parents is a necessary but unenviable task.

Joan's reaction was one of shock, denial and disbelief. "*You must have made a mistake, did the tests get mixed up, you have the wrong child. NO!*" Faulkner et al., (1995) indicate that there is no way of softening the blow for parents when telling them

their child has cancer, but the experience can be made more harrowing and confusing through inept handling before and at the time of breaking the bad news.

After several invasive medical procedures such as blood transfusions and bone marrow aspirations Alan was allowed home for the weekend. Joan turned to her family for support and her mom, sister and other members of the extended family arrived from the coast.

Joan describes the word “cancer” as the most terrifying in the English language. She did not expect this to happen to her child, after all the fundamental role of a mother is to protect her child. Martocchio (1985) suggests that for most people, especially a parent, the word cancer provokes fear and they are terrified by it, conjuring up images of relentless disease. It is often equated with unavoidable death (Redler, 1994).

After breaking the news to the family, Joan and her husband went through all the emotions of fear, guilt, despair, self reproach, rage. They were plunged into a series of events over which they had no control and this led to further anxiety and uncertainty.

Joan wanted to escape, to run away from the hideous hospital and to put as much distance between herself and this illness as possible until she was introduced to a Dr Jane who would start Alan’s treatment. In Dr Jane’s office Joan immediately felt reassured, perhaps she says, because there was a certificate on Dr Jane’s wall saying “To the best mum in the world”. This gave Joan comfort as it made Dr Jane more human instead of another cold doctor explaining to her what the likely scenario would be in the next two years. This empowered Joan and her husband resulting in a shift in perspective which led her to learn unpronounceable names of different medications, to study and become conversant with all the terminology involved in leukemia, thereby gaining knowledge about this disease and being better able to help Alan fight back to health. Woolley, Stein, Forrest and Baum (1989) suggest that the way information about a life-threatening illness is given can affect the parent’s ability to come to terms with the diagnosis and if done inappropriately (as in Joan’s case with the first Doctor) can cause additional unnecessary stress. For a collaborative and trusting relationship to develop as in the case of Joan and Dr Jane, professionals need to remember the

human vulnerability to illness and show sympathy and protection towards their clients (Kaye, 1996).

The context of Joan's story will now be discussed in terms of emerging themes.

EMERGING THEMES

FAMILY CARE AND FAMILY CLOSENESS

Children are the most cherished and vulnerable members of a family, and when one of them becomes ill with a life threatening disease the entire family is catapulted into an arena of confusing and conflicting emotions. In her opening paragraph Joan selects very rich descriptive words to describe her home and her son. I immediately was bathed in an atmosphere of warmth when I read the following: *"I sit in the late afternoon sun in a corner of my kitchen, watching as my child, his brows locked in thought, toys absently with his pen as he considers his homework assignment"*. I saw a parent with many hopes and dreams for her child which were shattered. *"It is hard to believe that shortly we will be celebrating his third birthday. Not the joyful day he made his noisy arrival into this world; but the day that changed and shaped our family's lives irrevocably"*. The closeness of the family and the care is further expressed in the following description: *"March 10th was a typical late summer's day. As the rising sun slowly bathed the Pretoria skyline in its glow, the darkness in my heart intensified. I gazed at my precious boy sleeping peacefully in the hospital bed, his still baby face illuminated by the dawn's soft light and I knew in my heart that today we would hear news that would shatter us"*. Although Joan's family lived far from her she did not feel uneasy about breaking the news to them. She could just not say the diagnosis which was leukemia, it was too painful for her as she says: *"Phone calls to Natal, Mum, it is that disease that begins with 'L'"*. Joan received help from her sister and her mom almost immediately. *"The Cavalry in the form of my mother and sister joined us from the coast later that day, and we turned home grimly to prepare ourselves for what lay ahead"*. Joan felt overwhelmed, drowning in sorrow, rage and despair. Having an open communication with her extended family did provide an amount of support for Joan.

Cancer is probably one of the most feared words in any language. It is a metaphor for evil. Joan indicates this by not being able to pronounce the name of the diagnosis to her mom. Fear of cancer is real and rational but it can be tamed by understanding the disease.

UNCERTAINTY VS CERTAINTY

Joan's anxiety and uncertainty about her son's malaise is indicated in the following words: *"My dear sweet, gentle son, who had started school six weeks before was dreadfully ill. Many trips to the doctor over the past month had failed to pinpoint the reason for his uncharacteristic lassitude and ghastly pallor"*. She had no clarity on what was wrong with her son. She was trying to find some solution as she says: *"Surely the dreadful, sudden loss of his dear grandfather three months previously couldn't manifest in such symptoms. And the virus the doctor had thought responsible should have started to work its way out of his system by now"*. She was uncertain but she felt that *"today she would hear news that would shatter them"*.

This uncertainty became a certainty upon receipt of the diagnosis. *"That morning, our worst fears were confirmed by the pediatrician. A man who 24 hours previously had been a stranger to us. 'Your child has acute lymphoblastic leukemia'. Blunt, cold words"*. Upon receipt of this news Joan was shattered. Nothing was the way it was before nor would it be in the future. The stress of the diagnosis fell suddenly like a blanket that seemed to smother her lying beneath it. Her shock, denial and disbelief is reflected in the words: *"You must have made a mistake, did the tests get mixed up, you have the wrong child. NO!"*

When a child is diagnosed with cancer it becomes a family illness as no-one remains unaffected. Joan felt unsettled as the outcome was unknown and she felt disrupted because the normal patterns in her life (her routine which gave her certainty) would not be the same for years. According to Putnam (1987), children who are seven years or older (Joan's son was seven at the time of diagnosis) seem to engender the most parental stress. This is because developmentally children at this age start formal

schooling and as a result start to develop a kind of independence. They start to form their own circle of friends, and they have a social life. Therefore, serious illness is highly disruptive and can drastically alter their lives.

The doctor's words of comfort *"if a child in my family had to get cancer, this is the best one to have"*, only plunged Joan into more despair as she says: *"The best? How can there ever be a better type of cancer, especially when it is happening to a child"*. Joan found it difficult and painful having to bare her most private thoughts and fears, hoping that if she *"did not acknowledge them then they wouldn't be real"*. The certainty of the diagnosis soon started to become real for Joan and her family and she knew she had to start finding ways to cope in order to help her son through this crisis. Her vacillating between denial and trying to cope is depicted in the following words: *"Smells, sounds, people, laughter all took on an unreal quality. How could life carry on around us? The events and details of that day and the weeks and months that followed are so firmly inscribed in every fibre of my being. On the Friday of the diagnosis, confirmed following a battery of unpleasant tests, my son was given a blood transfusion and allowed home for the weekend"*.

LACK OF CONTROL VS CONTROL

Joan's lack of control over her son's diagnosis and the medical profession plunged her into anxiety and self-blame as she says: *"We started to question ourselves. How could this have happened? What had we neglected to do, where had we gone wrong? Fear, self reproach, guilt, despair, rage - we ran the whole gamut of emotions. Most of the tumble of thoughts that swirled through my mind were irrational - punctuated by the word leukemia which became a chant which followed me through every waking and sleeping moment"*. Joan and her family were suddenly plunged into a world of incredibly high technology with a foreign language that nobody bothers to interpret. *"We were plunged into a series of events over which we had little, or no choice, if our child were to have a chance of recovery"*. Hospitals are complex social systems that seem bent on maintaining as much secrecy as possible separating the professional personnel from the "outsiders" which are patients and their families. These experiences

are disconcerting, frightening and often maddening and always stressful because they lead to the parent, as in Joan's case, feeling no sense of control over their child. This coldness and lack of concern is stressed in the following description that Joan gives: *"Despite having an appointment, we were told to wait in the waiting area. To our distress we found ourselves surrounded by adults who were obviously going through various stages of being treated. Most were apparently used to the routine; many had made provision for what they, from experience knew would be a lengthy wait. We spent four agonising hours in the waiting corridor; not daring to move in case we would be called. During this time we considered 'escaping' - putting as much distance between ourselves and this hideous place as we possibly could"*. This lack of control that Joan was experiencing led to paralysing stress. She questioned the wisdom of being in this particular hospital thinking that if she went somewhere else she might have more control.

Joan's anxiety turned to reassurance and she felt a little in control of her fears when she was introduced to the pediatric oncologist who was going to treat her son. She says: *"As she spoke to us my eyes scanned the room. I saw photographs on a wall of what must be her children and a certificate to "the best mom in the world". I don't know why this gave me comfort, somehow it made her more human instead of a professional who was trying to explain to us what the likely scenario would be over the next two years or so"*.

When Joan and her husband were informed that their son had a good chance (60%-70%) of achieving full remission and eventually cure she was angry once again. Joan says that *"these odds rather than being a comfort were unsettling, almost like gambling stakes. I would not bet money on a wager that had such a vague promise of returns. How could our child's life be discussed in percentage probabilities?"* Joan decided not to allow this to plunge her back into uncertainty and loss of control so she and her husband adopted the mindset that their son would be cured and thereby progressed from fear to hope and a positive attitude.

INFORMATION VS IGNORANCE

Fear of cancer is real and rational but it can be tamed by understanding the disease i.e. how its various types differ from one another, how the body reacts to the presence of the invasive cancer cells and how those cells are affected by treatment.

Joan decided that she was going to gain more control over the situation and fear less. She was going to empower herself by gaining as much knowledge about the illness as she could. She knew nothing about childhood cancer so she did not know what to look for and was afraid that her ignorance about the disease might lead her to question *“the necessity of lengthy, uncomfortable, often painful treatment”*. According to Cincotta (1993), in childhood cancers, if parents are given some responsibility for, and thus control over, the treatment, they will understand more and be less afraid. Childhood cancer can be very disruptive to families but Joan and her husband decided not to allow it to bring unmitigated gloom. She was a smart woman and after the initial shock she and her husband decided that there were two ways they could deal with this situation as she says: *“We could allow ourselves to be carried along on the tide of the unfamiliar, the unknown, and hope and trust that our son was in good hands; or we could make the decision to become informed as possible about what was happening and consider what, if any, choices we could make on our son’s behalf”*.

During her son's treatment Joan controlled her fear of childhood cancer by learning about it and understanding how the disease behaves. She wanted to know everything that was going on during treatment, from basic facts right down to the precise dosage of each drug given to her child. She spent hours in the medical library. She says: *“We soon learned unpronounceable names of different medications and their effects and purpose; we studied blood counts and became conversant with lymphocytes, neutrophils, platelets; to the point where we eagerly read and interpreted them and knew what sort of precautions we would have to follow to protect our son from infections. We felt empowered by the knowledge we gained about the disease and better able to help our son fight back to health”*.

According to Chesler and Barbarin (1987) being active and assertive as well as having an open family communication system are two effective coping mechanisms helping the parent of the child with cancer to gain control. Joan and her husband were active in the sense that they learned as much as they could about the disease. They took a highly active role in caring for their child and also initiated a support group for parents having children with cancer. Joan stresses that one of the things that she took seriously right from the beginning was *"the importance of compliance to the treatment"*. She says that *"at no time over the next 30 months could we afford to be careless or sloppy about ensuring our son received his medication. This in all likelihood could result in his death"*. Joan took control of her son's well-being *"by not letting him over-exert himself as his heart was struggling as a result of his blood being so devastated by the cancer cells"*. She had to be careful her son did not injure himself as he had *"not been producing haemoglobin or platelets, the components that carry oxygen around the body, and help the blood to clot"*.

Having an open communication within the family meant that feelings and information were shared, and that the truth was told. As Joan says that she and her husband *"often stood back and observed themselves with wry amusement as they discussed the merits of different chemotherapy protocols. We found ourselves learning much about a subject which we had previously found painful as spectators"*.

Having empowered herself with knowledge Joan found that she could also be more tolerant and patient with peoples' *"generalisations and misconceptions"*. She says that she learnt along the way that cancers affecting children are different to those affecting adults even though they might share the same name. She recounts the following: *"We countered many misunderstandings from well-meaning individuals, typically, 'Oh, leukemia, that is a common childhood disease. They usually outgrow it don't they?'"*

FINDING MEANING IN SUFFERING VS BEING DEBILITATED BY SUFFERING

Having had cancer in the family means that things change and people change. It is in fact a watershed experience. In Joan and her family there was a sudden and drastic

change once her son was diagnosed with cancer as discussed earlier on. She could no longer continue the pattern of her past way of living. All she had was the immediate moment. This she used to look after her son and to become informed about childhood cancer so that she could regain her lost sense of control over making choices and coping. Joan's old secure footings in life were gone once she heard her son had cancer. She was in a position of helplessness and dependency on the medical profession. She felt cornered and trapped at first and could not escape anywhere. This is reflected in her following words: *"During this time, we considered 'escaping' - putting as much distance between ourselves and this hideous place as we possibly could"*.

Shantall (1996) says that no one can suffer for us, we suffer alone. This is indeed how Joan felt. Stripped of her past defences and familiar way of doing things she found herself in great doubt and in panic of indecision. She did not know how to tackle this illness of her child. It was something bigger than her from which she could not protect her child. She felt naked and exposed and felt in confrontation with herself. Her and her husband's whole life came up in review. They were called to task somehow as is reflected in the following words after the diagnosis of leukemia was confirmed: *"You must have made a mistake, did the tests get mixed up, you have the wrong child. NO! That weekend we started to question ourselves. How could this have happened? What had we neglected to do, where had we gone wrong? Fear, self-reproach, guilt, despair, rage - we ran the whole gamut of emotions. Most of the tumble of thoughts that swirled through my mind were irrational - punctuated by the word leukemia which became a chant which followed me through every waking and sleeping moment"*. This suffering brought Joan to the crossroads. She and her husband had to decide one way or another as she states in the following words: *"After the initial shock had settled, my husband and I decided that there were two ways we could deal with this situation. We could allow ourselves to be carried along on the tide of the unfamiliar, the unknown, and hope and trust that our son was in good hands; or we could make the decision to become as informed as possible about what was happening and consider what, if any, choices we could make on our son's behalf"*.

Finding meaning in suffering is a powerful method of helping us cope even during the most trying times in our lives. Shantall (1996), says that the sufferer suffers alone and yet it is this very fact that can make suffering, in the way it is borne, the sufferer's own achievement. Frankl (1968) said that man is ready and willing to shoulder any suffering as soon and as long as he can see a meaning in it. This is what Joan did. She transmuted her predicament into an achievement. With a heightened sense of responsibility she started finding her feet by empowering herself with knowledge of the disease as she says: *"We felt empowered by the knowledge we gained about his disease and better able to help our son fight back to health"*. She and her husband were set on a course of *"making a commitment to see that their son followed the treatment through and that he adhered to it"*. They made progress as is expressed in the following words: *"My son is now in remission - a term which means the disease is under control. We look forward to the day when we will hear the words 'he is cured'. His wonderful specialist says that things are looking good"*.

In finding meaning in her suffering, the spiritual side of Joan emerged. She felt deeper and more profound about life and had a stronger sense of self. She indicates this in the following description in her story: *"The past three years have been a turning point in the lives of all our family. We have enjoyed many blessings and endured many heartaches. Along the way we have met many dear people whose children have died; we remember them fondly every day, and continue to be thankful that we still have our son with us. We have learned much about cancer in children; especially that there is a great need for information, and even a greater need for support for families. One of the most valuable lessons we have learned is not to take anything for granted. Our 'cancer' journey is not over yet; but we are on a smoother path after negotiating many bumps and obstacles along the way"*.

Joan's suffering caused her to mature and grow. As she realised this she found further meaning in this suffering by re-evaluating her life and *"coming out of this stronger and with a better sense of what is important"*. She and her husband lost their sense of fear of the disease and had a clear and unshakeable conviction that life retains its meaning under all circumstances, even those of suffering and in the face of death itself. This

resulted in taking the initiative to become involved in the formation of a support group for families of children with cancer where *“many friendships have grown and families have been put in contact with each other to pool emotional and practical resources in order to fulfil many areas that need to be urgently addressed”*.

HOW JOAN TRIED TO COPE

Once Alan was diagnosed with cancer Joan was plunged into a world of uncertainty faced with difficulties and problems on a daily basis. Coping is how we respond to these situations of uncertainty and may take the form of a range of thoughts, feelings and actions. Joan’s method of coping took two main forms namely problem-focussed coping and emotion-focussed coping.

According to Atkinson (1993) problem-focussed coping involves either tackling the problem in an attempt to resolve it or developing strategies to avoid it altogether. The other way of coping is known as emotion-focussed coping and entails dealing with the emotions that may be experienced as a result of the stressor. The aims of these strategies are to reduce the unpleasant feelings that may be associated with being stressed (Beresford, 1993).

Joan’s problem-focussed coping strategies included first trying to escape and then seeking information as a method of empowerment which lead to joining our support group. Her emotion-focussed coping strategies were denial, finding meaning and re-evaluating her life. Sloper and While (1996) indicate that both these strategies are used for coping either at the same time or at different times.

Let us look at the way Joan tried to cope in more detail.

When Joan first heard the breaking news of her son’s diagnosis she denied its existence completely. Her reaction was one of disbelief: *“You must have made a mistake.....you have the wrong child. NO! How can this happen to a six year old child”*. Using denial as a psychological technique, can have benefits as well suggests

Weissman (1976). It can lessen the pre-occupation with the disease, and it can minimize the terror that accompanies a parent's every waking hour.

Joan's next move was to try and find a way out of this, she wanted to escape, to flee, to run as fast as she could. She could not bare the hospital environment anymore as she says: *"To our distress, we found ourselves surrounded by adults who were obviously going through various stages of being treated. Most were apparently used to the routine; many had made provision for what they, from experience knew would be a lengthy wait. Some read quietly, others brought along family and friends for support. We spent four agonising hours in the waiting corridor. During this time we considered escaping putting as much distance between ourselves and this hideous place as we could."* Atkinson (1993) indicates that trying to avoid the problem altogether is not an unknown response. Faulkner et al. (1995) also suggest that distancing is seen as a particularly useful strategy.

After the initial shock had settled Joan decided that there were two ways she could deal with this situation. She could allow herself to be carried along on the tide of the unfamiliar, the unknown and hope and trust Alan was in good hands or she could make the decision to become as informed as possible about what was happening and consider what, if any, choices she could make on her son's behalf. She soon learnt unpronounceable names of different medications and their effects and purpose; she studied blood counts and became conversant with lymphocytes, neutrophils and platelets, to the point where she eagerly read and interpreted them and knew what sort of precautions to follow to protect Alan from infections. She felt empowered by this knowledge she gained. Gibson (1991) indicates that parents need to understand what is going on with their child. Furthermore he states that gathering information and learning as much as possible makes it easier to interpret medical information. These activities help parents to manage practical problems as it did with Joan. Joan empowered herself, she did not rely on the medical staff. Empowerment of parents is essential in redressing the balance between everyone involved in the sick child's care. Gibson (1991, p. 357) says the following: "Healthcare professionals cannot empower people; people can only empower themselves. However, they can help the parents

develop, secure and use resources that will promote or foster a sense of self control and self-efficacy.”

The next coping mechanism Joan used was to re-evaluate her life and find meaning in what happened. When she did that she realised that she still had her son and her daughter and her home and her job. Her son was now in remission and his specialist says that things are looking good. Joan shifted her perspective of seeing things and decided to never take anything for granted. Although Joan is not a religious person she displays spirituality. Neuberger (1987) suggests that while a person's religious tradition may offer valuable assistance in finding meaning, even those who do not subscribe to a religious worldview may find meaning and value behind their suffering upon careful reflection. This is what Joan did and through this she was also able to accept her husband's death through cancer.

Joan also became very involved in the support group which was her strongest way of coping. The contribution of the support group will now be discussed.

THE CONTRIBUTION OF THE SUPPORT GROUP

Introduction

The reason that Joan and her husband joined the support group was because they were feeling isolated and stigmatised as the “cancer family” in the rural town where they lived. Joan was tired of fighting on her own to keep her sanity and her children's too in the midst of rejection from the community. She needed support to integrate the new experience, the new routines, the new circle of friends, the new reality into her existing lifestyle. Murray (1995) indicates that groups can sometimes accomplish what individuals alone cannot as there is strength in numbers plus peer pressure and shared understanding. For Joan joining the support group was a positive upshot of her personal journey. Many firm friendships have grown and families have been put in contact with each other to pool emotional and practical resources in order to fulfil many areas that need to be urgently addressed.

Joan needed the support group to help her acknowledge the cancer and accept it as a reality of life. Her life was completely disrupted and she needed guidance to continue living her life in a way that is meaningful to her and with some satisfaction. Weisman (1976) suggests that if the family is able to accept the reality of this experience, even though it is unpleasant, they will find a new normality, that creates a more mentally healthy atmosphere.

Another reason why Joan joined the support group is because she felt her child was treated as a “miniature adult” and not as a child. She needed support to help her child accept the cancer because the impact of cancer and diagnosis is different for the parents than for the child. Parents will often mistakenly think that although their children may have child-like feelings, with enough information and explanation they can be made to understand and reason like adults says Harding (1996).

Joan wanted her child to develop and mature despite the illness. She wanted him to express his likes and dislikes and not be afraid to do so. Bowlby (1982) suggests that even though children may spend up to several months at a time in and out of hospital, if they continue to have the right contact, love and support from their family, are able to have the opportunity to play and learn, they will have the potential to continue to develop and mature.

My relationship with Joan

When I first met Joan she seemed a very strong person wanting to share her experiences with the others in the group and thereby helping them to not feel alone, deserted or stigmatised. She spoke a lot within the group always trying to teach the others what to do. The acknowledgement she got from the group ensured that she got the support she needed too. But behind this attitude of “knowing everything” masked by her tent-like clothing, was a mother in turmoil looking for a “partnership” to care for her child. She did her part in order to gain control but she could not go all the way alone. She was tired of the child-doctor-mother threesome and needed to move beyond that. She was tired of doctors making all the decisions about her child. I

allowed Joan to express her "expert" opinion gained through experience and listened and reflected her thoughts which made her feel empowered. I also identified with her sensitivity and how she had to learn to mask this in order to cope within the hospital setting. Robinson (1985) describes how parents are expected to be clinical experts in the home yet relinquish these skills in the presence of doctors or nurses. In paediatric oncology care where parents are required to take on new skills in caring for their child, a supportive and educational partnership is needed, allowing the child to reach its full potential and keeping the parents' role consistent. I recognised Joan's need to be able to function socially, emotionally and physically within her work and community at large. I also validated her feeling of how difficult this can be. Joan externalised her problems (White, 1995) through her rich descriptions of her journey. I tried to be sensitive to all aspects of Joan's character. May (1939) indicates that voice, posture, facial expressions, dress and accidental body movements are essential aspects of a client's character that need to be looked at in order to enter into a deep personal relationship with the client. Let us now look at how Joan communicated with the group.

Joan's communication pattern

Joan provides a very different dimension to the cancer experience by using descriptive language to convey her emotions. She starts off by describing her home and her relationship with her son. *"I sit in the late afternoon sun in a corner of my kitchen, watching as my child, his brows locked in thought, toys absently with his pen as he considers his homework assignment. March the 10th, 1995, was a typical late summer's day. As the rising sun slowly bathed the city skyline in its glow, the darkness in my heart intensified. I gazed at my precious boy sleeping peacefully..... his still baby face illuminated by the dawn's soft light...."* Joan starts off with longer, slow moving, balanced sentences depicting a mood of peacefulness, tranquility and beauty. Her description then changes to short, abrupt groups of words to create a sense of urgency with the illness of her son. Joan starts to use direct speech in her description of the diagnosis of her son which colours the experience more. Examples are the following: *"Your child has acute lymphoblastic leukemia.' Blunt cold words spoken with no gentleness. You must have made a mistake. Did the tests get mixed up. You have*

the wrong child. NO!" This is the way Joan felt when her son was diagnosed with cancer. The exclamations used and the words and phrases add an emotional dimension to the description which help to recreate the respondent's experience and convey it vividly to the reader.

As I said previously she starts off with long slow moving sentences depicting a mood of peacefulness in her life and perhaps positive energy flow and then she moves onto shorter abrupt sentences depicting the urgency and gamut of emotions associated with the illness of her son and perhaps negative energy flow and then ends off with longer sentences again. Examples are *"My son is now in remission, a term which means the disease is under control. The past three years have been a turning point in the lives of our family. We have enjoyed many blessings and endured many heartaches. Along the way we have met many dear people whose children have died, we remember them fondly every day, and continue to be thankful that we still have our son with us. We have re-evaluated our lives and hopefully we shall all come out of this stronger and with a better sense of what is important."* This ending indicates an attempt to get back to normality and tranquility again, and positive energy flow.

Joan's emotional state is clearly depicted in her communication pattern. She did not dwell in negativity but tried to move beyond that. I am listing a number of Joan's statements which indicate her shift from negativity of the past to living productively in the present according to May and Yalom (1989).

1. *"Cancer is one of the most horrifying words in the English language."*
2. *"No mother or father ever contemplates cancer happening to their child."*
3. *"Parents are catapulted into an arena of confusing and conflicting emotions."*
4. *"The events and details of that day and weeks and months that followed are so firmly inscribed in every fibre of my being."*

5. *"We were plunged into a series of events over which we had little, or no choice."*
6. *"During this time we considered escaping."*
7. *"We could make the decision to become as informed as possible."*
8. *"We soon learnt unpronounceable names of different medications."*
9. *"The past three years have been a turning point in the lives of all our family."*
10. *"We have learnt much about cancer in children."*
11. *"We have re-evaluated our lives."*
12. *"We have become very involved in the formation of a support group."*
13. *"One of the most valuable lessons we learnt is somewhat clichèd; not to ever take anything for granted."*

When I looked through Joan's set of assertions what stood out for me as answer to the question "what happened to you once your child was diagnosed with cancer?" was the change of perspective in this mother. The prime factor that allowed her to deal effectively with the difficult situation of her child's illness was her capacity to shift perspective in other words to view the situation from a different vantage point and thereby gain control of it as we see in assertion (7). She changed the way (perspective) she looked at the events and then practised this change. The assertions (1 to 6) indicate her initial perspective and then (7 to 13) indicate her new perspective. Joan discovered a positive angle to a bad situation (8), (9), (10), (11) and through this process of learning and getting used to the situation she was able to deal with her son's illness and also become involved in a support group (12) for parents of children with cancer. Joan's sense of efficacy in this ordeal is derived in her shifting perspective about the illness. It is this assumption that governs what happened to Joan after her

son was diagnosed with cancer, leading her to conclude assertion (13).

What was helpful to Joan

Joan said that one of the main contributions of the group for her was that she always left the group feeling energised. This was in contrast to her everyday living (work demands, family demands etc.) where her energy would get “killed”. She felt that after the group meetings she needed to use her energy to help other parents in every way she could before it got neutralised by her normal everyday living.

She felt that the atmosphere in the group was electric. New insights were triggered, energy was shared and there was a feeling of integration. The group context provided the opportunity for each individual “to meet”, “to pull together”, “to converge”. This convergence according to Joan was followed by a phase of divergence, where each individual had to stand alone after each group meeting and “take” from the group meeting that which was personally meaningful and of interest. What Joan did is to create the sort of context outside of the group which allowed for the opportunity to think, read, write, act or reflect about those aspects, experiences, comments or ideas that emerged in the group process. Her training as a teacher assisted in this.

Joan in other words experienced the group as “rejuvenating”. Her old energy was always replaced by new creative energy to attend to the “business like” ventures of the group too. As a result of this new energy she helped in arranging fund raising projects etc which the group needed to survive.

Joan also experienced the group as fun as we often arranged “braais” at someone’s home offering the opportunity to socialise with each other outside the context of therapy.

The support group also assisted Joan into realising that ultimately there is no escape from some of life’s pain and from death. In the beginning your only way of coping is wanting to leave. Eventually Joan realised that she cannot leave and ultimately she did

not want to leave. The following description of a cancer ward that Joan gave really touched me and the group: *"The first step into a children's cancer ward seems like a step into unreality. Mothers are weary waiting, teenagers with no hair, children with two or three strands of hair. They all look like veterans of some long war. They are all children waiting for death. The first step into a children's cancer ward brings with it a queasy feeling of hopelessness and there seems to be only one way of coping with it - leaving."*

Joan further commented on the impact myself and Petra had on her. She said that she did not think of us as her therapists but as her friends. We helped her realise the importance of responsibility, awareness, freedom and potential. She took more responsibility for her life. May, Angel and Ellenberger (1958), suggest that a client very often becomes more responsible partly because of the relationship built with the counsellor. In the relationship, Joan became more aware of personal freedom. Her life did not need to depend on the judgement of others in the community, rather her activities were evaluated by her first. This shift of perspective helped Joan to improve her encounters with others thereby slowly eliminating the stigma they attached to her family. May (1975) suggests that such a shift in perspective allows the client to establish a will to meaning and to make decisions about both present and future directions in life.

The support group assisted Joan to appreciate what she had and to bare what cannot be changed. She ends her story with the following words: *"One of the most valuable lessons we learnt is never to take anything for granted. Our cancer journey is not over yet but we are on a smoother path after negotiating many bumps and obstacles along the way. We have re-evaluated our lives and hopefully we shall all come out of this stronger and with a better sense of what is important."*

CONCLUSION

When Alan was diagnosed with cancer, Joan, was catapulted into an arena of confusing and conflicting emotions. She could not escape the disbelief, horror, anger,

fear and feeling of impotence. Smells, sounds, people, laughter all took on an unreal quality. How could life carry on around her? She questioned everything from why her child to the wisdom of being in a particular hospital to the meaning of life.

Forming a relationship with Joan afforded me the opportunity to get to know her behind her mask and together we discovered her unique strengths and capabilities. I concentrated on being authentic with her and entered into a deep relationship with her in order to understand her pain and turmoil. I shared a lot of my personal experiences with her which helped to create an atmosphere of shared humanness and struggle.

In summary the following themes emerged from Joan's story:

- The theme of family care and family closeness
- The theme of uncertainty versus certainty
- The theme of lack of control versus control
- The theme of information versus ignorance
- The theme of finding meaning in suffering versus been debilitated by suffering

Joan's coping mechanisms were discussed. They are:

- Joan tried to cope by denying Alan's diagnosis
- Joan tried to cope by trying to escape the aftermath of the diagnosis
- Joan tried to cope by making a decision to become as informed as possible about what was happening and consider what if any choices she could make on her son's behalf
- Joan tried to cope by re-evaluating her life and finding meaning in what happened
- Joan tried to cope by joining a support group

The contribution of the support group is discussed in terms of the following factors:

- The support group helped Joan acknowledge the cancer and accept it as a reality of life. Her life was completely disrupted and she needed guidance to

continue living her life in a way that is meaningful to her and with some satisfaction.

- Joan needed support to help her child accept the cancer because the impact of cancer and diagnosis is different for the parents than for the child. The support group assisted her in finding a way to deal with that.
- The existential effect of the group was that it helped Joan to come to the insight that the meaning of life changes but it never ceases to be.

My relationship with Joan within the group is discussed. Joan's communication pattern is described in terms of the language she used as well as my perspective of what was helpful to Joan. The following factors were helpful to Joan:

- The support group energised Joan. New insights were triggered, energy was shared and there was a feeling of integration. The group context provided the opportunity for each individual "to meet", "to pull together", "to converge"
- Joan also experienced the group as fun
- The support group also assisted Joan into realising that ultimately there is no escape from some of life's pain and from death
- The support group helped her realise the importance of responsibility, awareness, freedom and potential.

Finally this assisted Joan to appreciate what she has and to bear what cannot be changed.

CHAPTER 7

VICKY'S STORY: NEEDING TO LET GO AND SUBMIT TO GOD'S PLAN

INTRODUCTION

Participant: Vicky

Age: 40 years old

Children: Two sons, Daniel (14 years old) and Neil, diagnosed with lung cancer, and died at 15 years old.

Occupation: Housewife

Marital status: Married

Vicky joined the support group two months after it started. Her son, Neil, had just passed away due to lung cancer. She is a very pretty lady and very petite. What touched me was the fact that she was dressed in black, mourning her son's death. I realised that I would have a very special bond with Vicky due to our shared Mediterranean cultures. She was fluent in English with a touch of an accent. Vicky joined the support group without her husband. He refused to join, feeling that he could deal with the pain of his son's death on his own.

Vicky joined the support group when she heard from the doctors that I was the facilitator of the group together with Petra. She felt isolated and rejected by many people as they could not understand her interpretation of her son's illness and death. Her behaviour was also very different to all the other parents who had a child diagnosed with cancer and this concerned her. Vicky's mourning of her son was almost

not acceptable to others. She felt that my Mediterranean background could be helpful by sharing her views, beliefs and values and from this she could derive support. Bond and Bond (1991) suggest that the definition of what constitutes health and illness varies between individuals, cultural groups and social classes. The same disease or symptom may be interpreted completely different by two people from different cultures and in different contexts and this will affect their behaviour and the treatment they look for (Cornwell, 1984).

Vicky is a very religious person, always leaving early in order to attend Mass held on a Saturday evening. She also always wore a gold cross symbolising her belief in Christ. Vicky often cried during the group sessions. She cried more than the other group members. We all treated her with compassion, love and care. Her sadness touched us all.

THE STORY OF NEIL'S CANCER

Neil had left in perfect health on the morning of 26 September 1996 to go to school. Vicky went about her daily chores at home and was about to go and help her husband in his Cafe when she got a phone call from Neil's teacher. Neil could not breath and had chest pains. She thought it must be related to him having fractured his arm three weeks ago. After going to the doctor and getting X-rays of his chest, Vicky was told that her son had nodules on both lungs, one being the size of a golf ball. The same day she took Neil to a lung specialist who said that a biopsy would have to be done to see if the nodules were malignant or not. That night he was admitted and the following day he was operated on. The doctor removed a nodule from the right lung which caused it to shrink. Vicky and her husband and her younger son were all waiting outside the theatre. When the doctor came out Vicky asked him what is the result? "*Your son has cancer, you must be strong*", he said. Vicky wished that the doctor had lied to her and said her son was fine. She had to go and see Neil in Hi-care but could not. What would she say to him? Buckman (1992) suggests that until recently it was not always regarded as standard medical practice to tell clients the truth. However, there have been great changes in policies and attitudes over the last two or three decades, and it

is now generally accepted that clients or the parent in the case of a child, have absolute ethical, moral and legal rights to any medical information that they require and request. It is important to break bad news and tell the truth in order to maintain trusting relationships, reduce uncertainty, prevent inappropriate hope and allow appropriate adjustment (Kaye, 1996). The debate about breaking bad news has moved on from *whether* to tell to *how* to tell. Buckman (1992) proposes that insensitive truth telling is as deleterious in its own way as insensitive truth concealment.

When Vicky walked into the ward her son shouted, *"Mom what is wrong with me?"* She decided to get a second opinion first and then to tell him the truth. *"My son whatever it is you will get better"* Vicky replied. Parents face a dilemma in deciding what or how to tell the sick child what the problem is. Medical opinion recommends that children should be informed about their diagnosis (Eiser, Parkyn, Havermans & McNinch, 1994) although this may be dependent on several factors (Chesler, Paris & Barbarin, 1986) including the child's age and religion. A week later when he was discharged Vicky took him for a second opinion and the diagnosis was confirmed. She told her son that he has cancer and he continued to cry asking *"Mom am I going to die?"* He was 13 years old at the time and could understand the implications of such an illness. *"Why did you not tell me, I'm sure you knew long ago?"* Neil continued. Waechter (1971) showed that children who were not told their diagnosis in order to protect them had heightened anxiety, as in Neil's case. If children are told the diagnosis at a later stage they may feel betrayed, shocked and more fearful of consequences (Slavin, O'Malley, Koocher & Foster 1982).

Neil was referred to a pediatric oncologist, Dr Ben, who was going to do the chemotherapy. Vicky was very impressed with Dr Ben as he explained all the various drugs and medication Neil would be taking during the course of the chemotherapy. He also explained each drug's purpose, how much Neil would receive and how it would be administered, as well as the side effects. Dr Ben was also very caring and allowed Vicky to express her feelings and to talk. Pinkerton et al., (1994) suggest that despite their distress parents wish to be informed so that they could understand what they might have to face and plan for the future while knowing that they would be supported

throughout the illness. This lessened the sense of helplessness and isolation. Research by Sharp, Strauss and Lorch (1992) indicates that parents' strongest preferences were for doctors to show caring (97%), to allow parents to talk (95%), allow parents to show their feeling (93%), share information (90%) and be confident (89%).

Neil never went back to school in 1996 but was promoted to Grade 9 because of the good work during the first two terms. The treatment ended in September 1997 and Neil began to lead a normal life again. He was confirmed in his local church, his hair was growing back and he felt fine, or so he thought. In February 1998 he started getting bad headaches and upon examination the cancer had metastasised to the brain. The neurosurgeon removed it but Neil was still not well. His cancer had reached the stage that only a stem cell transplantation could save him. Neil made his own big decision and said to Vicky, *"No mom, I am tired of been cut left, right and centre, I am not going through any more pain"*. Vicky respected his choice and that was it! She still felt an enormous responsibility for her son's choice but decided to hand her son over to God. This gave her some relief. Hinds et al. (1996) suggest that the desire of parents to see their child recover is balanced against the importance of limiting suffering. Difficult decisions have to be made, and although these are made together with the health care professionals, parents bear the greater part of this responsibility. The same authors reveal in their research that as time progresses, parents consider the limitations of the treatment, balancing the child's response to, and tolerance of, the regimen, against the suffering involved. These considerations add to the emotional turmoil that parents experience when their child has a life-threatening disease.

The last couple of months were a nightmare to Vicky. Neil became paralysed and kept on calling her for everything. He must have said the word "mom" about thirty times a day. His friends deserted him too. This was very difficult for Vicky to understand. Neisser (1988) suggests that adolescence is a life period which implies a re-organisation of the self-system and of one's relationships with the social world. During healthy adolescent development an individual evokes a strong sense of personal uniqueness, along with a commitment to wider society but when faced with a terminal illness, role confusion results coupled with an inability to settle on a meaningful and

societal role (Petersen, 1988). This could lead to isolation as adolescents have enough demands to cope with and cannot deal with the specific events of a terminal illness (Spirithall & Collins, 1984). This could explain why Neil's friends deserted him.

Neil's condition was deteriorating and this tore Vicky apart. Her only consolation were the words of the parish priest in her local church. He said: *"Obviously cancer is not something good. It is bad. However, the amazing thing about our human nature is how we can handle with God's empowering grace even bad experiences in a positive and productive manner. This, in fact, is the only thing that counts in life. How do we respond to whatever comes our way? How do we cope?"*

Eventually Neil slipped into a coma and Vicky felt strong enough to encourage her son to *"stop hanging in there and to go to Jesus in heaven"*. Within seconds his breathing pace changed and he concluded his human life and entered the glory of Christ's resurrection.

The context of Vicky's story will now be discussed in terms of emerging themes.

EMERGING THEMES

UNCERTAINTY VS CERTAINTY

The diagnosis of cancer in one's child is a watershed experience. The diagnosis itself is the only certainty a parent has. From that point on everything is uncertain. The shock of sudden and drastic change that the diagnosis brought about in Vicky's life is described in her opening sentence when she says *"I must say my life changed on 26 September at 12 o'clock when I got a phone call from the school that my son could not breathe and had chest pains. He left in perfect health that morning I took him to the doctor and he sent him for X-rays. When the X-rays came back he had a whole lot of nodules on both lungs. One was the size of a golf ball. I was stunned. He was referred to a lung specialist"*. According to the literature (Faulkner et al., 1995; Adams & Deveau, 1984) the symptoms of cancer are often vague and slow to develop and

parents may have to take their child many times to the doctor for consultations and investigations before a final diagnosis is made. As Vicky says she thought that her son's chest pains "*might be related to him having fractured his arm three weeks ago*". The way in which this stage of the child's illness is handled clearly influences how parents respond when they are faced by the person who confirms their worst fears. For Vicky the diagnosis came "*out of the blue*", an unwanted, unexpected and devastating discovery. The lung specialist said her son had to be hospitalised for a biopsy as he suspected cancer. The next day her son was taken into theatre for a biopsy. Vicky says the following: "*When the doctor came out I asked him and, he said, 'your child has cancer you must be strong' in a very cold way and walked away*".

While Vicky was telling the story I could see from the look on her face and her tone of voice that she was actually reliving that whole moment of the diagnosis. The blank look on her face reflected the numbness she felt at the time of the diagnosis but her scratchy voice indicated the pain associated with it. She felt she wanted to see her son but had to wait as he was taken to intensive care. This mother was told the diagnosis "casually" in the corridor. There is no way of softening the blow for parents when telling them their child has cancer but for Vicky the experience was made more harrowing because of the manner in which the news was broken to her. She felt patronised and condescended to.

HONESTY VS SECRECY

The next step for Vicky after seeing her child was deciding whether she was going to be honest with him immediately, or whether she should let some time go by before she told her son about the diagnosis. Faulkner et al. (1995) strongly support the need to be honest but sometimes parents need time to understand their own feelings before they are able to talk to their children. Vicky says "*I saw my son in intensive care, it was a terrible sight for me*". This is a personal difficulty many parents have to overcome. To a parent his/her child is the most competent, most beautiful, most precious possession so to admit that your child is a terrible sight is a horrifying experience for the parent. I noticed Vicky breathing deeply when she was recounting this which meant

from a therapeutic point of view that she was addressing an internal obstacle. She sighed after a while and continued. I realised that we achieved an intimate connection in this interview and that Vicky's defences were down. I could see the same fear she probably experienced when faced with having to tell her child he had a life threatening illness. Such knowledge according to Copeland, Pfefferbaum and Stovall (1983) could upset the child more than the illness. When her son asked her once again, *"Mom what is wrong with me?"* She had to say something. At this point she did not want to flood her child with information and her answer was aimed at conveying hope to her child so she said, *"My son whatever it is you will get better"*. It seemed to me as if Vicky wanted to create an atmosphere of comfort, reassurance and trust before she told her child. According to Adams and Deveau (1984) children respond less to information than to love and security based on comfort and trust. When her son returned from hospital and was in the secure environment of his home he asked Vicky what is wrong with him, and she told him *"you have cancer"*. He was 13 years old and he could understand. School age children can be very verbal and they want to know detail. He started crying because he knew what cancer was. Immediately he asked *"Mom am I going to die?"* Once again she had to be strong and show hope by saying affirmatively *"No, you are not going to die"*, although I as a researcher could sense uncertainty in her voice.

The way a parent deals with childhood cancer is unique in every family. Depending on what works for them, every family creates its own way of communicating the illness to the child. The important aspect according to the researcher is that every parent should trust his/her solution and there should be congruence between verbal and non-verbal communication.

COMPASSION VS APATHY OF MEDICAL PROFESSION

After Vicky took her son for a second opinion and the diagnosis was confirmed her son started chemotherapy. The doctor who treated her son discussed the various drugs and medication with her and her son. This explanation was in direct contrast to the coldness she received previously from medical professionals and made things a little easier. It was as if her child was going to receive appropriate treatment now.

According to the literature (Faulkner et al., 1995) a good relationship with those who provide care for the sick child is crucial. It felt to me as though Vicky would relate to this doctor treating her son in a manner which was different to the previous health care professionals. This is indicated in the following words: *"I asked the doctor what were my son's chances for survival, hoping he would say something like 80% but he said 'it's not for us to know but for the Almighty to decide'"*. Vicky had a coherent belief system in God and it is as if this doctor spoke her kind of language. So even if he did not give her hope directly (as she hoped he would say her son had an 80% chance of survival) he spoke to the side of her that counted. *"At least he was honest"* she continued.

Although Vicky tried to remain strong and hopeful for her son's sake there were times when she felt desperate and alone as she recounts: *"When I walked into the doctor's room who was doing the chemotherapy I saw a whole lot of photos of children on the wall and as this was all new to me I asked if all these children had cancer and if they died. The doctor said some of them had died. I thought 'oh dear'"*. To me this was the most powerful statement in the whole story. For the first time I became part of Vicky's pain. I could feel her pain and despair. I could feel her being intimidated by all the photos of the children who had died from the same illness her son had. The "oh dear" was a sigh of will she as a mother survive this ordeal. This was juxtaposed by a detailed description of the bone marrow test her son went through. According to White (1995) "how you talk about" something determines how you think about it and how one thinks about situations determines how one responds to situations. In a way one could say that in order to cope Vicky tried to focus on the practicalities of the disease and tried not to concentrate too much on the emotional side. This is also indicated in the fact that Vicky's story contains more an account of what happened in terms of a practical account and her duties and responsibilities rather than an emotional account.

TREATMENT FOR CURE VS TREATMENT FOR COMFORT

Vicky's devastation is reflected in her words *"...all the treatment he went through and still died, was it worth him going through all the pain"*. Her son died anyway despite all the pain he and she went through. Her son's decision to discontinue treatment and not

go for a stem cell transplant and rather opt for comfort rather than cure was a very difficult time for Vicky. This was a time when her hope had to change from a wish for a long life for a sick child to a desire for a pain controlled period of terminal care. Her investment in her religion provided her comfort. She respected her son's decision of being *"tired of been cut left, right and centre"*. This was something that I also noticed in my research with terminal children. When death is close treatment must change. Most dying children cannot tolerate the strong dosages of medication nor surgery to cure cancer. Treatment must be redirected towards comfort rather than cure towards the end.

The turning point in Vicky's life was not when her son decided to stop treatment but when he became paralysed. She says: *"... the saddest look I saw on his face was when he became paralysed"*. She carries on to describe how she tickled his feet and he could feel nothing. The final moments of her child's life were near. No parent can really predict how his/her child will die. Vicky's son went into a coma after his paralysis and died. In her description of her son's final days she mentions the words "feel nothing" a lot. She says that when the nurse came to clean his sores she kept on apologising and he said he feels nothing so she can carry on as she likes. These words to me were a reflection of how Vicky feels now. She feels dead inside. She said if people ask her how she is, she says fine, but she is not fine, she is dead inside. It is almost as though the comfort that her son opted for was not really there. He became paralysed which meant he did not feel any physical pain but emotionally the pain was there for mother and son. She says: *"The cleaning of sores was traumatic, it was as though his body was rotting away"*. This meant that he was never really pain free and neither was his mother.

As a parent she tried to comfort her son by doing every practical thing possible. She tried to comfort him with gentle backrubs and massages. She fed him and bathed him. She tried to keep him occupied with puzzles. Because he was a very active child it was difficult for him to be dependent. So even if a child opts for comfort rather than cure the child is never really pain free.

ISOLATION VS SUPPORT

For a child the thought of dying threatens plans, hopes and dreams. It is devastating for them to see their bodies deteriorate so that they no longer look like their friends. For Vicky it was really devastating to watch her son be deserted by his friends. This is a time when a child, especially at 13 years old, needs his friends to chat and to confide in. Vicky was the only person in her son's life towards the end which meant that she had added pressure. She had to be a mother and a friend. She had to face a double tragedy, her son dying and being abandoned by his friends. The emotions of grief and anger were what she had to cope with. Despite this she had to give her son hope by showing him that she is there for him up until the end. Her son kept on asking her why his friends had deserted him? She had no answers and had to admit to not knowing. She asked him if she could phone some of them and he said no. He was angry and that anger spilt over to Vicky too. When her son died and some of his friends volunteered to be pallbearers Vicky said no, she had already picked the pallbearers.

The saddest thing for me was to see all these emotions that Vicky had to cope with as a parent alone. The isolation of her son is also a reflection of her isolation. She never once mentioned her husband. When I asked her, she said he never really helped in anything and she wants to leave it at that. In effect she was a single parent without any social support. It was too painful for her husband to handle, so he left everything up to her. She says: *"The last couple of months were a nightmare. My son could not even draw anymore, not even hold a pen in his hand. His life was very unpredictable the last couple of months"*.

ACCEPTING SUFFERING VS RESISTING SUFFERING

Shantall (1996) suggests that facing up to the facts of human nature and dealing with it as best we can is the only reasonable way to deal with the inevitability of conflict and suffering. According to Chesler and Barbarin (1987) using a coherent belief system to face the suffering is a very effective coping pattern. This is what Vicky had to help her through this ordeal. It was her belief in God and her parish priest that helped her and

her son accept the inevitable. The critical importance is understanding and accepting what comes your way in order to survive.

Vicky's search for meaning in her suffering began with her religious tradition. Although different religions may have different ways of understanding the meaning and purpose of human suffering every world religion offers strategies for responding to suffering based on its understanding and beliefs. As a Christian, Vicky believes the universe was created by a good and just God and even though we do not always understand His plan for us our faith and trust in him allows us to tolerate our suffering more easily. She says: *"We all grew spiritually, especially our relationship with God grew"*. So her suffering with her child's illness potentially strengthened her faith and one can say that growing spiritually could mean loosening the bonds with the material world and moving closer to God in a very fundamental and intimate way. The following was said at a sermon for Neil: *"Obviously cancer is not something good. It is bad. However, the amazing thing about our human nature is how we handle with God's empowering grace even bad experiences in a positive and productive manner. This, in fact, is the only thing that counts in life. How do we respond to whatever comes our way? How do we cope?"*

Vicky found refuge with her parish priest. She could not imagine losing her son *"could not let him go"* but the priest's words *"not to try and predict the future but to take one day at a time and cope with each situation as it occurs"* brought an *"incredible sense of peace and strength"* over her. This priest was a major support to Vicky helping her to understand her own feelings about death and life after death so that she could assist her dying child. Christian faith was part of Vicky's family life and it is this belief which the priest strengthened to help Vicky let go of her son. The priest brought Vicky's faith forward just when she needed it most. With this spiritual strength when her son went into a coma she could speak to him and try and communicate her love and support up until the end. Then she found the courage to tell him to *"stop fighting to live but to let go and go to Jesus who is waiting for him"*.

When Vicky was describing her son's death there was a kind of peace and calmness

over her in contrast to her tearfulness when sharing what went before. It was almost the same type of calmness she felt when he died.

Vicky ended her story in a positive and reassuring way. She told us about her son always trying to find humour in everything to alleviate the stress. She also described how her son thanked her before he died for being a “*good mom*”. That made her feel content, she fulfilled all her duties as a mother. She could do nothing more except pray and that she did up until the end. She faced her son’s illness with him until the final stretch, the finishing line of life. The last thrust in any race is often the hardest, but her belief in God turned her suffering to spiritual victory. Shantall (1996) says that there is no point in experiencing life as meaningful when things are going well. What counts in life, as Vicky says in her story, is how we respond to bad experiences in our life. The true foundation of Vicky’s life was exposed by her suffering. She saw it as a challenge which she faced with God’s empowering grace. She is now a richer and stronger person although she has changed a lot.

HOW VICKY TRIED TO COPE

Once Neil’s diagnosis was confirmed as cancer Vicky was thrown into a world of ambiguities. It was a world of uncertainty, a world of secrecy, a world of isolation, a world of suffering. This ties in with Chesler and Barbarin (1987) who declare that families of a child with cancer often cope by having a powerful and coherent belief system. Reliance on religion, acceptance and taking good care of her child before he died and thereby avoiding the possibility of guilt, were the three coping mechanisms that Vicky found helpful.

Vicky and her family are very religious, belonging to the Catholic church. Vicky taught her son about God and His love from a very early age. When Neil went to primary school he also enrolled in his parish’s religious education programme. Vicky encouraged her son to go through the various celebrations associated with the Sacraments of Catholicism and in this way Neil’s growth continued in the Catholic faith. By adhering to these religious practices during Neil’s illness and ultimately his death,

Vicky was able to derive emotional comfort from her personal relationship with God. She quoted the following text from Ephesians 6: 10-13, as her anchor through her son's illness: *"Finally, grow strong in the Lord, with the strength of his power. Put God's armour on so as to be able to resist the devil's tactics. For it is not against human enemies that we have to struggle but against the Sovereignities and the Powers who originate the darkness in this world, the spiritual army of evil in the heavens. That is why you must rely on God's armour, or you will not be able to put up any resistance when the worst happens, or have enough resources to hold your ground"*.

According to Kushner (1981) religious beliefs provide some parents with a cognitive system for making sense out of the illness and perhaps the death experience. According to Spinetta, Swarner and Sheposh (1981) a coherent theology may be especially useful for parents' success in coping with the death of a child from cancer as is the case with Vicky. She says that she followed Jesus' example of coping on the Cross. *"How did I cope? The best example of coping is Jesus Himself - the way He coped even to the last moment of His human life on the Cross of Cavalry. This is why our parish motto is so meaningful. It comes from the lived experience of Jesus. He literally 'hung in there' to the last moment of his earthly life. So each of us is called to follow his example."* Featherstone (1981) remarks that being part of a religious congregation is a great help to many parents. It provides a place to go for religious, spiritual and practical help and it gives an opportunity for members of the congregation to be of help.

Acceptance of their child's situation according to Featherstone (1981) is another coping strategy that parents adopt, as did Vicky. Her parish priest encouraged her to accept the situation as she says: *"I prayed that my son would live up until the last moment. I couldn't imagine losing him, I couldn't let him go, I had to keep him alive at all costs. Our parish priest tried to encourage me not to predict the future but to try and accept what each day brings. It is incredible how these words of our priest brought an incredible sense of peace and strength over me on the day my son breathed his last breath."* Acceptance does not mean surrender, however. Accepting the reality of a serious and chronic childhood illness does not mean that one puts in less effort. It does

mean that we realise that “although we can help, we cannot cure” (Featherstone, 1981, p. 216).

Vicky also coped with her son’s death by taking good care of him at home before he died. She hired a nurse to assist in cutting out the dead tissue from his flesh during the final months. Once he became paralysed she did not leave his bedside except to go to church. She bathed him and comforted him effortlessly. She says: *“Another aspect that will remain with me is how often my son called me “mom” sometimes 30 times in a day. This indicate his closeness to me and the central role I played in his life. One of the greatest consolations to me is that before he died he told me several times what a good mom I was to him.”* Chesler and Barbarin (1987) suggest that taking good care of the child and avoiding the possibility of guilt may help parents maintain their emotional balance which leads to inner peace and allows one to continue with life as it did with Vicky.

Vicky also tried to cope by searching for help from others when she joined the support group.

THE CONTRIBUTION OF THE SUPPORT GROUP

Introduction

When Vicky joined the support group she expressed a need for a space to cry, a space where she did not feel abnormal because of her way of grieving, a space where she did not have to pretend she was fine. Pinkerton et al. (1994) suggest that perhaps the most important work to be done with families is to normalise the feelings that they are experiencing. This acknowledgement and validation of emotions are invaluable. Vicky needed to know that her feelings were not abnormal and needed the provision of appropriate facilities (that is the support group), to express them.

Cohesion was the other reason Vicky wanted to be part of a support group. She came from a very close and extended family whose support she lost once Neil was diagnosed

with cancer. Yalom (1995) suggests that the affective sharing of one's inner world and then the acceptance of others is of paramount importance especially when dealing with loss. Vicky needed to belong and be accepted, she needed continued close contact with people, she needed to reveal embarrassing things about herself and still be accepted, she needed to be understood so that she could move on.

Another problem Vicky experienced was that there was no open communication within her family about Neil's illness. Her husband never wanted to speak about it, seeing the illness as some sort of curse on them. He kept on telling Vicky not to tell anybody that their son had cancer. Her family did not have a climate that allowed for the expression of emotion and this stifled Vicky. Koocher and O'Malley (1981) found that more open family communications lead to a better recovery. Vicky needed a way out of all this and thus joined our support group.

Vicky also had vivid images of her son "rotting away" as she put it. She remembers his sores and how cleaning them was traumatic. She knew her son was never pain free although he did not complain too much. She felt that people who have not seen something like this, would never understand, and if she described it to them, they would see her as repugnant. Yalom (1995) proposes that to be accepted by others within a support group brings into question the person's belief that he/she is unacceptable or unlovable. This is what Vicky looked for when she joined our support group.

My relationship with Vicky

When Vicky joined the support group we all immediately welcomed her with compassion. She had something special about her which made her likeable. I made some assumptions about Vicky on the basis that we shared a Mediterranean culture but being from different countries I could not assume categorically that I knew how she felt. In order to overcome this I decided to ask Vicky many questions about herself. Littlewood (1988) suggests that although it is possible to make some assumptions and generalisations about a person based on culture and/or religion, we must be aware of the individuality that exists within it and it is only possible to identify a person's cultural

features by asking the person. By answering the questions I posed to her, which were mainly centred around her way of life, I wanted the group, myself and Petra to share interpretations, impressions, opinions and feelings with Vicky in order to make her feel that we were not judging her. Cultural diversity results in a wide variation in lifestyle, health behaviour, religion and language and may affect how people perceive ill health (Hussein-Rassool, 1995). I wanted the group to get to know Vicky's way of life and in turn her perception of her son's illness and death. This helped to alleviate her stress.

As communication differs from culture to culture according to Hussein-Rassool (1995), I tried to develop a warm, supportive, empathic, friendly and equalitarian relationship with Vicky in order to encourage her to open up. The group also followed my example. According to Gladding (1996) this kind of relationship helps to assess why clients are oriented to a certain way of thinking and behaving.

Let us now look at how Vicky communicated with the group.

Vicky's communication pattern

Vicky was the only group member whose child had died from cancer. The language that Vicky used to describe her experience was very emotive depicting pain and despair. She was very demonstrative (constantly making the sign of the cross with her right hand) and always cried consistently and inconsolably. Her pain is depicted in the following words which she said with her eyes closed as if she was back in the doctor's room. *"When I walked into the doctor's room ... I saw a whole lot of photos of children on the wall and as this was all new to me I asked if all these children had cancer and if they died. The doctor said some of them have died. I thought 'oh dear'."*

She also asks penetrating questions such as *"Why did his friends have to desert him?"* indicating her desperate attempt to find an explanation for what happened. Vicky's world is bound by explicit connections to the past. The direct speech she uses when discussing her son's paralysis is as if she cannot disconnect from that yet. He said *"Mom why are you looking at me?" "Mom what are you doing?"* I said, *"I'm tickling your*

feet". He said "I feel nothing". "That minute I realised he was paralysed. That was the saddest look on his face." But Vicky's explicit connection to the past is her vivid metaphoric description of how she felt when her son was ill. Vicky says the following. "It was like going up a river, an empty stream. There was no joy in anything not even in sunshine. The long stretches of the river ran on like the chemotherapy and the pain into overshadowed distances. I often lost my way on the river as you would in a desert, and plodded all day long trying to find the right channel till I thought that now I was cut off for ever from everything I had known once - somewhere - far away - in another existence perhaps. There were moments when the past came back to me and how happy we all were as a family and the dreams and hopes I had for my child, but it came in the shape of an unrestful dream, remembered with wonder amongst the overwhelming realities of this strange world of needles, medication and cancer. When the river was still it did not resemble peace. It was always like a brooding stillness of a relentless force with impossible intentions to destroy. One cannot fight that."

Vicky's emotional state is clearly depicted in her communication pattern. In speaking to Vicky I noticed that she held strong traditional beliefs, such having to wear black for at least a year to mourn her son's death. This, the group found strange but nevertheless accepted Vicky as she is. Once again Vicky's spirituality was the dominant feature in her communication with the group. The group in turn gave Vicky feedback on their ideas and behaviours. This feedback proved to be very useful to Vicky. Corey (1995) suggests that when feedback is given honestly and with care, group members can gauge the impact of their actions on others and attempt new behaviours. I am listing a number of statements which Vicky made, depicting this spirituality.

1. "My life changed on 26 September at 12 o'clock when I got a phone call from the school that my son couldn't breath and he had chest pains."
2. "I saw my son in intensive care, it was a terrible sight for me."
3. "I asked the doctor what were my son's chances for survival. He said it's not for

us to decide but for the Almighty to decide.”

4. *“The saddest look I saw on his face was when he became paralysed.”*
5. *“Cancer patients are never pain free.”*
6. *“His friends deserted him. It really broke my heart to see his friends disappear.”*
7. *“We all grew spiritually especially our relationship with God grew.”*
8. *“This, in fact, is the only thing that counts in life. How do we respond to whatever comes our way? These words of our priest brought an incredible sense of peace and strength over me on the day my son breathed his last breath.”*
9. *“My final words to my son were to stop fighting to live but to let go, and go to Jesus who is waiting for him.”*
10. *“Despite all the suffering my son always looked on the positive side of things.”*
11. *“One of the greatest consolations to me is that before he died he told me several times what a good mom I was to him.”*
12. *“His death impressed upon me the need to let go and submit to God’s plan.”*

Vicky’s sensemaking of her son’s diagnosis is directed towards a spiritual dimension in her life. A governing assumption of Vicky’s approach is that one has to submit to God’s plan (12) which is a level of spirituality which has to do with religious beliefs. Vicky embarked on a spiritual path that was best suited to her mental disposition, natural inclination, temperament, belief, family and cultural background (11). Her religion nourished her human spirit (7), (8) and (12).

What was helpful to Vicky

Vicky said that when her son was diagnosed with cancer she was very shocked. She needed to join a support group, so when she discovered TOUCH she became a member and attended all our meetings. She found it very helpful to relate with people who were in the same situation as her. She could talk about her son and his illness, with a comfortable feeling. No matter how she felt the group understood and did not get tired of hearing the same story over and over again. Vicky lost all her friends who disappeared after a few conversations regarding her crises.

The group was also full of love and support. No one rushed her to get better. The group reflected Vicky's need to grieve and let her understand the bereavement is a long process. Her uniqueness in grieving was validated and she was allowed to grieve in her own way.

Vicky found that she could identify with members in the group. There were people who were better adjusted than she was and that gave her hope. Seeing that others could reveal embarrassing things and take other risks and benefit from it helped Vicky do the same.

As for me and Petra, Vicky said she admired us and found that she could pattern her behaviour after us.

Self-understanding was another important aspect for Vicky. Learning about likes and dislikes about various people in the medical profession, which really had little to do with the people but more to do with her as a person. Vicky learnt why she thinks and feels as she does. She discovered and accepted many previously unknown and unaccepted parts of herself. The feedback of the group not only helped her to deal with her son's illness but also to realise aspects of her personality and how she relates to her family.

In conclusion the group gave Vicky support and took her out of her isolation and in so

doing she was able to accept the suffering and move on, rather than resist it and remain stuck.

CONCLUSION

When Vicky joined the support group she was suffering from an energy sapping depression. She felt powerless and out of control. She felt she could not kiss her child and make the pain go away. The *hugeness* of cancer took over her life. Vicky was not only grieving the loss of her son but also the loss of the way things were. She needed a platform to cry and to talk openly about her son's death.

In my supportive relationship with Vicky I tried to help her incorporate and accept all aspects of her life. Passons (1975) proposes that an individual cannot be understood outside the context of a whole person who is choosing to act on the environment in the present. I emphasised her uniqueness and how anxiety, being part of her culture, is not abnormal. Yalom (1980) indicates that this is a very humanistic way of working with others. I emphasised the global view of human existence which according to Jackson (1987) allows one to focus on the person without regard to ethnic or social background.

In summary the following themes emerged from Vicky's story:

- The theme of uncertainty versus certainty
- The theme of honesty versus secrecy
- The theme of compassion versus apathy of medical profession
- The theme of treatment for cure versus treatment for comfort
- The theme of isolation versus support
- The theme of accepting suffering versus resisting suffering

Vicky's coping mechanisms were to

- cope by relying on her religion
- cope by accepting her son's situation

- cope by taking good care of her son during the final months to avoid any guilty feelings of neglect afterwards.
- cope by joining a support group

The contribution of the support group is discussed in terms of the following factors:

- The support group helped to normalise the feelings that Vicky was experiencing. This acknowledgement and validation of her emotions were invaluable.
- The support group provided group cohesion in which Vicky felt safe to reveal embarrassing things about herself and still be accepted. Vicky felt understood and consequently could move on.
- The open communication system within the group allowed Vicky to trust the unfolding process and not be impatient with what transpires in the group.
- The support group assisted Vicky to accept and incorporate the problem being experienced without feeling the pressure to solve the problem. The support group embraced her with love and in turn she was able to embrace her situation for what it was.

My relationship with Vicky is discussed. Vicky's communication pattern is described in terms of the language she used as well as my perspective of what was helpful to Vicky.

The following factors were helpful to Vicky:

- She found coming together and being with people who were in the same situation as her, as very helpful. She could talk about her son and his illness, with a comfortable feeling. No matter how she felt the group understood and did not get tired of hearing the same story over and over again.
- The group reflected Vicky's need to grieve and let her understand the bereavement is a long process. Her uniqueness in grieving was validated and

she was allowed to grieve in her own way.

- Vicky found that she could identify with members in the group. There were people who were better adjusted than she was and that gave her hope.
- Vicky found my behaviours and approaches to problems very helpful and modelled my methods of defining and solving problematic situations.

Finally, Vicky was able to use her religion to her advantage and submit to God's plan. She could now pay more attention to her other son and husband and continue with her life. When I last spoke to her she was not wearing black clothes anymore.

CHAPTER 8

DEBBIE'S STORY: I CAN HELP OTHERS

INTRODUCTION

Participant: Debbie

Age: 41 years old

Children: A daughter Nikki, 14 years old and diagnosed with Acute Myelogenous Leukemia (AML) and a 10 year old son, Sam

Participant's occupation: Housewife

Marital status: Married

Debbie was the only participant who had a "togetherness" about her, right from when she first joined the support group. She joined the group alone although her husband, George, did accompany her to our social occasions. She is big in stature but has a kind of femininity about her which made her very appealing. She and her husband and their two children (Nikki diagnosed with AML and a younger son, Sam) lived on a farm setting outside Pretoria. She could not attend every session and when she was absent Petra and I missed her as she was the one that could instil hope in the group. Nikki was in remission now and looked very beautiful with her long blond hair, back as it was before the diagnosis. Nikki accompanied Debbie most of the time, keeping herself busy by making tea for the group and helping us clean up afterwards. She was an inspiration to the other parents.

The reason why Debbie joined our support group was because she wanted to let parents, who are going through the ordeal of their child being diagnosed with cancer,

know that it is OK. One does actually cope with it and there is a life beyond the illness. Faulkner et al. (1995) suggest that the experience of childhood cancer is not all dark. For many parents there are positive aspects which help to illuminate the way forward. This is what Debbie wanted to portray to the group.

THE STORY OF NIKKI'S CANCER

During June 1995 Nikki got chicken pox and the first thing that came to Debbie's mind was "*oh good one of the childhood illnesses will be over*". But soon it became clear, this was not the case. After the chicken pox Nikki started to get a sore throat which progressed to such a stage that she could not eat. She was treated by the doctor for throat infection, then ear infection, but when she developed a fever that would not go away as well as pains in her arms and legs, Debbie took her to a pediatrician. Nikki was also losing weight and had a sore on her lip which would not go away. The pediatrician hospitalised Nikki for blood tests. Debbie felt lucky as she was allowed to stay with her daughter in hospital. The nursing staff were fabulous which made things easier.

Nevertheless when Nikki was diagnosed with Acute Myelogenous Leukemia (AML), Debbie went numb. She fell on the ground crying and sobbing. The doctor as well as the nursing staff on duty remained with her. They promised Debbie a partnership in the care of her child and that nothing would be done without negotiating with her first. This empowered Debbie which in turn led to her being able to pick herself up, tell Nikki about her diagnosis and make decisions about her treatment procedures. According to Fradd (1996) negotiation with the parent can help to diminish later misunderstandings and disappointments, thus promoting the relationship between parents and the health care team.

George was away on business at the time of the diagnosis so Debbie could not look for support from him. The nursing staff of the hospital made up for his absence though, says Debbie. When Nikki was told that she had AML, a severe form of blood cancer, she panicked. She was 11 years old at the time and could therefore understand.

Debbie said that the family figuratively split up after the diagnosis of Nikki. Debbie stayed in the hospital with Nikki and George stayed at home with Sam. One of them had to be at home looking after the interests of the child at home and one of them at the hospital. As it was far to travel back and forth to the hospital, Debbie informed George over the phone about Nikki's condition. Mott (1990) indicates that it is a common phenomenon that at the time of diagnosis parents may find they are separated from each other for the first time since the beginning of their relationship. This separation may occur because the father has to continue going to work or he has to care for any other children as was the case with George. Lansky, List, and Ritter-Sterr (1985) suggest that separation generally continues throughout the treatment process because one parent usually the mother accompanies the sick child during hospitalisation as was the case with Debbie.

Debbie was always fully informed by the doctors about Nikki's condition and treatment. By the end of July Nikki had her first chemotherapy session. Many parents in the ward offered their support but they could not take the pain of Nikki's hair falling out and her starting to look like a phantom, away. By this time Debbie could not remain in the hospital full time so she travelled there and back everyday. Some evenings she just fell asleep on the chair next to her daughter's bed and found a blanket over her in the morning. The nursing staff were very understanding. Savage, Durand, Friedrichs and Slack (1993) indicate that nursing staff are in a unique position to offer support and guidance, as they have more extended contact than any other health care professional and probably develop an extensive database of the family's values, expectations and coping styles.

Nikki kept on getting relapses and was in and out of isolation ward, the uncertainty of it all killing Debbie. She was so ill from the chemotherapy that her doctor had to stop treatment for a while. In September the doctor started the chemotherapy again and towards the end of October she was allowed home for the weekend after three months. All her friends came over to see her. They were of course prepared emotionally by their parents not to expect to see the "old" Nikki, but even so, her appearance shocked them. This supports Pinkerton et al. (1994) who state that friends and siblings of the

ill child are bewildered in the beginning. They need time to adjust to the multiple changes brought about by the treatment of cancer.

On Monday morning Debbie took Nikki back to the hospital to be examined. The doctor said she could go home and come back every two weeks for blood counts and chemotherapy. Debbie was delighted and so was Nikki. This continued for a year. After a year a bone marrow test was done and Nikki was now in remission. Till today she has not been to hospital for anything. She is back at school and continuing with a modelling course she started before the illness. Her long blond hair is back and her blue eyes are sparkling again. Debbie is very thankful and would like to be a safety net for parents who are going through it all now.

The context of Debbie's story will now be discussed in terms of emerging themes.

EMERGING THEMES

UNCERTAINTY VS CERTAINTY

For Debbie the uncertainty began when her child got one of the childhood illnesses. It was only chicken pox so she thought "*oh good one of the childhood illnesses will be over*", but when her daughter started getting a sore throat and could not eat she began to worry. The doctor treated her for throat infection but a week later the fever was still there upon which the doctor diagnosed ear infection and prescribed the usual antibiotics. After her child developed leg pains Debbie became very uncertain and took her back to the doctor. By this time she had developed a sore on her mouth and she continued losing weight because she could not eat. The doctor diagnosed a viral infection and when the antibiotics did nothing this time Debbie took her daughter to a pediatrician. She started to feel very apprehensive and uncertain when the pediatrician asked her many questions. After his examination he said that her daughter definitely had a problem in her blood upon which he hospitalised her for more tests. The uncertainty of all the symptoms all made sense when Debbie's daughter was diagnosed with cancer. This was a certainty. Her child had cancer, no one could change that.

The shock was really too much as she says *"when the tests confirmed the diagnosis of cancer I hit a blank"*.

Before Debbie and her husband could accommodate the diagnosis of leukemia more tests on their daughter confirmed that she had AML which is a severe form of leukemia. Once again the uncertainty started. What would the treatment entail and how long would it last. Would it help to go through with all this pain? How would they handle the side effects? Debbie describes it as follows: *"By the end of July she started her first treatment. For three months I drove everyday there and back. The hospital was my second home. Every evening I used to open the Bible, which I carried with me, and read her a piece trying to answer her questions that way"*.

Further certainties were that Debbie's child's hair began to fall off. She was ill from the treatment and Debbie and her husband were plunged into uncertainty once more because the chemotherapy had to be stopped. Debbie says her daughter *"looked terrible with catheters and a nasal tube for feeding because she could not eat"*. Going in and out of isolation ward was another reason to make Debbie and her husband uncertain about the situation. She describes it as follows: *"One day when we arrived at the hospital she was out of isolation ward. We were so pleased, but the next day she was back in isolation because the fever came back. The uncertainty of it all was killing"*.

The theme of certainty vs uncertainty is something that prevails throughout Debbie's story. Not knowing what was wrong with her daughter at first, then once they were certain it was cancer, the uncertainty of the treatment was killing. Then when her daughter was allowed to come home for the first time it was wonderful, but the uncertainty of when or whether she would come home after this was worrying Debbie and her husband as she says: *"She completed the chemotherapy towards the end of October and they let her home for one day after three months. It was a Sunday and everyone was very excited including our daughter as she could be outdoors after such a long time in hospital. She asked so many questions on the way home about everything she missed. It was terrible having to take her back to hospital on Monday"*

morning again because now we did not know when we would bring her home again”.

After her daughter was released from hospital the uncertainty continued as they had to take her for blood tests and chemotherapy every second week for a year. Debbie says *“waiting for the results was horrifying”*. After a year of chemotherapy Debbie took her daughter for a bone marrow to see if she was in remission. She describes it as follows: *“A whole lot of what if’s went through my mind. Luckily when the doctor phoned us he said she is in remission. We were so happy we phoned everybody to tell them the good news. Till today she has not been back to hospital for fever or anything else but the uncertainty of it coming back is still within me and my husband”*.

Debbie seems to be content for now but this contentment is not certain as the uncertainty of this monster coming back is there. But her belief in God helps her to cope with it all.

CONTROL VS LOSS OF CONTROL

While reading through this story I got the feeling that Debbie did not lose control of her emotions at any time during the ordeal of her child been diagnosed with cancer. Yes she did go through the normal emotions of fear as she says *“I started to shake because I felt something was not right. As he (the doctor) sat in his chair my heart started palpating”*. Once the diagnosis was upon her she was shocked as she says *“I felt as though my legs became numb”*. Then the fear and shock turned to grief as she says *“I was crying and my daughter kept on asking me what was wrong and I could not tell her”*. But through it all it felt to me like she contained herself and tried to do what was right. She did not feel any compulsion to suddenly run to gather information to control the disease. She was not angry blaming the medical staff for anything although she did pick up problems in the ward. As she says she *“tried to be strong and hopeful”*. She went through the illness of her child feeling everything and not denying any emotion. Perhaps the fact that she had support helped but I feel that Debbie as a parent remained focussed and concentrated on doing what was right in terms of treatment and thereby not losing control of her emotions. She and her husband tried

to control what they could as she describes: *“One of us had to be in hospital and one at home. I stayed at the hospital and he (her husband) did not visit often because he had to look after our other child and go to work and look after the house. Our life was a mess but we tried to stay in control”*.

Telling her child that she had cancer was very difficult for Debbie as it will be for any parent. She was alone in the hospital but luckily the doctor proved to be very compassionate which gave her more strength to control her emotions as she says: *“This doctor was exceptional because he asked me if I wanted him to tell her (the child) what was wrong. I said yes but I wanted to be there too. He went up to my daughter in hospital and told her in a very compassionate way. This made all the difference to me. Although my child cried and said she did not want to die, I felt I would be able to help her through it. It was a nightmare but somehow I felt in control of myself”*.

While reading this story it felt to me as though Debbie achieved a breakthrough with dealing with the diagnosis of cancer in her child. She was the only parent who did not seem to be in a panic about the disease. As I said earlier, she did go through all the emotions, but somehow I got the feeling she contained herself well. Mentally and physically she was in control. It was as though Debbie connected with the input and committed herself to going through the situation so instead of fighting it I feel she rather embarked on a journey of finding out what this was all about.

ISOLATION VS SUPPORT

Throughout her story I did not get the feeling that Debbie's life was ground to a virtual halt. It was different to all the other stories. There was a kind of warmth in this story, one of support and not isolation. The most positive and encouraging aspect of support was her good relationship and perseverance, when necessary, with the health care professionals. Debbie's first form of support came from the specialist treating her child when he suggested that he will break the news to her daughter. He further suggested that Debbie should stand by her daughter's bedside when this happens. Although her husband could not give her all the personal support she might have wanted, he did

support her in a different way as she says: *"When my husband came back he supported me but one of us had to be in the hospital and one at home. I stayed at the hospital and he did not visit often because he had to look after our other child and go to work and look after the house"*.

Her other form of support was her family and friends. She describes it as follows: *"Our family and friends were supportive, telling us not to worry as they know of a child who had leukemia when she was 5 years old and now she is thirty and married and fine. This was a ray of hope to us"*. She continues to say that *"many parents in the ward came to offer their compassion and support but the pain remains"*.

Debbie's final form of support was her coherent belief system. Her faith in God helped maintain perspective and also helped her guide her child through this illness. She describes it as follows: *"Every evening I used to open the Bible, which I carried with me, and read her a piece trying to answer her questions that way"*. She ends off by saying *"it was a difficult time for our family but today we are down on our knees saying thank you to God for giving our daughter back to us"*.

Her other form of support was of course the fact that she joined this support group and had been given the opportunity to tell her story to everyone who wanted to listen.

HOW DEBBIE TRIED TO COPE

According to Faulkner et al. (1995) both the individual history of the diagnosis as well as the circumstances in which parents are told the diagnosis, influences their adjustment. Although Debbie felt the emotions of shock, helplessness, confusion, questioning, blame and anger after the diagnosis of her daughter with cancer, there were five mechanisms she used to cope with it: obtaining information, sharing the care of her daughter with the nursing staff, the sense that doctors were *doing* something about the illness, and seeing her child respond to the treatment despite the traumas of the treatment itself, making use of complementary therapy, and her belief in God.

When Nikki was hospitalised and diagnosed with AML, Debbie was reassured by the

general feeling of the specialist centre her daughter was in, that she had reached a milestone where she would be given reliable information and some hope for the future. Faulkner et al. (1995) suggest that major factors which help adjustment are the provision of information and the way the information is given. Debbie felt better when the doctor explained to her the type of cancer her daughter had, and what its causes were. Through these explanations she gained a general understanding of the disease and its implications in terms of treatment and prognosis. She felt better by simply knowing that there was a treatment for this illness and there was a chance of recovery. The facts of the cancer were also given to Debbie in a direct, professional and sensitive manner which helped to build up a relationship of confidence and trust.

Being given time and space to absorb all the information and being treated as an individual also helped Debbie to cope. At first she was in a state of shock and could not take any of the information in, so she was given a booklet to read about the disease in her own time. Stewart (1994) proposes that information helps to demystify the illness which in turn helps the parent through chaos to find the way ahead. As they learn more about the details of the illness and its treatment feelings of anger and guilt lessen and parents start to look at ways of restructuring family life to accommodate the disease and treatment, suggest Pinkerton et al., (1994). This is what Debbie did. She reshaped her family's lifestyle to fit in with the diagnosis and treatment, which was very different from that before the diagnosis. It was now more centred on the ill child and less concerned with future planning. This fits in with research done by Ekert (1989) who said that concentrating on one thing at a time gives parents some form of control.

Dearmun (1992) found that it is important to make parents feel that they are equal partners in the planning and decision making process of the sick child. Debbie had a need to "*parent*" her child not only at home but in public too, so the fact that the ward staff were prepared to negotiate their philosophy of caring with that of Debbie's assisted in coping with the hospitalisation and treatment of Nikki.

This fits in with Darbyshire's (1994) findings that sharing the care of the child lessens the parent's uncertainty and confusion. Debbie felt valued in the ward and could

choose her level of participation. Debbie in turn allowed the nursing staff and doctors to take a bigger role around goal setting and problem solving when it came to treatment procedures. Smith (1995) suggests that as negotiated care is a two way process between the nurse and the parent, this must be based on a relationship of trust and respect, where both parties are equally valued.

The third aspect that helped Debbie cope was the sense that the doctors were consistently doing something about Nikki's condition. As Debbie says: *"After the first course of chemotherapy Nikki was very ill, so the doctor immediately did a bone marrow test which showed she was not in remission yet. She looked terrible with a catheter and nasal tube for feeding because she could not eat, but at least I knew these things had to be there for her to eat and wee. When her fever came back and her liver started to enlarge she was taken to isolation ward immediately and after many blood cultures the germ was picked up and put under control. The sense that the ward staff and doctors acted immediately gave me a sense of relief"*. Carter and Dearmun (1995) state that a child with cancer requires pro active care from doctors and nursing staff as when a parent sees something done about his/her child's condition they feel relieved and alleviated from the feeling that they should now do something.

Debbie had the philosophy that a parent needs to look after him/herself before he/she can really be of help to his/her child. Once Nikki was discharged from hospital and Debbie had a little more time she and Nikki used aromatherapy as a therapeutic technique. Aromatherapy is the therapeutic use of concentrated essential oils. These oils are usually taken from medicinal or aromatic plants and are generally applied externally by massaging them into the skin. According to Arkko, Arkko, and Kari-Koskinen (1980) aromatherapy, as a complementary therapy, has been used and found to bring about relaxation, calmness and general comfort when facing a stressful situation such as cancer. Debbie and Nikki found this complementary therapy to enhance their general health.

Finally Debbie's faith in God was also tested during Nikki's illness. Initially Debbie felt that childhood cancer is unfair and that it does not fit in a just and orderly world created

by a just and orderly God. But her faith was not broken by the diagnosis and this helped Debbie to cope in the dark, early hours of many mornings. Edelstyn (1974, p.157) notes, "frequently religious faith is tested, if not broken by the diagnosis".

THE CONTRIBUTION OF THE SUPPORT GROUP

Introduction

Debbie joined the support group with the idea of working together with me and Petra to share her story with the group and perhaps thereby help them to overcome negative behaviours and make positive changes in their lives. She wanted to share her views and beliefs with the group. Debbie had a firm belief that one must exert effort to establish new patterns of behaviour. She used the following metaphor, which the group found very appealing, to illustrate what she learnt from her journey through Nikki's illness.

"Odysseus was a traveller, as Homer chronicled in his ancient classic, The Odyssey. He constantly ran up against disasters and villainous monsters, but always overcame the odds. Odysseus thought up one of his cleverest ruses as his ship was nearing Circe, the bewitching siren of the rocks. If he or his sailors heard Circe's song, they would become hypnotised and crash against the rocks in a horrible death. Rather than pray to the gods or tell his sailors to use self control, Odysseus simply filled their ears with beeswax, effectively stopping them from hearing the siren's call."

This story is used as a metaphor to illustrate the following according to Debbie: *"Don't always try to use self control if you know its not going to work. Instead, figure out a way to circumvent the problem."*

Beresford (1993) indicates that children with cancer and their families are likely to be under tremendous stress and one should never underestimate the various mechanisms or strategies that may be employed to reduce the impact of this. He goes on to say that stressors usually produce behavioural-focussed responses and

emotional-focussed responses and that events experienced by two different people may produce very different responses. Debbie did go through the emotions of uncertainty, loss of control, isolation and despair but her behavioural-focussed responses of conviction, determination and effort not to allow Nikki's illness to get her down helped on a personal level. She now wanted to share this with other members of the community going down the same road and thus joined the support group.

My relationship with Debbie

Debbie was like a breath of fresh air in the group. Her alternative way of thinking was very appealing to me and I encouraged her participation as well as her input. I supported her philosophy that childhood cancer is a crisis so urgent that people need to join forces and respond to the crisis. As she sadly says: *"Unfortunately, often we don't have that sense of urgency"*.

Debbie had this strong sense of enthusiasm to bring about a change in the group's thinking which I could identify with. I could also identify with her discussions of the preciousness of human existence and this generated a sense of confidence and enthusiasm within the group.

Debbie's initiatives led to many members in the group wanting to imitate her coping methods. Bandura and Walters (1963) suggest that the importance of imitative behaviour in the therapeutic process should not be underestimated. They go on to say that by observing the therapy of another patient with a similar problem constellation - a phenomenon generally referred to as vicarious or spectator healing occurs. This fits in well with my observations of the group members after every session where Debbie was present. She helped to unfreeze certain individuals enough to experiment with her suggestions. Many members in the group tried bits and pieces of Debbie's advice and relinquished what did not work for them later.

I encouraged Debbie's way of relating to the group. Bandura (1977) theorises that almost all important learning takes place through the social-modelling modality. He

continues to say that social modelling or imitation is directed towards positive behavioural change and of little or no risk to clients.

Now let us look at how Debbie communicated with the group.

Debbie's communication pattern

Debbie's story is different to the rest of the group members as it is a description of a positive approach to the diagnosis of her child with cancer. Chesler and Barbarin (1987) suggest that when one has a positive approach, it is almost as if that offers the freedom and opportunity to attract support from others and to do what one deems is important at the time. In her communication with the group Debbie used many positive assertions, her aim being to overcome the kind of apathy that the group had at the time and to generate commitment and enthusiasm, to overcome negative behaviours or states of mind. She made the group constantly aware of the destructive effects of negative behaviour and if a parent does not look after his/herself he/she cannot ultimately be there for his/her ill child. She says: *"There is a considerable capacity for overcoming the disease, if that capacity can be stimulated into activity."*

Debbie communicated thankfulness to the medical staff who valued what she did at the time of Nikki's hospitalisation. *"We say thank you to all the medical staff for supporting us and encouraging us all the way. Very often the nurses looking after my child would say that I am a good mom staying with my daughter in hospital. The doctors also encouraged me to keep on being strong for the child"*. What empowered Debbie was the fact that the medical staff looking after Nikki allowed Debbie to assert control over many factors which affected her life. Stewart (1994, p. 248) says that *"empowerment is about giving control and choice; about participation and consultation. It requires having information to work on and the ability to respond"*. Within the context of her ill child, Debbie was allowed some of the control which is usually relinquished when a sick child is taken to hospital. Debbie's style of communication empowered the group. I learnt a lot from Debbie too. I am listing a number of assertions which depict her style of communication.

1. *"Oh good one of the childhood illnesses will be over."*
2. *"I was lucky enough because they allowed me to stay with my child in hospital."*
3. *"The doctor was really exceptional because he asked me if I wanted him to tell her what was wrong."*
4. *"I picked up problems in the ward but I insisted on staying there with my child."*
5. *"Friends and family were supportive...."*
6. *"I tried to be strong and helpful."*
7. *"Every evening I used to open the Bible..... and read her a piece trying to answer her questions that way."*
8. *"...doctor phoned us....he said she is in remission...we were so happy we phoned everybody to tell them the good news."*
9. *"She has not been back to hospital for fever or anything else."*
10. *"It was a difficult timewe are down on our knees saying thank you to God for giving our daughter back to us."*
11. *"We would like to say thank you to the medical team treating our child."*

Debbie rarely made negative assertions. She talked about the medical staff (2), (3) in a positive manner, tolerating any difficulties from them (4). Debbie's statements about others such as family (5) were non judgemental. The list of assertions generates a governing assumption "it was OK". She creates a sense of efficacy within the hospital environment and herself, with her good will and her connecting to others. She

connected with the medical staff and they with her rather than separating and isolating herself (10).

What was helpful to Debbie

Debbie's concern once her child was in remission was the following as she says: "*All this suffering cannot go to waste. I have to share it*". Debbie felt she had discovered another angle to the question "*Why my child?*" or "*I shouldn't be experiencing this.*" One should accept it, tolerate it and go with it instead of fighting it. "*It is like a bad night,*" she says, "*which seems eternal, but it does end*". The support group gave Debbie a platform from which she could share her "findings" of this experience. She found this very helpful. Klapman (1950) indicates that within support groups there is also an implicit educational process. Some group members can impart valuable information which can form part of the therapeutic process, as Debbie did. She used one session during which she gave the group a lecture on aromatherapy and other alternative therapies. She also used a session to do relaxation with the group which they enjoyed thoroughly. Lieberman (1975) called what Debbie did psycho-education and believed in the importance of lectures during group therapy, both for the members giving the lecture, as well as for the members receiving the lecture.

The other helpful aspect for Debbie was that the group members validated and confirmed what she said. They found her inspirational, enthusiastic and wanted to mimic her behaviours. Murray (1995) suggests that there is often a need to have one's own beliefs and interpretations of situations confirmed as being appropriate. He calls it appraisal support. Debbie's story gave the group members a chance to retrospectively examine their experience and perhaps see it from another angle. Yalom (1995) suggests that in group therapy it is important to examine the members' misconceptions and self-defeating responses to the illness, and that is what Debbie did.

The support group sessions and the exchange of information that took place there was very different to Debbie's everyday life. "*Being in intimate conversation with the group was so effortless,*" she said. "*...very different to my conversations with my husband and*

other members of my family". This Debbie found very refreshing and relaxing. For the first time people confirmed what she said and found value in her beliefs. Harding (1996) indicates that very often in support groups a state of effortless effort is achieved where there is not too much planning or thinking. It is only the being and doing that matters. This is exactly what Debbie found very therapeutic in our group.

CONCLUSION

When Debbie joined the support group there was a desire to deepen her connection with others. She needed her suffering to be appreciated. This was the only way she could find meaning in her pain. The support group provided an arena for her where she could share what she found had worked for her, with others in a similar situation and in that way be of help. Powell (1975) indicates that parents in a support group may serve as a reference for one another or as points of comparison for defining or understanding appropriate behaviour in a new situation.

In my relationship with Debbie I tried to give her as much freedom as possible to talk and to guide. I mainly functioned as a consultant and facilitator in the change process Debbie brought about in the group. Gilliland, James and Bowman (1989) point out that when a therapist acts as a consultant or facilitator in a group process it creates an atmosphere which is conducive to learning, relearning or unlearning specific ways of behaviour by the group members at their own pace. This can be very therapeutic.

In summary the following themes emerged from Debbie's story:

- The theme of uncertainty versus certainty
- The theme of control versus loss of control
- The theme of isolation versus support

Debbie's coping mechanisms were to:

- gather information in order to be able to interpret the significance of the

diagnosis and to manage other practical problems

- share the care of her daughter with the nursing staff
- have the assurance that doctors were *doing* something about the illness and seeing her child respond to the treatment despite the traumas of the treatment itself
- make use of complementary therapy
- believe in God.

The contribution of the support group is discussed in terms of the following factor:

- The group gave Debbie a platform from which she could share her story, her views and beliefs

My relationship with Debbie is discussed. Debbie's communication pattern is described in terms of the language she used as well as my perspective of what was helpful to her.

The following factors were helpful to Debbie:

- The group members validated and confirmed Debbie's beliefs and this made her feel wanted and useful
- The support group contributed towards Debbie's feeling that her suffering did not go to waste
- Doing things within the group without planning too much was very therapeutic to Debbie
- My support as advisor and facilitator gave Debbie the safety to be herself in the group and to trust her behaviours

Debbie had a very profound influence on the group. She actually trained the group to make a steady effort to bring about positive changes in their lives. In turn the warmth and support she received from the group made her feel that there was meaning behind her suffering. This very thought freed her mind.

CHAPTER 9

MARIUS AND MARY'S STORY: A PATH TO RECOVERY

INTRODUCTION

Participants: Marius and Mary, a married couple

Age: Marius (35 years old) and Mary (32 years old)

Children: Three sons, Garry 10 years old, James, 8 years old and diagnosed with Acute Lymphoblastic Leukemia and Andy, 6 years old.

Participants' occupation: Marius is a management consultant in an Information Technology (IT) company and Mary is a primary school teacher

Marius and Mary are one of the two married couples in the group. They are both trendy looking, Marius a dark-haired Mediterranean man and Mary a fiery red-head bubbling with enthusiasm and ideas, and also the youngest members in the group. They live in a beautiful house in one of the up market suburbs in Pretoria and have volunteered their home for many of the group's fun activities. They were always present together, in every group session. Their three sons accompanied them to the group sessions, keeping themselves busy in the park across the road. James was in remission now, a very vibrant and intelligent little boy keeping all the children busy in the park while we had our group session.

Marius is not a big man in stature. He comes across as a very practical, strongly charactered and logical person. He also impressed me as a solid, forthright man. Mary has a friendly disposition, seems down to earth, open and very fashion conscious. She

brought colour to the group, both literally with her clothing and figuratively with her character. Marius seemed a little reserved and guarded.

Marius and Mary joined the support group for two reasons. Firstly they felt that, having been through the whole experience and also having visited cancer centres overseas they could make a difference by offering support to others going through the same ordeal and secondly they felt that the stress of James' cancer was causing a deterioration in their marriage and they wanted to prevent this. Their marriage was showing signs of distress after this adverse life event as Marius says: "*We were very close at the time of the diagnosis and treatment but now I feel I want to run away when Mary starts to whine about what will happen with James in the future. I feel we will tackle the future when we get there. I try to bring in some humour at times to break the depression but it does not always help.*" According to Kaplan, Smith, Grobstein & Fischmen (1973), high rates of marital breakup are reported following childhood cancer. Studies by Dalquist et al. (1996) have found that the death or serious illness of a child in the family may lead to marital problems and divorce. Marius and Mary wanted to prevent this by joining a support group instead of withdrawing in their own private suffering.

THE STORY OF JAMES' CANCER

Marius and Mary had a very stable and wonderful life together with their three sons Garry, James and Andy. "*James was one of those joyful bundles that had an enormous zest for life*", says Mary. He and his elder brother, Garry, were great friends and always on the go. During the December holidays of 1993 James started waking up in the middle of the night with leg pains. Marius and Mary thought they were growing pains but when they persisted they took James to a doctor. He suggested blood tests, so on their return from vacation they went to the pediatrician for blood tests. After the blood tests the doctor called Mary and told her to come to his consulting rooms together with her husband. Mary knew something was terribly wrong but she never expected cancer.

In January 1994 James was diagnosed with Acute Lymphoblastic Leukemia (ALL) which is a type of blood cancer. He was 3½ years old at the time. James had to go for a bone marrow aspiration to confirm the diagnosis. Marius and Mary were shattered. James of course could not understand what was going on so Mary explained his condition to him in terms of metaphors. She told him that there were bad little men in his blood that had to be killed with medication given by the doctor. James was an autonomous little boy but after the diagnosis he started regressing and, according to Mary, saw all the medical procedures as a punishment because he always wanted to do his own thing. In order to prevent James from regressing further Marius and Mary tried to reassure him with love and support to help keep his fear in control. Whaley and Wong (1991) suggest that the diagnosis of cancer which the toddler has no perception of can interfere with his development. Their search for autonomy is hampered by the painful procedures. Pinkerton et al. (1994) propose that this may result in regression in their behaviour, as it did with James, and affect their development of trust. Haley (1978) indicates that their autonomy can be encouraged by giving the child choices within reason.

After the diagnosis was confirmed James was hospitalised for 28 days to undergo chemotherapy. Suddenly James was not the carefree, joyful little boy Marius and Mary knew. His smiles disappeared and his face mirrored anxiety, pain, aggression and questions. Hayes (1988) suggests that children between three and five years old may react with anger and aggression at the disruption to their lives caused by the diagnosis of cancer and lack of understanding. They may see cancer as something bad that they have caused to happen and that they are being punished for it by treatment and restriction on their activities. This is exactly how James felt. Every time he had to go for chemotherapy he screamed for help from his parents and they could do nothing. Mary still remembers those screams. She says very often when she hears a child scream in a supermarket she leaves her shopping trolley on the spot and walks out. It is as though she can hear James scream all over again. She never thought that those screams would have such a far reaching effect on her. Culling (1988) states that the occurrence of childhood cancer within the family is a major and highly stressful event and it can have far-reaching effects on everyone involved with the sick child,

especially the parents, and therefore should be treated as a family disease.

James' hair started falling off in big chunks after the third week of treatment. Marius and Mary tried not to make a big thing out of this. *"We warned him in good time that it would happen and we just carried on as if it's the most normal thing in the world to lose your hair"*, says Mary with tears in her eyes. Fortunately James responded well to the chemotherapy and was discharged from hospital. He had to go in once a week for treatment after that.

Marius and Mary had to be strong not only for James but for Garry and Andy too. They were told in good time what happened to James and what he would look like when he came home. Mary says her elder son, Garry, has developed such empathy for his brother and an increased ability to help his parents when needed with James. It is recognised that the serious illness of a child can cause negative outcomes for the healthy siblings, such as increased anxiety, feelings of isolation and behavioural changes. However, Ross-Alaolmolki, Heinzer, Howard and Marszal, (1995) indicate that sometimes positive outcomes result such as the development of an increased ability to cope with stressful situations, improved sibling relations and empathy for others. This is exactly what Garry displayed.

Mary and Marius said that they tackled one day at a time. They tried not to think too far ahead. After thirty months the treatment stopped. They were jubilant. The joy soon subsided when Mary saw that her son's behaviour was very different from before. Aggression, depression and anxiety were some of the emotions that got out of hand. James felt different and acted differently towards his friends and family. Marius and Mary took him for psychotherapy. Cincotta (1993) indicates that the cessation of treatment would appear to be a positive event and one to look forward to, however, it is becoming obvious that it is not always the case. In fact, this event can often lead to a crisis where families may need help from other professionals in order to facilitate coping.

Marius and Mary are over the worst now but they will never be the same again. They

are trying to be optimistic about the future but the uncertainty of the illness coming back is always at the back of their minds.

Mary calls their journey “a path to recovery” because that is what it is for her. *“A path full of obstacles, uphill and twists but luckily, with God’s help, also even and straight with good prospects in the horizon”.*

The context of Marius and Mary’s story will now be discussed in terms of emerging themes.

EMERGING THEMES

STABILITY VS CHANGE

Marius and Mary directed their efforts mainly at talking about how the diagnosis of their son with ALL changed their family life forever. It shattered them. Mary starts off by describing the illness of her son as *“a path to recovery”*. It is a path which changed her life but instead of seeing it only as *“a path full of obstacles, uphill and twists”* she shifted perspective to see it also as a path *“with good prospects in the horizon”*.

Mary describes her family life as stable and her son as *“one of those joyful bundles that had an enormous zest for life. He and his brother who was 13 months older than him were great friends and were always on the go”*. When he developed leg pains during the December holidays of 1993 Mary and Marius thought they were growing pains but when they persisted even through the night they took him to their doctor. Their doctor referred them to a specialist who suggested their son goes for blood tests. Mary describes it as follows: *“For a child of three and a half the drawing of blood is very traumatic. At that stage little did we know of all the injections, lumber punctures, blood tests and painful bone marrow aspirations which were to follow and our son still needed to go through”*. To me it was almost as though Mary was amazed at how she and Marius actually coped with all this. She goes on further: *“After the blood tests our doctor called me and my husband in. When he said my husband should come too we*

knew something was terribly wrong but NEVER did we anticipate CANCER”.

The emotional reaction to hearing the diagnosis of cancer was certainly tremendous. Even now with her son in remission, when Mary talks about the diagnosis it is as if it happened yesterday. Her whole non verbal behaviour is one of alertness. She indicates with her hands the enormity of the word CANCER. It was as if she and her husband suffered a physical blow. They say: *“We were hit between the eyes by this big word CANCER”.* When they were both called in by the doctor they suspected something bad and thought they were prepared but when they actually heard the diagnosis they had a surreal feeling. Mary and Marius say the following: *“For a full four days it felt as though we were floating in another planet”.* Despite this feeling they had to mobilise their emotional forces to help their child, and this they did together. They took their son for a bone marrow aspiration to confirm the diagnosis. Once again as soon as they thought they were over the first blow this second blow was even worse. Mary describes it as follows: *“it is quite impossible to describe how you as a parent feels to hear your child scream while four nurses hold him down and pierce a thick needle into his little hip AND THERE IS NOTHING YOU AS A PARENT CAN DO. We were not even allowed inside. Only God knows how shattered we as parents felt inside”.*

Once the diagnosis was confirmed it became a family illness, no one was unaffected. For them and James *“the nightmare had just begun”.* They did not know what lay ahead and the normal patterns of their life would not be the same. Also the young age of their son (three and a half years old) affected Mary's level of stress and anxiety. According to Copeland et al. (1983) children younger than four years old engender the most parental stress. Mary says, *“our son did not know what was going on”.* He was vulnerable and still in need of constant protection and Mary felt even more helpless to watch her baby suffer without been able to do anything for the pain, or explain what was happening or tell him when it would be over. All she could do was to explain to him in baby language about *“bad little men in his blood that had to be killed with medication”.*

The diagnosis of her son changed her family's life forever, as she says at the end of her story *"we will never be the same again"*. Once a parent is told the life of their child might be taken, this threat changes their life and priorities forever proposes Culling (1988).

CONTROL VS LOSS OF CONTROL

Once the diagnosis is confirmed treatment begins immediately. Once her child was hospitalised Mary felt a total loss of control. Her son's personality changed and she could do nothing about that. She says, *"suddenly our son was not the carefree, joyful little boy we knew. His smiles disappeared and his face mirrored anxiety and pain"*. Treatment is a time of enormous physical and emotional stress for the parent indicate Faulkner et al. (1995) and for Mary and Marius the emotional stress was worse. They felt totally useless and helpless as parents because they could do nothing to make the situation better for their son. Mary lost control over her emotions, her son's condition and her responsibilities for the rest of her family. She says: *"Every time he had to undergo chemotherapy he screamed for help from us and we as parents could do nothing. I can still remember those screams. In fact for three years after that I could not even handle a baby crying in a supermarket. It shattered me because it was as though I was hearing my child scream all over again"*.

The side effects of the treatment also made Mary feel she could do nothing to protect her son. James' hair starting falling off the third week of treatment and Mary and Marius tried to protect their son from this pain by not making a big deal out of it. She says the following: *"We warned him in good time that it would happen (that he would lose his hair as a side effect of treatment) and we just carried on as if it's the most normal thing in the world to lose your hair"*. The pain in her voice when she said this, made the whole group tearful. Her control over what was normal and not normal was lost. The only thing that mattered was to help her son. She and her husband could only try and control their real feelings about this illness and pretend in front of James that they were in control. She describes it as follows: *"When we were in front of him we suppressed our tears but we both cried in the bath or in bed at night. We tried not to*

think too far ahead and tackle each obstacle as it came and each day at a time". This was the only way to control the chaos of the cancer.

Mary felt she had really lost control over their son. *"He was traumatised" as she says and his "aggression, depression and anxiety got out of hand". She realised that James "was different and also acted differently. For eight months after he was discharged from hospital he did not smile or laugh. He just ran around in circles. Is there anything that can be worse for a parent?"* So she and Marius decided to take control of this by taking him for psychotherapy.

INFORMATION VERSUS IGNORANCE

The theme that Marius spent a lot of time talking on was information. He felt that there is no effective communication between the health care professionals and the parents. He feels the parents should be more involved in the decisions that are taken for their child. *"One is intimidated by the amount of new information that one has to absorb quickly without any explanations. A parent is in shock and stressed out, now you still have to keep your head together to make sense of big words".* It is natural not to understand medical procedures and terms the first time round suggests Monarch (1990) and what Marius is perhaps suggesting is that medical professionals should take the time to inform parents of what is happening.

ADVICE VERSUS BEING LEFT IN THE DARK

The next theme which Marius mentioned is this of advice. *"Often what happens is that there is a power struggle over who knows the child better and who has the ultimate control over his/her welfare. Parents often feel they know better but this is not always the case. That is why parents have to be very careful not to give advice to other parents when it comes to treatment and medical procedures. There your doctor knows best. What parents need is a booklet or a telephone service giving them advice on practical issues, what one would perhaps call informal help. How would a parent for example phone up his/her friends and tell them our child has a life threatening illness.*

A parent needs to tell his story but who really listens? This why telling our stories here in the support group has really helped to an extent”.

As Marius was describing his dilemma and possible alternatives to move towards an understanding of this disease I realised that when a child has cancer it is not the same as telling someone your child has mumps. What Marius was expressing here according to Gallo et al. (1991) is that there is still a kind of stigma attached to cancer and it is never easy to predict how people will react to the news of cancer in the family. This uncertainty creates anxiety within a parent states Mott (1990). *“Many people treat the disease like leprosy. They think it’s contagious and shun your child. This hurts like crazy”.* For the first time I saw tears in this father’s eyes. We could all hear the pain in his voice. *“I will always support anybody who is ill after my experience with my son’s illness. That is when you need others”.*

I noticed a kind of anger in this otherwise sophisticated man. He was successful in his work and at home. The illness threw him off balance and perhaps made him feel weak because the role of the father is to protect the child at all costs. *“I slept with my child in the ward making sure the nurses treated him properly”.* As a traditional father he focussed, in the beginning, on practical issues perhaps feeling that if he channelled his nameless fears onto practical tasks it would reduce the amount of stress and anxiety. But his emotions soon became evident. *“It rained with tears the day I heard my son was ill with cancer. I still cry in church every time we sing. I also cry in the shower”.*

THE THEME OF FUNDRAISING

Fundraising is the next important theme on which Marius concentrated. *“Fundraising is the principle of asking, asking again and asking for more. You have to repeat, repeat, repeat your requests in different ways”.* The repetition of the words emphasises the importance of perseverance in finding money to build new structures for children with cancer.

SURVIVAL VS CAPITULATION

The survival of the parents and the success of the cancer treatment can be measured as much by the way the child re-enters normal life as by the results of blood tests and biopsies state Eiser et al. (1994). They explain that this is because cancer is as much a life altering disease as it is a malignant proliferation of a group of cells. Although Mary thought they would never survive this ordeal nor the long haul afterwards, they did. Survival is a process rather than a phenomenon in itself and this is what Mary and Marius mean when they call it "*a path to recovery*". Mary does not feel she and her family have recovered nor will they ever be the same again but she says "*today I can thank God my son is himself again. A loving, bubbly child full of energy and zest for life*". The drawing he drew for her at the time of the interview was testimony to what she said. He drew a boy (himself) on a skateboard.

Mary ascribes her and her husband's survival to their coherent belief in God. She says the uncertainty of a relapse is always at the back of their minds and they are always alert about it but they feel God has a plan for James. Her son's newfound strength made Mary and Marius feel that God did not forsake them. Their thankfulness and sincerity is evident when at the end of their story they look up and say "*thank you Jesus for touching our child*".

HOW MARIUS AND MARY TRIED TO COPE

Marius and Mary were torn between the needs of their sick child and those of their other children. They also had to hold down their jobs and maintain their regular lives. Mary said that it was difficult focussing on anything but the cancer. Their goal was therefore to attend to their sick child while maintaining other aspects of their life. Marius and Mary coped by developing the following coping patterns: being active and assertive, having an open family communication, dividing the roles between them, depending on their strengths and weaknesses, and using a coherent belief system.

Marius and Mary tried to be actively involved in all the aspects of James' illness.

Marius tried to solve practical problems by implementing specific courses of action to deal with the specific stressors. For example he increased his working hours to raise money to meet the medical expenses of his son. Marius and Mary rearranged schedules to be with James in the hospital. Marius says he had the mind set that *"I am stronger than whatever the problem is."* Marius and Mary learnt all they could about James' diagnosis and treatment. They kept a journal of medications and schedules. They made a list of all the questions they wanted to ask the staff each day. Franz (1983) suggests that keeping a log or journal of each day's events is a valuable record which could be useful later. Marius says that becoming actively involved in solving problems helped him and his wife to adapt to stress. This fits in well with Adams and Deveau (1984, p. 77) who say: *"Active involvement in the treatment of the child can help you adapt to the illness....When you are involved and busy you have less time to worry and you will gradually become conditioned to the impact of the illness."* Sloper (1996) proposes that enabling the parents to take an active role in the care of their child helps parents develop their mastery skills and reduces their sense of loss of control.

Marius and Mary said that one of the major contributions to them surviving this illness of James was the open pattern of communication they had as a family. They could talk to each other about their fears and feelings and gained strength by facing difficulties together. Kahn (1990) indicates that unclear communications are believed to be a major contributor of poor family functioning. Findings from research that has examined the adaptation of families to chronic and long-term illness have consistently demonstrated that a central factor in healthy family functioning is the presence of open, honest and clear communication in dealing with stressful health related issues (Spinetta & Deasy-Spinetta, 1981; Kahn,1990). Marius said that the open communication between him and Mary, as well as the health care professionals, helped them adapt to the reality of the situation. *"In order to be able to actively find solutions you need to know exactly what the problem is,"* says Marius, *"you do not have energy to deal with walls of silence."* Brett and Davies (1988) suggest that parents must be convinced of the value of open communication and be made aware of how to use it. They agreed that open communication is beneficial in dealing with the crisis of childhood leukemia.

Marius and Mary were also open and honest with Garry and Andy about James' condition. They tried to be reassuring when talking to Garry and Andy. They took time to answer their questions and concerns about their brother James. This helped to prevent resentment to their sick brother because he was getting so much attention. Moore, Kramer and Perin (1986) suggest that visiting the sick child and being involved as much as possible, helps to decrease the siblings' feelings of isolation. Brown (1989) states that it gives them a better understanding of the sick child's condition, experiences and situation and helps prevent a build up of resentment to the sick child. Siblings too need the opportunity to express their emotions.

Marius and Mary found that division in roles, thereby adapting the burden of each procedure to the strength or resilience of the other partner, was a major coping style for both of them. *"Then only one of us would be distraught for the day and the other could comfort,"* says Mary. *"For example I could not bare it when the nurses came in with the blood test results or any results for that matter. Marius was the one speaking to the ward staff about James' results or progress. He then would come and tell me in a way he knew would not upset me too much. I often felt I could not bear anything bad anymore so I walked out when the doctor or nurse wanted to discuss a result."* Mary took care of the nurturing tasks such as helping to feed James and clean him up. This is how they supported each other. Van Dongen-Melman et al. (1995) suggest in their research that a division of roles is often seen at events that are perceived as extremely stressful by parents whose child is diagnosed with cancer. Parents often make arrangements about who has to undergo the burden of being present at certain procedures, state the same authors.

Marius and Mary were also able to gain explanations for the illness of their son through their belief in God. They found comfort through prayer and faith that God has a plan for their son. They say the following: *"We feel Jesus has a plan for our son. Without Jesus we could not have climbed this mountain nor walked this walk. He did not forsake us."* Hussein-Rassool (1995) suggests that while medical advances can be applied with little change to people from a variety of cultural backgrounds, religious beliefs can make a major difference in the responses and adaptation of individuals to

an illness such as cancer.

Marius said that whatever the circumstances are that we are faced with, this day is the only day in which we can deal with them effectively. The New Testament puts it a simple truth: *"Why worry about tomorrow, when today has sufficient cares of its own?"* Marius says, *"Like many other simple truths its very simplicity causes it to be overlooked, underestimated or ignored. Yet it is a basic ingredient of happiness."* Van Dongen-Melman et al., (1995) suggest that because childhood cancer is characterised by uncertainty and loneliness, religion may comfort parents and provide a framework to interpret their experiences as it did with Marius and Mary.

THE CONTRIBUTION OF THE SUPPORT GROUP

Introduction

Marius and Mary joined the support group as they felt that their path to recovery was not over yet. *"Many people do not realise that the path to recovery does not end after the treatment ends and your child is in remission,"* says Mary. *"It is the long haul after that, that is part of the journey too."* *"For a long time after James' treatment ended, it was right there - in my face,"* says Mary. *"I thought about it all the time, I worried about it coming back. It was and still is just there"*.

Marius and Mary felt they needed an avenue to process the events they experienced. Stuber (1995) proposes that it cannot be assumed that once a child has become a survivor that parents can put the experience out of their minds. The memories of the procedures, the moments of extreme fear, the pain, the isolation, leave lasting marks on everyone.

Koocher and O'Malley (1992) suggest that parents who remain symptomatic, as in the case of Marius and Mary, can and should obtain assistance through access to social support groups. This will give them a chance to compare notes with other parents who have a mutual understanding of the situation. Also simply letting parents know that

such responses are common can be powerfully liberating to the parents suggest the same authors. This fits in well with Marius and Mary's need to open more lines of communication between themselves and other parents "in the same boat".

My relationship with Marius

When I first met Marius I did not feel at ease with him. He had this sense of self efficacy which was quite intimidating but after a couple of sessions it subsided which made the relationship more comfortable. Marius wanted to act as a consultant to other parents because he felt he knew and understood a lot about childhood cancer. I also found his interruptive manner very disruptive in the beginning. He was very reserved and guarded when asked intimate detail and instead focussed his energy on trying to find practical solutions for other parents going through what he did. Yalom (1995) indicates that behind the mask of competency may lie a personal issue that the group member is grappling with. I attributed this mask of competency that Marius displayed as a natural consequence of the culture of competition that operates in the IT world in which he works. This culture of competition demands high levels of competence and will not tolerate failure. As time passed Marius' humanness and frailty surfaced making it easier to have him in the group.

Now let us look at how Marius communicated with the group.

Marius' communication pattern

Marius did not share his full story with the group. He left that to Mary. Marius made several cynical statements such as "*..people treat the disease like leprosy*", "*...nobody understands you and nobody loves you.*" Stuber (1995) suggests that fathers who have been studied thus far appear to be somewhat removed from giving direct responses. More investigation is needed to clarify the interaction of fathers within a support group. Nevertheless the therapeutic context created by the group allowed Marius to drop the mask of competency and he engaged in therapeutic talk about concerns, doubts and frailties. I am listing a number of assertions from Marius which depicts this.

1. *"One is intimidated by the amount of new information that one has to absorb quickly without any explanation."*
2. *"A parent is in shock.... you still need to keep your head to make sense."*
3. *"Parents often feel they know better but this is not always the case."*
4. *"Parents need a booklet or telephone service giving them advice on practical issues."*
5. *"A parent needs to tell his/her story, but who really listens?"*
6. *"Many people treat the disease like leprosy."*
7. *"I will always support anybody who is ill after my experience with my son's illness."*

Marius makes assertions about a variety of issues rather than what happened to him when his child was diagnosed with cancer. His assertions are indicative that he does spend time thinking about concerns, issues and doubts but he operates on a different level of sensemaking than the other group members. A governing assumption of Marius seems to be that solutions to the problems parents experience are within their grasp. I named him the "solution peddler" for the plight of parents whose child is diagnosed with cancer.

My relationship with Mary

Mary is a down to earth, open and friendly person which makes relating to her easy. Her moods did swing as during some sessions she was quiet and others very verbose. I always paid careful attention to what she was saying and tried to go beyond mere appearances. I felt that beneath the fiery red hair and the fashionable clothing was a negative self evaluation no matter how good her outward behaviour was or how well

she succeeded in looking after James. The unconditional acceptance she received from me and the group allowed her to drop her defences and trust us with her innermost thoughts and experiences of her child's illness. Rogers (1977) proposes that one of the main ways to assist people to cope with situations is by helping them become a fully functioning person who has no need to apply defences. To do this I tried to understand Mary's private world of experiences and to validate them. This was something her husband did not always do. Rogers (1974) contends that a person's experience is his/her reality.

Now let us look at how Mary communicated with the group.

Mary's communication pattern

Examination of the context of Mary's description in terms of language indicates that it is built around active verbs. Examples are *"world came crashing down"*, *"punched between the eyes"*, *"cried in the bath or in bed at night"*, *"floating in another planet"*, *"how shattered we as parents felt"*, *"monitored my feelings of fear and anger"*, *"learnt all about my child's diagnosis and treatment"*. The active verbs appear to be the most useful clue as to what happened to Mary once her child was diagnosed with cancer. One can almost visibly see the devastation in these parents, crying, floating, being shattered. I could almost visualise a window pane breaking, shattering in front of me. *"How does one put those pieces back again?"* I thought. Despite this, Mary and her husband decided to take action and be active and assertive in all the spheres of their son's illness. She was always alert when her child was in hospital and her husband at work and helped staff to monitor James' medication. She helped James form good relationships with the ward staff. I am listing a number of assertions which depict Mary's style of communication.

1. *"I call it a path to recovery because this is what it is for me."*
2. *"We had a stable family life and our son was one of those joyful bundles that had an enormous zest for life always."*

3. *"We knew something was terribly wrong but NEVER did we anticipate CANCER.."*
4. *"We were punched between the eyes by this big word CANCER.."*
5. *"For a full four days it felt as though I was floating in another planet."*
6. *"It is quite impossible to describe how you as a parent feels to hear your child scream while four nurses hold him down and pierce a thick needle into his little hip AND THERE IS NOTHING YOU AS A PARENT CAN DO."*
7. *"Only God knows how shattered we as parents felt inside."*
8. *"I could not handle a baby crying in a supermarket it was as though I was hearing my child scream all over again."*
9. *"His hair started falling off we tried not to make a big thing out of this..... we warned him in good time that it would happen and we just carried on as if it's the most normal thing in the world to lose your hair."*
10. *"In front of our son we suppressed our tears but cried in the bath or in bed at night."*
11. *"We tackled each obstacle and each day at a time."*
12. *"After the treatment ended we soon realised that our son could not get over the trauma so we took him for psychotherapy."*
13. *"Today I can thank God that he is himself again."*
14. *".....a path full of obstacles, uphill and twists but luckily also even and straight"*

with good prospects in the horizon.”

15. *“We are trying to be optimistic....”*

16. *“Without Jesus we could not have climbed this mountain.”*

The emphasis of Mary's assertions is how she recovered by making a sustained effort to be strong for her child by concentrating on what had to be done and not on the problem as such (9), (10), (11). She recognised the difficulties in her path (12) but realised that with time and consistent effort she would get her son to recovery. She remained stoic (10), (11), (14), (15), which made her valuable to her child. She never lost sight of the importance of having a realistic attitude, of being very sensitive and respectful to the concrete reality of her situation and she proceeded on the path towards recovery. She did not escape any of the difficulties inherent in a child being diagnosed with cancer as we see in her assertions (3 to 12), and with time and consistent effort she was fortunate enough to find the path of recovery in the horizon (14).

What was helpful to Marius and Mary

Marius says that in the beginning this was really *“not his cup of tea.”* *“To be reminded of the most terrible and hurtful time and experience of one's life once a month is not exactly what I would call having a good time,”* says Marius. But *“I must admit,”* he says, *“healing came slowly but surely and not only did we learn how to deal with our own situation but we also realised that there's other people just like us that could identify with the pain we felt and are still feeling all along”.* Marius feels that emotional distress reported by parents has not been appreciated until recently. This fits in well with Culling (1988) who proposes that parental distress during treatment should be addressed promptly, as an intervention of long term value for the whole family. The medical team should let parents know that the cancer experience will need to be integrated into their lives, rather than forgotten.

The group made Marius realise that life does not just revolve around them but that there are lots of other parents out there who are in desperate need of medication, accommodation during treatment and emotional and psychological support. *“As a group we can make a difference,”* says Marius. The instrumental support of a group should never be underestimated suggests Murray (1995). He continues to say that this entails providing financial support or giving direct help which enables parents to function better.

Mary felt very inspired by all the ideas of the group members to make life just a little easier for parents and children with cancer. *“Being involved with TOUCH brought us into contact with other Parent Support groups all over the world that have achieved so much already. We can try and adapt their methods to suit our local conditions. It is very inspiring and challenging,”* says Mary.

Marius shared many of his ideas of fundraising with the group and said he would like to make that his area of help. His success with many of his ventures due to the various contacts he had, brought a lot of relief to parents with financial difficulties within our group and also to parents who were not part of our group. This really gave meaning to his business like ventures in the group as the amounts he raised were not trivial. He said the following about fundraising: *“Fundraising is the gentle art of teaching the joy of giving. Fundraising is the principle of asking, asking again and asking for more. You have to repeat, repeat, repeat your requests in different ways. Often organisations start by giving small, you have to nurture them and they will be motivated to give more. Personal contact is more effective.”* Marius’ solution peddling seemed to bring him a lot of satisfaction as a member of the group. His solutions were working and the group members were behind him all the way. According to Chesler and Barbarin (1987) fund raising can be a major focus in a social support group. They continue to say that by helping to solve problems of transportation of children to special treatment centres, drug purchases, low cost lodging near the treatment centre and gifts for the ill child, social support groups can really support parents who have no family members nor friends or community assistance.

Marius and Mary also commented on the importance of just being able to *“sit and talk, to cry on someone’s shoulder, to have someone to listen.”* This is the type of emotional support the group provided for them. This fits in well with Murray (1995) who proposes that support groups provide opportunities for parents to share feelings of joy and pain, hope and despair and validate their emotional responses to prolonged and uncertain illness.

Marius and Mary also commented on my contribution to the group. They said the following: *“Maria laid a platform where we could share our feelings and talk about our fears, pains and those things that we would rather not talk about. Her gentle way of communication and the warmth about her made it easier for us to share and bare all before her. She always had the right and appropriate information and advice when we were lost.”* Mary said the following: *“When Maria asked me to share my story with the group I did so from beginning to end. Prior to this I could hardly talk about the pain we had gone through to anyone as it hurt too much. I feel whole again.”* I used a lot of self disclosure, caring, clarifying and explaining as well as structuring and suggesting procedures, which according to Yalom (1995) have a positive effect on the outcome of support groups, with Marius and Mary in order to help them connect with me, and it seems to have helped. What seems to have helped Marius and Mary is that I tried not to allow members to experience so much emotion that they were unable to process the material being discovered in the group nor did I structure the meetings so rigidly that no emotion could be expressed. This corresponds with Yalom (1995) who contends that group leaders should find a position between the two extremes of emotional stimulation and executive function for the well-being of the group. Marius said that, from the sessions of our support group he realised that there are ten points to remember when another parent tells you their story which helped him in his marital conflict which he and Mary were experiencing lately.

- (1) *“Most important is to LISTEN.”*
- (2) *“Show respect and understanding and don’t judge.”*
- (3) *“Let parents feel their emotions are normal.”*
- (4) *“Don’t interrupt too soon.”*

- (5) *"Don't tell your own story."*
- (6) *"Try to find out what the real question is."*
- (7) *"Each question is important."*
- (8) *"Let parents make their own decisions."*
- (9) *"Always ask open questions."*
- (10) *"Be careful with solutions."*

CONCLUSION

When Marius and Mary joined the support group they were experiencing a "block" in their marriage. This corresponds with Dahlquist et al. (1996) who suggest that there can be changes in parents' marital functioning over the course of the child's illness and remission. They wanted to explore this before it got out of hand and they could do nothing about it. They felt the support group would confront them with their personal issues within an environment of compassion and empathy.

Marius also needed to find a way to give meaning to this experience. The only way he seemed to be able to do this was to use the contacts he had in the business world to provide what Murray (1995) calls instrumental and informational support to parents coping with their child's diagnosis of cancer. This entails fundraising and providing information and guidance which enables other parents to function better. He found the support group an ideal place to begin.

In summary the following themes emerged from Marius and Mary's story:

- The theme of stability versus change
- The theme control versus loss of control
- The theme of information versus ignorance
- The theme of advice versus left in the dark
- The theme of fundraising
- The theme of survival versus capitulation

Marius and Mary's coping mechanisms were to:

- be active and assertive
- have an open family communication
- divide the roles between them depending on their strengths and weaknesses
- use a coherent belief system.

The contribution of the support group is discussed in terms of the following factors:

- The group provided Marius and Mary an arena to process the events they experienced
- The group gave them a chance to compare notes with other parents who have a mutual understanding of the situation
- The group fulfilled their need to open more lines of communication between themselves and other parents "in the same boat"

My relationship with Marius and Mary is discussed. Marius and Mary's communication patterns are described in terms of the language they used to engage with the group as well as my perspective of what was helpful to them. The following factors were helpful to Marius and Mary:

- In everyday life, as Yalom (1995) suggests, people neither learn about others' feelings and experiences nor avail the opportunity to confide in, and ultimately to be validated and accepted by others. After hearing other members in the group disclose concerns similar to their own, Marius and Mary reported feeling a powerful sense of relief. The group made Marius realise that life does not just revolve around them but that there are lots of other parents out there who are

in desperate need of help.

- The support group brought Marius and Mary into contact with other Parent Support groups all over the world that have achieved so much already. The possibility of liaising with them was very inspiring and challenging to the rest of the group members.
- Engaging in fundraising gave Marius a sense of purpose
- The emotional support of the group in terms giving love, being empathetic, encouraging, caring and showing understanding as well as being trustworthy was a major help to unblock the stuckness they experienced in their marriage
- My committed support gave Marius and Mary the therapeutic playground in which they could find themselves after they were lost in the chaos of James' illness.
- The support group allowed Mary and Marius the space and openness to talk about their story without creating the atmosphere of *we have heard it all before* and this was very therapeutic.

Marius and Mary became the driving force behind the group. Their ideas as well as their ability to carry them through brought new meanings in the group members' lives. The group members felt they could make sense of what they had learned from the illness of their child and were able to expand this knowledge in a meaningful way. Marius and Mary gave the group a life of its own.

CHAPTER 10

PAT AND CLAY'S STORY: TRYING TO CREATE ORDER OUT OF THE CHAOS

INTRODUCTION

Participants: Pat and Clay, a married couple

Age: Pat (34 years old) and Clay (36 years old)

Children: Twin daughters Esmé (12 years old) and Emma (12 years old and diagnosed with retinoblastoma [cancer of the eye]) and David (5 years old)

Participants' occupation: Pat is a nursery school teacher and Clay works for a telecommunications company

Pat and Clay are the other married couple, and perhaps the quietest members in the group. Both are "salt of the earth" type of people looking very hurt and very vulnerable, more so than the other members in the group. As they are of a lower socioeconomic status than the other members of the group, their plight is even more difficult. Pat and Clay always arrived a few minutes late, entering in a very quiet and timid way. They attended all the sessions together with their three children, who played in the park while we had our group session. Emma is in remission now, still looking very thin and frail with a startled look in her face. Perhaps the fact that she can only see with one eye makes her seem more alert.

Clay is quite a biggish man and has a casual and informal manner about him. This allowed me to feel comfortable with him. He has a pale complexion and there seems to be a bluntness of emotion. He came across as a very quiet man, almost as if he was

depressed. He never displays any joy, sadness or anger. When he speaks it is as though he is merely stating facts. Pat is very thin and frail, like Emma, and is always dressed casually in a tracksuit and "tekkies". Pat always seems full of expectation when she arrives at the group meetings.

Pat and Clay joined the support group on Pat's insistence as she felt maintaining an emotional balance had become an impossible task. She felt Clay was withdrawn emotionally and did nothing to help her which caused her to become very angry with him and then feeling guilty about her emotional outbursts towards him as he did not even react to that. Koocher and O'Malley (1981), in their interviews with parents of children who have survived cancer, suggest that coping strategies fail or break down in the face of overwhelming crisis, and maintaining an emotional balance can become an impossible task. The things that usually work to prevent extreme mood swings from interfering with meeting family obligations and caring for the sick child seem to fly out the window, propose the same authors, and the vow to take each day as it comes, is broken. This is the time to realise that one needs help, suggest Chesler and Barbarin (1987), as Pat did. She managed to persuade Clay to join her in her efforts to restore some order in the chaos of their lives.

THE STORY OF EMMA'S CANCER

Pat and Clay had a very mundane but normal life, following the routine of working from eight to four every day in their respective jobs. In September 1996 Emma's eye was a little red and Pat took her to the doctor. After examining her the doctor said that Emma was not able to see with that eye, something neither Emma nor her parents realised. On further tests at the eye specialist they found that the retina was loose upon which an operation followed to attach the retina. For a couple of months things seemed fine until in December when Pat and Clay realised that a knob had appeared in Emma's tear gland. They thought that maybe the attachment of the retina was not so successful. Upon examination the eye specialist diagnosed Emma with Retinoblastoma (cancer of the eye).

"It felt as though my whole world came to a standstill," says Pat, *"one always feels it happens to others and not to you, but now I was the person everyone feels it happens to"*. Eiser et al. (1994) suggest that no amount of broken bones and high fevers of common childhood ailments can prepare parents for the mind-numbing terror of the diagnosis of cancer and what lies ahead. After doing a biopsy the doctor confirmed the diagnosis and Pat and Clay had to tell Emma what was wrong with her eye. She was 10 years old at the time. Pat and Clay were very afraid of telling Emma about the diagnosis as they felt that it would damage her social interactions with her friends. She was a very fragile child to start off with and did not make friends easily and Pat felt she might lose the couple of friends she had too. Whaley and Wong (1991) suggest that the school going age is a very decisive period in the child's social relationships. Children are capable of doing mental operations but are not yet able to deal with abstract concepts states Hayes (1988). According to Piaget's concrete operational stage, it is a time for classification and order (Smith & Cowie, 1988). A diagnosis of cancer threatens their increasing independence and self image and disrupts the establishment of relationships outside the family setting (Hockenberry and Coody, 1986). This is exactly what happened to Emma once her parents told her she has cancer of the eye. *"Emma cried and cried bitterly questioning us all the time as to why this happened to her"*, says Pat.

Pat and Clay went through all the emotions of questioning, then looking for answers, then denial only to wake up in the mornings and to find that the illness was still there. *"I went to sleep every night praying that a miracle would happen and Emma would be cured,"* says Pat. In January 1997 Emma started with chemotherapy. Initially she did not have to be hospitalised and went for chemotherapy on an out patient basis. She was very nauseous and every evening Clay sat beside her bed. Pat says she started worrying about Clay when she got up one evening and he was not sleeping but reading the bible. This continued all night and for four nights after that. Then one morning Clay said to Pat. *"Our child is healed, I saw it in the bible"*. He insisted to such an extent that he had to be hospitalised in a psychiatric ward. He fell into a deep depression after that. Gross (1992) suggests that if coping mechanisms are used in such a way that the stress is not being dealt with, and the distortion or deception of reality is a long term

coping mechanism, as was the case with Clay, then this is viewed as unhealthy and undesirable and professional help should be sought. Clay's hospitalisation in a psychiatric unit was inevitable as Pat could not deal with both him and Emma at home. Pat says that she too was close to breaking point but when she looked at Emma, Esmé and David and how much they needed her, she regained her strength.

From here onwards Pat had to cope on her own. After the tumour was reduced by the chemotherapy Emma's eye was removed with surgery in March 1997. The doctor told Pat that Emma would need radiotherapy and referred them to a doctor in Cape Town. By this time Clay was out of hospital but was in a coma like state as a result of all the medication he was taking. Pat decided to take Clay with to Cape Town. Esmé and David remained behind as they had to go to school.

After a week of radiotherapy in the Cape the doctor was pleased with the results and Pat and Clay decided to stay a week longer, which did them the world of good. A colleague and friend of Pat's gave them access to her apartment in Cape Town which was close to the treatment centre.

When they arrived back in Pretoria they had to look for an artificial eye for Emma. In the meantime she had to go for a few more chemotherapy treatments after the radiotherapy. Emma is now in remission and has an artificial eye. Pat has still not accepted what has happened. Clay is still under medication for depression but is better and tries to encourage Emma where he can. Emma is becoming a teenager now and she feels different to her peers. *"But that is another bridge we will have to cross soon,"* says Pat with sadness.

The context of Pat and Clay's story will now be discussed in terms of emerging themes.

EMERGING THEMES

UNCERTAINTY VS CERTAINTY

Pat's uncertainty began in 1996 when her *"daughter's eye was a little red and she took her to the doctor"*. After examining Emma the doctor said that she cannot see with this red eye, something she did not even realise. This was really something unexpected and caused Pat to cry. Emma was sent to a specialist afterwards who on examination found that the retina was loose and during a short operation attached the retina. This did not bring any relief to Pat and Clay as they *"realised that a knob was appearing in her tear gland"*. They were very uncertain about this and thought that maybe the attachment of the retina was not so successful and took their daughter to the specialist again who after another examination told them it was cancer. The biopsy was done and the diagnosis of cancer was confirmed. *"It felt as though my whole world came to a standstill"*. The certainty of this horrifying news came just before Christmas and for Pat and Clay the festive season *"is never the same anymore because it always reminds her of how her child's life was changed"*.

Telling their child that she has cancer was one of the hardest things Pat and Clay had to do. They dreaded it because they did not have time to internalise it themselves but having an open communication system within the family they felt they could not hide it from her that something was wrong. Also treatment had to begin almost immediately so they could not postpone the task of telling their daughter. There is evidence, according to Slavin et al. (1982), that early knowledge and discussion of the diagnosis and not evasion and concealment, is linked to better psychosocial adjustment in the child. Pat describes her initial response to the diagnosis as follows: *"One always feels it happens to others and not to you. But now I am the person everyone feels it happens to. Now we had to tell our child. We left the consulting rooms crying, myself and my husband. Our daughter asked us why we are crying. We told her she has cancer and she cried bitterly"*. Chesler and Barbarin (1987) describe two ways of telling a child about a cancer diagnosis: the protective approach and the open approach. Health professionals who work with children with cancer advocate the open approach as they

say that lack of candour about what is really going on does not enhance honest communication within the family. Pat and Clay chose the open approach. The uncertainty of their child's eye problem was now a certainty in the form of retinoblastoma.

SOCIAL SUPPORT VS SOCIAL REJECTION

Although Pat felt very isolated in terms of her husband's support she did not let that stop her from telling others about her child's illness and thereby gaining support. She says that they did get many *"new friends but many of the people they thought were their friends turned their back on them"*. After the operation during which the eye was removed Pat and Clay were told to take their daughter down to the Cape for radiotherapy. They were struggling financially but their support came from Pat's work context as she says: *"At the nursery school where I work they started to gather funds for us. I was not even aware of that. They handed the funds over to us with a teddy bear for my daughter. The teddy bear went down to the Cape with us"*.

After they got back from the Cape and Emma's treatment went well Clay also started getting better. At that point they both made an effort to find sources of social support from the community for themselves and their child and thus joined the support group.

CONTROL VS LACK OF CONTROL

Pat and Clay tried to be active and assertive in order to control the chaos of the disease. Pat says: *"My husband and I did research on the internet to find out more about the illness"*. After the operation when they were told to take their child to the Cape for radiotherapy Pat directed her efforts at the maintenance of family integration, co-operation and optimism thereby trying to maintain some emotional stability in the midst of her husband's collapse. She organised for them to arrive in the Cape two days in advance thereby giving them a gap to relax before the hospitalisation of their daughter. This did promote the family's well-being.

The treatment down in the Cape went well and this encouraged Pat and Clay. He also started feeling better and participated in the routine of visiting Emma in hospital and taking and fetching his wife from the hospital. Pat says: *"The sisters treated my child well. After a week of radiotherapy the doctor was pleased with the results. We decided to stay a week longer in the Cape for a holiday"*. This helped the interpersonal communication and assisted Pat and Clay to achieve a balance in individual growth with meeting the needs of their sick child as well as the other two children.

When they arrived back in Pretoria they had to make arrangements for an artificial eye for their child and also for the chemotherapy treatment their daughter still had to complete. White (1995) says that how one thinks about a situation will determine how one will respond to it. Pat's coherent belief system and her open way of communicating with people helped her to stay in control of the illness and to help her child and husband through it. She remained positive and optimistic about the survival of her child and family through this.

THE THEME OF DEPRESSION

The emotions of depression and isolation were the most prevalent themes for Clay. *"It was as if we committed one or other kind of sin and this was our punishment"*. The loneliness of this quite biggish man is very evident. He saw the illness of his daughter as a punishment without knowing what for. Therefore he gave himself over to his religion reading the bible as his Pat said. His depression and isolation prevailed and he had to be hospitalised leaving his wife alone to cope with the illness of their child.

According to research findings (Chesler & Barbarin, 1987), seeing the illness of your child as a type of punishment is very dangerous psychologically. One usually tries to find meaning as to why things happen, suggests Shantall (1996), and according to this meaning we make sense of what happens to us. Now if one sees it as Clay does, a punishment, one does feel that one committed a sin and not really knowing what drastic sin this is, one will tend to become depressed. This is what happened to Clay.

The positive aspect of this father was that although he showed a typical male response to suppress real emotional feelings he was aware of what he was doing and wanted to change. Him and his wife joined the support group which did alleviate their isolation to an extent. At first he said *"one feels cut off not only from people but also from God"*. He also agreed to be hospitalised in a psychiatric hospital to deal with his depression. *"My depression affected my wife and my sick child"*, he said.

Although Clay did not say a lot during the group sessions his non verbal behaviour and his presence were enough. He seemed to listen most of the time and also write down things that were important to him.

When I asked him to describe his depression to me he said *"it is a kind of blackness a kind of guilt about what is happening which leads to loneliness and listlessness. It all stems from a kind of powerlessness to change the situation. All my life I had control over things. If I decided to do something I did it. For the first time I was in a situation I could not change. This changes the way you see life and this change is a process of pain before you eventually see the light"*.

This father tended to see the illness more in broad philosophical terms. At first he could not possibly imagine anything good happening so he fell into the *"darkness of depression"*. He was isolated and felt guilty so the only source of help he could think of was his belief in God. He prayed day and night as his wife also says and sat next to his ill child with the bible hoping for a miracle. At one stage his will to control the situation as a father and make his child right again was so strong that he told his wife one morning their daughter is healed. He became religiously fanatic in order to cope.

Now that his daughter is in remission he feels that life is moving towards a kind of stability although it still remains unpredictable so he has to *"live comfortably with the fact of uncertainty"*.

SUFFERING AS A CHALLENGE VS SUFFERING AS DEFEAT

Shantall (1996) suggests a struggle is involved to find the meaning of our suffering. It is difficult to find meaning in the face of fear and shock as well as the deep anxiety caused when a child is diagnosed with cancer. Once Emma was diagnosed with cancer Pat and Clay were confronted with questions they had never considered before. Their past way of living was disrupted and they had to take one day at a time. This diagnosis was something bigger than themselves, something they could not face. Pat felt naked and vulnerable especially when Clay had to be taken to a psychiatric hospital. She describes it as follows: *"My daughter's hair started falling off. It was a shock to all of us. She never went anywhere without a hat. I was very angry and confused at that stage. I prayed and asked God, first he takes my child's eye away, then my husband who is suppose to support me, now it is only me. 'Why is all this happening to me?'"* But she knew that she had to be strong for her child. The spiritual side of her nature emerged and helped her find perspective and gave her strength as she says: *"Every evening when I went to sleep I did not know where I would get the strength to get up the next day, but I did with God's help".*

One has to exercise courage and this is what we see in Pat. Despite all the adversity of her husband collapsing and her being alone to face the challenge of her child being diagnosed with cancer she made it. She says: *"The year 1996 was full of pain and I thought the sun would never shine again. It will only be dark clouds. But if I look back this has made me a better person. I cannot thank God enough for making my child well".*

Pat still has to face many challenges and one of them is to fully accept the fact that her daughter will only see with one eye. She says: *"I hope to accept this situation one day. I was there for my child and my husband but I did not get any support. My daughter still asks me why did it happen to her. She is becoming a teenager now and her peers mock her".* Pat's suffering is not over but she sees it more as a challenge than as defeat with the help of her coherent belief system.

HOW PAT AND CLAY TRIED TO COPE

Pat and Clay were torn between the needs of Emma and those of Esmé and David. They also had to go to work and try to maintain some normality in the house. These conflicting needs made it difficult for Clay to adapt to the chaos of the treatment Emma had to have, so he tried to cope by finding refuge in God. *"My husband lay with her every evening because she was very nauseous after the chemotherapy. One evening I got up and realised that he is not sleeping but reading the bible all night. This carried on for four nights"*. Figley and McCubbin (1983) suggest that people cope with a crisis on two levels; internal and external. Internal coping protects the person from psychological disruption and paralysing anxiety and it diminishes discomfort. External coping represents mastery of a problem in a practical way. Although externally Pat was coping and taking Emma for treatment and doing all the practical tasks that she needed to take care of, Clay was collapsing internally. She describes it as follows: *"The next morning I wake up and find my husband up reading the bible again. He said 'our child is healed'. I told him this is not so. He was very confused and admitted to a psychiatric unit. At that time I was also close to breaking point but when I saw how much my child needed me I regained my strength. I was very angry and confused at that stage. I prayed and asked God 'why is all this happening to me?' First my child is diagnosed with cancer, then my husband who is suppose to support collapses emotionally and I am left alone to cope with everything"*.

According to Chesler and Barbarin (1987) having a coherent belief system is an effective coping mechanism. Pat found her faith in God strengthened and this created some sense of order out of the chaotic nature of having a child with cancer. This answered her questions of "why me" in a way that made sense to her. She says: *"Every evening when I went to sleep I did not know where I would get the strength to get up the next day, but I did with God's help"*. Chodoff, Friedman and Hamburg (1964) have pointed out that searching and finding some broad philosophical or religious framework to make the event of their child's illness comprehensible to them is a normal coping response used by parents of children with chronic illness.

Pat and Clay also tried to cope by educating themselves on this illness. Clay had access to the internet via his work and they tried to find out more about Retinoblastoma on the web. The health care team also played a vital role in educating Pat and Clay about the specific type of cancer Emma had. Carpenter, Vattimo, Messbauer, Stolnitz, Bell-Isle, Stutzman and Cohen (1992) suggest that from the time of admission families are continually searching for information and it is important to keep parents updated, giving them accurate feedback and advice as it becomes available, thus ensuring that they feel they have some control over the chaotic stream of events. Pat and Clay were provided with booklets explaining the cancer and treatment which helped them a lot. This corresponds with Robinson (1985) who proposes that written information given at the time of diagnosis is invaluable to families, as it gives them something to refer to at a time when it is very difficult to remember everything that is said to them about the sick child by doctors, nurses and other members of the health care team.

Clay's absolute powerlessness to change Emma's situation "paralysed" him emotionally. This led to him failing to meet expectations at his work which made him withdraw completely. In order to cope he went into what I call an "emotional coma" which led to him being hospitalised in a psychiatric unit. Seligman (1975) suggests that depression is very common in parents after the initial stages of the illness when its full implications have become apparent. It may arise from a sense of guilt associated with the illness since parents may perceive the illness as a punishment for past behaviour suggests Greer (1985), as Clay did. He says: *"It feels as though we have sinned and we are being punished for it now. I am a sinner in everybody's eyes"*. When this occurs parents may adopt a passive attitude, believing that the punishment is justified, which leads to very passive and withdrawn responses. This type of self blame can be a method of coping but there are occasions when these reactions are sufficiently strong to cause concern, suggests Weiner (1970), as was the case with Clay. According to Rapmund (1996) helplessness and powerlessness to change a situation can lead to severe depression. Depression then becomes a vociferous voice through which the person screams for help, suggests the same author.

Pat tried to cope by concentrating on one thing at a time. She followed the treatment

of Emma with great care and became so involved in it that all other interests and obligations were dropped. *"I could not cope with everyone and everything,"* she says, *"I left Clay and my other children in the hands of God."* Marks (1969) indicates that this type of reaction might be regarded as a healthy adaptive response but the danger is that it can become a total preoccupation and may ultimately be counter productive. It seems to work for Pat, though.

THE CONTRIBUTION OF THE SUPPORT GROUP

Introduction

Pat and Clay joined the support group so that they could find some order amidst the chaos of the illness. They needed to try and make sense of this unexplainable and unpredictable event that had come across their lives. Chesney and Chesler (1996) suggest that parents need to find a safe haven where they can express their emotions unconditionally. This fits in well with what Pat said: *"I am here because I need to talk and talk about this illness now. I cannot keep quiet anymore, and no one wants to listen to me"*. Many studies (Last & Grootenhuis, 1998; Clay, 1999; Spinetta & Deasy-Spinetta, 1981) have identified the importance for parents not only in expressing fears and related emotions about their child's diagnosis but also having these recognised and allowed by those around them as part of coming to terms with the illness. Pat and Clay needed acceptance by others in order to accept the blow life dealt them in the form of childhood cancer.

My relationship with Pat

What originally impressed me about Pat and continued to impress me throughout the group sessions, was her candour and down to earth nature. Although she seemed very vulnerable, she did not hesitate to feel the fear and say what she needs to say anyway. That I appreciated very much. Pat saw me as an expert in the group and always looked at me for approval. I realised that all she needed was a slight nod and she could continue. There were times when Pat would open up and share with us very

intimate detail, making her husband uncomfortable, and then he would react by withdrawing. Wallace & Vaux (1993) propose that it can be emotionally risky to be honest and to share openly too quickly. It is up to the group facilitator to help each group member to move according to his/her own rhythm regarding how much to share, how quickly to share it and finding the space and place to share it, suggests Yalom (1995). As the group sessions progressed and I got to know Pat better and better I tried to do just that.

Now let us look at how Pat communicated with the group.

Pat's communication pattern

Examination of Pat's description in terms of the illness, coping and relationships provides a picture of a straightforward approach to the experience of Emma being diagnosed with cancer. The factual language which dominates the emotive language is evidence of a very practical approach to the illness. Examples are: *"My daughter's eye was red and I took her to the doctor. They attached her retina and she had to remain one day in hospital. A knob was appearing in her tear gland and we thought maybe the attachment of her retina was not successful."* Later in her story Pat shows her practical thinking by describing practical things she did to make things better for her and her husband such as when they went down to the Cape for treatment of her child they *"decided to go and hire a television"*.

Pat could not really concentrate on her emotions at all. They were there but she focussed her energy on tackling the illness of her child. She saw the illness as an obstacle which had to be fought and removed. Then she would concentrate on herself and her husband. Her energy flow was directed at fighting the illness of Emma. She says *"All I could see was that I had to fight this illness. It was another obstacle I had to get through by fighting it"*. I am listing a number of assertions Pat made during the group sessions which depict Pat's way of facing her suffering.

1. *"It has made me a better person."*

2. *"It was a year full of pain."*
3. *"It felt as though my whole world came to a standstill."*
4. *"One always feels it happens to others and not to you."*
5. *"The little hope we had that it might not be cancer was shattered and we were forced to accept reality."*
6. *"My husband and I did research on the internet to find out more about the illness."*
7. *"I was close to breaking point but when I saw how much my child needed me I regained my strength."*
8. *"Every evening when I went to sleep I did not know where I would get the strength to get up the next day, but I did with God's help."*
9. *"The specialist phoned and told us to take her to Cape Town for radiotherapy. We hired a townhouse half an hour's drive from Cape Town."*
10. *"We arrived two days in advance."*
11. *"While she was in theatre we decided to go and hire a television."*
12. *"When we arrived back in Pretoria we went to a place where they make artificial eyes."*
13. *"I have been fighting this illness full steam but I did not get any support."*
14. *"I have come to realise that in this group and from the other parent's stories that*

I am not the only parent who has suffered.”

15. *“I hope to accept this one day.”*

Being in the group taught Pat that no one lives free from suffering and loss as she says in assertion (14). It was not only her that was singled out for this terrible misfortune. Although pain and suffering are universal phenomena that doesn't mean we have an easy time accepting them as she says in assertion (15). The emphasis of Pat's assertions is that she faced her problems head on (7 to 13). Pat did not try to avoid the problem although everyone around her collapsed (13). She directly faced and confronted her suffering and this put her in a better position to appreciate the depth and nature of the problem (14) and (15).

My relationship with Clay

Never overtly emotional or obvious in his friendliness, an unspoken type of special closeness developed between myself and Clay. The closeness deepened as the group sessions progressed. In the beginning he was very guarded and said very little, leaving all the talking to his wife, Pat. As the group sessions progressed and our relationship of trust and co-operation deepened he started to express his pain.

Now let us look at how Clay communicated with the group

Clay's communication pattern

Clay said more with his non-verbal behaviour than with words. We named him “the silent one” in the group as he had a powerful way of saying things in gestures, postures, facial expressions and mannerisms. His words were few and very depressing. I am listing a number of assertions he made which depicts this.

1. *“It was as if we committed one or other kind of sin and this was our punishment.”*

2. *"One feels cut off from people but also from God."*
3. *"My depression affected my wife and children."*
4. *"Usually if I decided to do something I did it, now it felt like I was in a dark hole and there was no way out".*
5. *"For the first time I was in a situation I could not change."*

Clay was a very quiet participant not saying much due to his depression. His guilt (1), dominated his thinking and he has fell into silence (2) because of feeling helpless as a father (4), (5). Although Clay said very few words he impacted on the group through his silence. Lieberman, Yalom and Miles (1973) suggest that silence is never silent. It is behaviour, they say, and, like all other behaviour in the group, has meaning both in the framework of the here and now and as a representative sample of the group member's typical way of relating to his interpersonal world. It became a challenge within our group to help Clay open up and share his real feelings of what happened to him once his child was diagnosed with cancer.

What was helpful to Pat and Clay

The *"emotional care"*, as Pat and Clay called it, of the group, allowed them to express their emotions in a way which was very helpful to them. There were five aspects to this *"emotional care"* which Pat and Clay spoke about.

Firstly the group created a *"safe haven"* for Pat and Clay to be themselves. This was because there was no conflict within our support group. All the members had no tolerance for additional anxiety and limited any form of conflict. *"We could be ourselves in the group. No one pushed us too hard and whenever we revealed too much and felt exposed, Maria and Petra intervened and made us feel OK,"* says Pat. *"When we arrived late, Maria always praised us for having shown up. We never felt unwanted,"* says Clay. White (1995) states that the desire for safety is an important reason why

people enter into support groups. Within a safe environment, proposes Greer (1985) the unexplained becomes explained, fear is tolerated and attempts are made to make sense of chaotic situations in the physical and social environment, as Pat and Clay did.

Secondly the safety of the group enabled Pat and Clay to recognise their own feelings. *"I often identified with other members in the group, as the way they expressed their feelings matched my feelings of despair, denial and anger,"* says Clay. *"I often have difficulty in knowing how I feel,"* says Pat, *"but the group helped me to recognise how I feel by reflecting back the underlying feelings in what I said.."* Rogers (1975) emphasises that creating an emotional atmosphere within a group in which a client can recognise his/her feelings is a powerful way of helping clients to feel understood and to identify and experience their emotions. After group members have recognised their underlying, less obvious feelings they can then go some way towards sharing and expressing these feelings, suggests Nelson-Jones (1982).

This leads us to the third helpful aspect of the group for Pat and Clay and that is the group facilitated the expression of their feelings. *"We were able to express how we felt and not just talk about it,"* says Pat. *"If I wanted to cry, I could, if I wanted to shout, I could,"* continues Pat. *"Being able to express what was bothering me instead of holding back was very helpful,"* says Clay. Expression of feeling has a cathartic effect which, according to Yalom (1995) is an important therapeutic factor in a group process. Seeing Clay express himself emotionally was one of the most rewarding experiences for me with TOUCH. His progress was visible from merely seeing events as facts, when he and Pat first joined the group, to feeling in his voice.

Fourthly Pat and Clay found understanding and acceptance within the group which they did not find anywhere else to such an extent. *"The respect, caring and warmth we received cannot be bought with all the money in the world,"* says Pat. According to Sloper and While (1996) understanding and acceptance are two commodities which parents, whose child has been diagnosed with cancer, look for constantly. They can never get enough of that, states Wong (1997). He continues to say that acceptance and understanding reduces the effects of isolation and normalises the feelings that

parents are experiencing. The group communicated understanding and acceptance of both Pat and especially Clay's dilemma which in turn assisted them to move towards an acceptance of Emma's illness. This in turn helped them to find some order amidst the chaos Emma's diagnosis brought into their lives.

Lastly Pat and Clay found the time and support the group offered to them, very valuable. *"When TOUCH came together, we knew, this meant time and support for us,"* says Pat and Clay. *"It was like our place in the sun, because no one out there had time for our emotions,"* continues Pat and Clay.

CONCLUSION

When Pat and Clay joined the support group they were under immense pressure at home and at work and that affected them mentally and physically. They could not see their way out of the chaotic situation they encountered. Cohen (1995) proposes that parents whose child is diagnosed with cancer experience a unique kind of stress. This stress, suggest Cohen and Wills (1985), is not linked to a specific stimulus but arises when a parent perceives and evaluates the whole situation as threatening and they do not know what to do about it. This was the case with Pat and Clay.

In summary the following themes emerged from Pat and Clay's story:

- The theme of uncertainty versus certainty
- The theme of social support versus social rejection
- The theme of control versus lack of control
- The theme of depression
- The theme of suffering as a challenge versus suffering as defeat

Pat and Clay's coping mechanisms were to:

- have faith in God

- educate themselves on this illness
- use depression as a silent voice to get help (Clay's coping mechanism)
- concentrate on one thing at a time (Pat's coping mechanism)

The contribution of the support group is discussed in terms of the following factors:

- The support group provided a safe haven for Pat and Clay and provided them the opportunity to find some order in the chaos of the cancer diagnosis of Emma
- The support group gave them an opportunity to make sense of the unexplained events that came across their lives
- The support group allowed them to be themselves and accepted and respected them as they are

My relationship with Pat and Clay is discussed. Pat and Clay's communication patterns are described in terms of the language they used to engage with the group as well as my perspective of what was helpful to them. The following factors were helpful to Pat and Clay:

- Making the situation safe, that is non threatening, which was very different to the situations they had encountered up to the present moment with Emma's illness
- Enabling them through listening and unconditional acceptance to recognise their own feelings
- Facilitating the expression of their feelings
- Communicating understanding and acceptance

- Giving time and support

The unconditional positive regard and acceptance as well as the respect and empathic understanding that the support group gave Pat and Clay enriched them to find meaning in this event in their lives and in so doing they were able to accept Emma's illness and move on.

CHAPTER 11

CONCLUSION AND RECOMMENDATIONS

In this concluding chapter there will be a general discussion of the study as well as a summary of the findings. The strengths and limitations of the study will also be discussed. The implications of the ethnographic and autoethnographic approaches to the support of the parent of the child with cancer will be noted. Four hypothesis generated from this study will be discussed and lastly recommendations for future research will be made.

GENERAL DISCUSSION OF THE STUDY

The aim of this study is an exploration of my journey, as a researcher and then as co-therapist within a support group for parents whose children were diagnosed with cancer. Within the support group there was no planning or striving, instead we slowly moved with the flow of circumstances as they arose. Parents spoke freely about their sick child, the diagnosis, the seriousness of the condition and the possibility of death. Their stories of coping with childhood cancer were explored and told from my vantage point. According to Denzin (1997) I needed to adopt an openness to the situation I was dealing with and allow things to evolve in their own way. This led to childhood cancer being investigated from a broader perspective, where emphasis was placed on wholeness, interrelatedness and complexity, studying the phenomenon of cancer as part of a network of complexly intertwined human relationships as proposed by Capra (1982).

Rich accounts of eight parents with a child diagnosed with cancer are presented. Their experiences told through story telling in a support group of parents gives the reader an opportunity to view the world from the vantage point of those who experienced the

death or pending death of their child. The story of each child's cancer was told through the eyes of the parents. Themes were identified which led to a delineation of how each parent coped with this trauma in their lives. In addition, a description from my perspective as to what was helpful to the group members is discussed.

A summary of all the different themes generated while interpreting the data from all the participants follows:

- bad news vs good news
- isolation vs support
- uncertainty vs certainty
- issues around treatment (for example to treat or not to treat, treatment for cure vs treatment for comfort)
- finding meaning in suffering (for example accepting suffering vs fighting suffering, suffering as a challenge vs suffering as defeat etc.)
- family care and family closeness
- lack of control vs control
- information vs ignorance
- social support vs social rejection
- honesty vs secrecy
- compassion vs apathy of medical profession
- stability vs change
- survival vs capitulation

In addition, the contribution of the support group from my perspective as to what I believed was helpful, was discussed. A summary of the factors which were regarded as helpful follows.

In Tessa's case:

- Looking at the "here and now" in the group
- The group became a playground in which Tessa could expand herself
- Tessa modelled a different way to relating to people within the group

- The group offered Tessa empathy, respect and freedom of choice, something she did not experience before

In Joan's case:

- The support group energised Joan. New insights were triggered, energy was shared and there was a feeling of integration. The group context provided the opportunity for each individual "to meet", "to pull together", "to converge"
- Joan also experienced the group as fun
- The support group also assisted Joan into realising that ultimately there is no escape from some of life's pain and from death
- The support group helped her realise the importance of responsibility, awareness, freedom and potential.

In Vicky's case:

- She found coming together and being with people who were in the same situation as her, as very helpful. She could talk about her son and his illness, with a comfortable feeling. No matter how she felt the group understood and did not get tired of hearing the same story over and over again.
- The group reflected Vicky's need to grieve and let her understand that bereavement is a long process. Her uniqueness in grieving was validated and she was allowed to grieve in her own way.
- Vicky found that she could identify with members in the group. There were people who were better adjusted than she was and that gave her hope.
- Vicky found my behaviours and approaches to problems very helpful and modelled my methods of defining and solving problematic situations.

In Debbie's case:

- The group members validated and confirmed Debbie's beliefs and this made her feel wanted and useful
- The support group contributed towards Debbie's feeling that her suffering did not go to waste

- Doing things within the group without planning too much was very therapeutic to Debbie
- My support as advisor and facilitator gave Debbie the safety to be herself in the group and to trust her behaviours

In Marius and Mary's case:

- After hearing other members in the group disclose concerns similar to their own, Marius and Mary reported feeling a powerful sense of relief. The group made Marius realise that life does not just revolve around them but that there are lots of other parents out there who are in desperate need of help.
- The support group brought Marius and Mary into contact with other Parent Support groups all over the world that have achieved so much already. The possibility of liaising with them was very inspiring and challenging to the rest of the group members.
- Engaging in fundraising gave Marius a sense of purpose
- The emotional support of the group in terms giving love, being empathetic, encouraging, caring and showing understanding as well as being trustworthy was a major help to unblock the stuckness they experienced in their marriage
- My committed support gave Marius and Mary the therapeutic playground in which they could find themselves after they were lost in the chaos of James' illness.
- The support group allowed Mary and Marius the space and openness to talk about their story without creating the atmosphere of *we have heard it all before* and this was very therapeutic.

In Pat and Clay's case:

- Making the situation safe, that is non threatening, which was very different to the situations they had encountered up to the present moment with Emma's illness
- Enabling them through listening and unconditional acceptance to recognise their own feelings
- Facilitating the expression of their feelings
- Communicating understanding and acceptance

- Giving time and support

EMERGING HYPOTHESES

A number of main hypotheses emerged from this study. Hammersley (1998) suggests that the most central task in an ethnographic study is to identify its main findings or hypotheses and the evidence presented in support of them. This is also called inductive data analysis according to Lincoln and Guba (1985). This means that these hypotheses and implications were developed as a result of working with the data rather than derived from previous hunches. This type of analysis, according to Creswell (1998) enables possibilities to emerge and understandings to develop, it enables the researcher to be playful with the data rather than confined. This does not imply constructing results that are not grounded in the data, but it allows a kind of mental freedom to think without restraint to bring sense to a larger picture.

The implications of these hypotheses according to Van Maanen (1995) could provide valuable information and in this particular study could serve as a guideline to those working with parents coping with childhood cancer. As the sample is small and unrepresentative these hypotheses do not lead to findings that can be generalised to a larger population. I will now discuss these hypotheses. After each hypothesis, I will give an explanation of its implications which could be of value to further research in this field. Through these explanations I attempt, as suggested by Hammersley and Atkinson (1995), to discern pervasive patterns which occur in the parent whose child is diagnosed with cancer.

Hypothesis one

Parents were alike in indicating that cancer in their child was the most overwhelming experience in their life.

Implications

The implications of this hypothesis are quite profound, particularly in the light of parents reporting that their distress was not always appreciated by medical staff or significant others in their lives. Parental distress during treatment should be addressed promptly, as an intervention of long-term value to the entire family. One of the important aspects the medical team needs to focus on is to allow the parent to integrate this experience and make it part of their lives. This is a process. Marius gave ten points or ways which could act as interventions of long term value. They are: (a) listen to the parent, (b) show respect and understanding and don't judge, (c) let parents feel their emotions are normal, (d) don't interrupt too soon, (e) don't tell your own story, (f) try to find out what the real question is, (g) each question is important, (h) let parents make their own decisions, (i) always ask open questions, (j) be careful with solutions.

Marius made a further claim which substantiates this hypothesis in that "*there is still a kind of stigma attached to cancer*". This results in uncertainty and isolation and creates anxiety in parents. Joan also confirms this hypothesis in that a "*shifting perspective*" was the only way she could gain control over this experience that overwhelmed her life. Although she did move towards gaining control of the disease by gaining information, the memories of the procedures, the extreme fear as set in her story as well as the pain have left lasting marks on her. Parents therefore need an avenue to process the events they have experienced, and the meaning this suffering has had in their lives. The participants of this study all said that they still remained symptomatic after their child's treatment was over. The advantage these parents had was that they obtained assistance to process this event both from myself as a psychologist and the social worker and also had the chance to compare notes with other parents in the support group. This they all said helped. Simply letting the respondents as parents know that such responses are common were powerfully liberating to the parents and furthermore encouraged them to open lines of communication with parents who have newly diagnosed children.

The themes elicited from each participant also bear witness to how overwhelming this

event was to each parent. The language used by each parent was also very evocative and portrayed each parent's "long walk".

Hypothesis two

Through the use of coping techniques the parents in this group did "rise to the occasion" and were able to do things for the welfare of their child that exceeded what they thought they were capable of doing.

Implications

Tessa says *"the only thing I saw and realised at that stage was suffering and hell, and that it was. I hated everything, I hated my son's father and his family, I hated God for doing this to us. It felt like every move I tried to make I was like an animal in a cage and could not escape"*. This is a powerful description of how overwhelming the diagnosis of cancer is for a parent. But she did "rise to the occasion" and asserts in the end that it did make her a stronger person. Tessa tried to cope by seeking assurances, preparing for loss, fighting to a point and assuming meaning.

In Joan's story we also see that she moved from *"wanting to escape"* to *"making a decision to become as informed as possible"* in order to help her son through it. A shifting perspective helped Joan to exceed her usual strength and help her son into remission. Joan's problem focussed coping strategies included first trying to escape and then seeking information as a method of empowerment which led to joining our support group. Her emotion focussed coping strategies were denial, finding meaning and re-evaluating her life.

In the case of Mary, Vicky and Pat it was their coherent belief system that helped them face the suffering and move towards recovery. Pat says *"I was close to breaking point but when I saw how much my child needed me I regained my strength"*. Vicky's assertions also bear testimony to the fact that with her spirituality she did "rise to the occasion", and although her son died he told her before he died that she was the *"best*

mom". That made her feel she did all she could and her son knew that. For Mary the path to recovery consisted of consistent effort and remaining stoic. She *"tackled each obstacle and each day at a time"*.

Marius and Clay were the only fathers in the group. Marius did "rise to the occasion" by looking for practical solutions and implementing these in our group. His efficacy comes from feeling strong to support newcomers in this dilemma. About Clay I am not sure. He did try but whether he did "rise to the occasion" is debatable.

The assumption I made about Debbie based on her assertions was that *"it was okay"*. The reader might say how can it be okay for a parent to have her child diagnosed with cancer, but it is not that. It is the calmness she displayed during the group sessions and the acceptance of what came her way. This helped her "rise to the occasion".

I feel that the main aspect, in this particular group of participants, which helped them "rise to the occasion" and do things they did not think they were capable of was the contribution of the support group as each one of them found it very helpful.

Hypothesis three

Both mother and child came out of the experience with a sense of strength largely due to the efforts of the mother.

Implications

In this study the implications of this hypothesis is that genuine inner transformation and change requires sustained effort. It is a gradual process which the mothers of this study indicated. This is in sharp contrast with the "quick fix" solutions proposed by the fathers in the study. I also want to emphasise that although the mothers served as buffers for the event and they did most of the talking most of them, except for Tessa and Vicky, referred to their husbands as being silent partners. This means that the fathers were there all the way but their role is less clear. Pat also stresses her plight

in being alone through this ordeal but nevertheless Clay is mentioned as making a silent contribution. Joan talks about “we” all the time indicating her husband's major part in this illness.

Debbie indicates a reason why fathers are silent partners and that is perhaps because they have to work and also be at home for the other siblings while the mother spends most of her time in hospital with the sick child. Further research is needed to clarify the interaction of fathers within the family system when a child has cancer.

Hypothesis four

The attitudes and beliefs of the health care professionals treating the child can influence health related behaviours on the part of the parents such as the decision where to seek medical help and compliance to the treatment of their child.

Implications

The implications of this hypothesis are very important as in the case of the participants of this study, it was only when they found a doctor they felt comfortable with that they complied with the treatment. This does not mean that there were no concepts, values or beliefs that were not shared between the health care team and the parents, but only that each parent selected some thoughts above others. Perhaps the level of shared experiences and valuing was difficult to clarify because it was taken for granted by the medical professionals that the parents understood automatically. Perhaps what is shared is integrated into the daily routine and action of the medical professional to such an extent that what can be articulated is only differences. The treatment of their child in the most traumatic time for the parent. In the analysis of themes I have pointed out the dilemma that parents have. With Tessa we see that initially she did not know what the treatment of her son entailed and that made her anxious. To treat or not to treat was an issue she and the doctors were grappling with which made “it hell” for her. Once she met Dr Anne and formed an alliance with her in terms of understanding what needed to be done she says “the chemotherapy went well and my son was not very ill

with it”.

Joan also describes her initial contact with the medical staff as a nightmare. She describes it as follows: “*Your child has acute lymphoblastic leukemia. ...if a child in my family had to get cancer, this is the best one to have’. The best? How can there ever be a better type of cancer, especially when it is happening to a child?*” She wanted to escape until she met the pediatric oncologist who was going to treat her son. She describes her as more humane instead of a professional who was trying to explain to her what the next couple of years would look like. This inspired Joan and her husband as she says to become as informed as possible about the disease to help their son.

Some of the parents found refuge in their belief system to cope with the treatment as they could not really “click” with any of the medical staff. Vicky describes the apathy of the medical profession as well as how the treatment did not help her son as the reasons why she agreed in opting for palliative treatment rather than more intrusive procedures in search for a cure.

Marius and Mary spoke about the “*power struggle over who knows the child better and who has the ultimate control over his/her welfare*”. During the group sessions Marius says that “*parents often feel they know better but this is not always the case*”.

Debbie spoke about the compassion of the medical staff and thanked all of them in her story. She seemed to have formed an intimate relationship with her doctor and the nursing staff which helped in agreeing and accepting what needed to be done. If she had not agreed it would have been problematic especially as her child underwent isolation and more intrusive procedures than the rest of the parents’ children.

This hypothesis implies that honesty and clarity of information works both ways. Parents and health care providers each need to feel that the other party is being open and forthright, and that serious issues are not being avoided.

STRENGTHS OF THE STUDY

This study focussed on social interaction through story telling within a support group of parents whose children were diagnosed with cancer and the information we gain from this is the story of the child's cancer, coping mechanisms and the contribution of the support group. This study, grounded in ethnography, adopted a radically different way of thinking (Hammersley, 1998) from the conventional, narrow and reductionistic conceptual frameworks underpinning most of the contemporary psychological research into childhood cancer. As a process ethnography involves prolonged observation of the group, typically through participant observation in which the researcher is immersed in the lives of the group members, (Agar, 1986). This is where the strength of the present study lies.

As a researcher I got so immersed in studying the meanings of behaviour, language and interactions of the support group that my role changed to that of co-therapist. Van Maanen (1995) suggests that in ethnographic research the researcher is a strategist and is the most important and sensitive instrument. Therefore, he continues, each strategist should adapt and employ any technique he/she intuitively feels will work. My change of role from researcher to co-therapist made an important contribution to giving a detailed description and analysis of each parent's themes and perspectives on the illness of their child. This led to what Wolcott (1994) calls a holistic cultural portrait of each member in the group that incorporated both the views of the participants and my interpretations. Each participant exists in his/her specific context and the themes generated, coping styles and what was helpful to each of the participants in the support group, fitted that person's particular cultural beliefs and values, life circumstances and relationships. Had a quantitative approach been used, the idiosyncratic attributions of meaning of each participant would have been lost. For example in the present study Tessa's seeking of assurances as a coping style and Marius' looking for practical solutions could be seen by the traditional psychometric evaluations as fixed personality characteristics but from the qualitative perspective of inquiry these behaviours were seen as attempts to bringing a balance in a life or system otherwise characterised by the chaos of the illness. In this framework the possibility of change is created as

suggested by Becvar and Becvar (1993).

In qualitative research the complexity of human functioning is respected. This is unlike the positivist-empirical tradition which according to Lincoln and Guba (1985) produces research with human respondents that ignores their humanness, a fact that not only has ethical but also validity implications. In the present study I formed a close and respectful relationship with each participant in the support group. Participants were viewed as a most reliable source of information and as experts in the field of coping with their child being diagnosed with cancer. Therefore qualitative research cannot be value free, which means that the researcher cannot, according to Lincoln and Guba, (1985) and Hammersley (1998), assume an uninvolved and objective position.

In qualitative research the traditional reliability and validity is conceptualised in terms of trustworthiness (Lincoln & Guba, 1985; Creswell, 1998; Meloy, 1994). In this study, the techniques of (a) prolonged engagement, (b) peer debriefing, (c) triangulation and (d) member checks were used for ascertaining trustworthiness.

Prolonged engagement requires the investment of sufficient time. The stories produced were the result of 15, 3 hour interviews with the support group which was made up of the participants. The time span during which the stories were told, lasted for 15 months.

Peer debriefing is necessary because “the process helps keep the researcher honest by exposing him/her to searching questions by an experienced protagonist” (Lincoln & Guba, 1985:308). Several friends served as peer debriefers, mainly providing the “opportunity for catharsis, thereby clearing the mind of emotions and feelings that may be clouding good judgement” (Lincoln & Guba, 1985, p. 308). Most often, however, I used the tape recorder to track my thoughts, doubts and concerns. When there was any doubt I listened to the recordings or read the transcripts again. Lincoln and Guba (1985) suggest “that the debriefer must be someone who is in every sense the inquirer’s peer, someone who knows a great deal about the substantive area of the inquiry and the methodological issues” (pp. 308-309). Within this light I used Petra, the

gatekeeper of the respondents, as my main debriefer.

Triangulation, according to Denzin (1997), is achieved through multiple data sources and data collection methods. In this study this was achieved by using the information from the group sessions, further interviews, journal writings, notes and reports from my co-therapist in the group, Petra.

Member checks “whereby data, analytic categories, interpretations and conclusions are tested with members of those stakeholding groups from whom the data were originally collected, is the most crucial technique for establishing credibility” (Lincoln & Guba, 1985, p. 314). In this study, when the interviews were transcribed the transcripts were negotiated with the respondents for accuracy to determine if I had captured their meaning. The respondents were always eager to share in my findings which made the process of member checks a pleasure. The stories and the themes which emerged were also shared and negotiated with the respondents in a group therapy session. The variety of foci were of interest to all the participants. The participants agreed with my interpretations and when there was disagreement, outcomes were negotiated.

Transferability is the next issue in a qualitative inquiry. Transferability means whether the study is applicable. In quantitative research this would be called “external validity” and would be expressed in the form of statistical confidence limits. According to Lincoln and Guba, (1985, p. 316) “the qualitative researcher cannot specify the external validity of an inquiry. The researcher can provide only the thick description necessary to enable someone interested in making a transfer to reach a conclusion about whether transfer can be contemplated as a possibility”. Since this study is a unique exploration of the researcher as the human instrument it cannot be replicated for verification. This study provides food for thought. The stories and conclusions are meant to be thought provoking. It will be up to the applier to determine which results and how well they apply to different contexts.

I disclosed the orientation of this study, the social and cultural context of the investigation was explained, and I interacted with the participants until redundancies

emerged in the information as stated by Lincoln and Guba (1985).

LIMITATIONS OF THIS STUDY

This thesis presumes individual construction of reality. The constructions may be shared or idiosyncratic, but the assumption is that realities are multiple i.e. there is more than one and they are constructed and holistic. From a traditional perspective this would be viewed as a limitation as the diverse meanings articulated in this thesis are not the only meanings that could exist. My descriptions represent a reconstruction of the participants' constructions and according to Moon, Dillon, and Sprenkle (1990) the mind tends to select data that confirms the meanings the researcher has identified.

The context of the present study may limit the applicability of the findings and the descriptive qualitative methods used means that this study cannot be verified by future research. The complexity of the context negates a linear model of cause and effect and the notion of variables which can be dissected and studied without connection to the context. This can be viewed as a limitation by traditional quantitative studies who, according to Lincoln and Guba (1985), select out for intense study one or a few variables while holding everything else constant.

A study of this kind involves intense personal interaction between the researcher and the participants which is not dispassionate and objective (Denzin, 1997). I selected a thesis of interest to me, one which fits my belief in the importance of the individual. The participants taught me a great deal and they too learned more about what they thought and about the realities they constructed for themselves. Reactions and interactions were a necessary part of this study. The limitation with this is that the connection between the researcher and participants is a very fragile one which raises important ethical issues (Moon, Dillon, & Sprenkle, 1990). Therefore my shift of role from researcher to co-therapist, which Van Maanen (1995) calls a change of strategy in ethnographic inquiry, was meant to attune me to this type of inquiry.

Because membership in social support groups is largely self defined, problems in

sampling and in the definition of the population being sampled are virtually insoluble. It is difficult to assure the validity of characteristics of the specific mode of operation of particular social support groups because of the high variability found in the practices of social support groups, even among those affiliated with the same national self help organisation as suggested by Levy (1976). Further, it is impossible to utilise any kind of research design involving randomised assignments either to alternative treatments or to control groups without doing violence to the essential nature of the social support group, even if they are willing to sanction such a study suggests Lieberman, (1983). Thus, as with all self report measures, the quality of the data obtained is entirely dependent upon the accuracy of the members' responses, which is difficult to assess.

It was considered as impractical to include the transcripts of the group sessions. Although this could be regarded as a limitation as it could have increased reader access, the transcripts were voluminous, and in this regard it was considered impractical to include them in the thesis. Pertinent extracts from the interviews are provided instead.

RECOMMENDATIONS FOR FUTURE RESEARCH

Unlike other diseases, cancer is unique in the ambiguity created for the child diagnosed with cancer and for the parent. For many illnesses, after diagnosis, a doctor can predict the course of the disease, specify the treatment and indicate the chances of recovery. Cancer represents a challenge because medical knowledge is still unfolding. Parents whose children are diagnosed with cancer do not receive clear statements but are presented with options. Outcomes are in probabilities. Psychological research can still do a lot in the field of cancer research for children. Research is needed from psychologists concerning medical decision making by the parent once his/her child is diagnosed with cancer. Perhaps a team of psychologists whose expertise is in cognitive psychology can look at how information is processed. Social psychologists can examine what social and environmental conditions influence personal decisions. Counselling and clinical psychology can explore what personality variables are involved. We need to understand and design approaches for parents that help them pursue the

decision making pathways that are appropriate for their child's individual situation, personal styles and values.

Ethnic diversity and a new understanding of culture encountered is needed. In order to address this, research on communication and communication processes should be a top priority. Doctors do not always have a good understanding of the gap between what they are saying and what the patient understands.

Chopra (1989) states that "a body that can 'think' is far different from the one medicine now treats," (p. 71). Because the implications of mind and behaviour are so extensive and the fruits of psychological research and intervention are potentially so great, many disciplines try to head off conditions and reactions that are challenging and new. Further studying and research is needed in the area of mind-body synthesis and if a holistic approach increases the quality of life of parents and childhood cancer patient.

This study concentrated on exploring stories of coping with childhood cancer in a support group for parents. Perhaps future researchers could look at exploring stories of coping with childhood cancer in a support group for children. Play therapy could be used as a basis of communication.

Much research has demonstrated the far reaching psychological effects of the hospitalisation of young children, therefore, whenever possible, support should be made available to enable sick children to be cared for within their own community. Further research could explore the support required to enable children undergoing treatment for cancer to be successfully maintained within their own community.

Finally, within recent years there has been a rapid growth of alternative approaches to the conceptualisation and study of social support groups, according to Powell (1994), many which promise to enrich our understanding of their operation by bringing different levels of analysis to bear and by broadening the horizon of meaning in addressing questions about outcomes and effectiveness (Luke, Roberts & Rappaport, 1994; Rappaport, 1994; Schubert & Borkman, 1994). I believe that the focus of these studies

should be on two broad objectives namely the assessment and enhancement of social support groups' effectiveness, and how social support groups can be most effectively integrated within a comprehensive approach to health care delivery, which will increasingly come under the constraints of managed care.

To achieve the first objective, programmatic research is needed to identify the processes that operate within social support groups and how they relate to outcomes. Achieving the second will require identifying the functions that social support groups are most uniquely qualified to perform, most cost effectively, in relation to the other components of the health care system in dealing with particular health and mental health problems. This question needs to be addressed by psychological researchers.

Research is also needed on the role of professionals in the growth and functioning of social support groups. While the potential contribution that professionals might make or, in some cases, have made to social support groups has long been recognised (Caplan, 1974; Powell, 1987), there has not been any systematic research concerning how they have worked with social support groups and with what effect.

CONCLUSION

This study is an exploration, through ethnographic and autoethnographic inquiry, of my personal struggle with this research topic. As the research process evolved my identity changed from researcher to co-therapist in a support group for parents who had a child diagnosed with cancer. This change of identity allowed me to explore the plight of a parent whose child is diagnosed with cancer through stories. Specific themes were highlighted as well as the coping patterns each parent used to cope with this trauma in their lives. The contribution of the support group was discussed as it applied uniquely to each parent. This information could prove to be valuable to psychologists working with parental support groups. The qualitative research method of ethnography proved to be valuable to gain this kind of information. Important areas for future research have been addressed.

This thesis is a representation and reflection of a unique personal journey. The format of this project may provide a research map for those researchers who embark on qualitative research projects that are embedded in group contexts. I am not claiming to provide any notion of truth in my thesis, and I am making no claim in providing the way of knowing. As Hobbs (1998, p. 228) states: *"It's always difficult to measure creative output since it is dependent on mood and energy levels, and what is written or painted or composed today may be changed, rearranged or even scrapped tomorrow."*

I conclude with a poem by Fred Rogers (1970), sent in by one of the parents whose child was diagnosed with cancer, entitled *"What do you do with the mad that you feel?"*

What do you do
With the mad that you feel
When you feel so mad you could bite?
When the whole wide world seems
Oh so wrong and
Nothing you do seems very right?

What do you do
Do you punch a bag?
Do you pound some clay or
Some dough?
Do you round up some friends for a
Game of tag or
see how fast you go?

It's great to be able to stop
When you've planned a thing that's wrong
And be able to do something else
Instead and think this song.

I can stop when I want to,
Can stop when I wish,
Can stop stop stop any time.

And what a good feeling to feel like this
And know that the feeling is really mine
Know that there's something deep inside
That helps us become what we can.

For a girl can be someday a woman
And a boy can be someday a man.

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APPENDIX A

CONSENT FORM

- Title of the study:** Exploring stories of coping with childhood cancer in a support group for parents.
- Purpose:** The purpose of the study is to explore, within a social support group setting, the stories of parents who have a child diagnosed with cancer. The story of the child's cancer will be looked at, as well as how each parent tried to cope and the contribution of the support group.
- Role of participant:** The parents of the support group who decide to become participants in this study will be respondents for a number of group sessions.
- Information:** The information shared during the interviews will be used as the basis for a doctoral thesis in psychology.
- Researcher:** As the researcher and co-therapist I intend to do my utmost to protect the confidentiality of the information shared as well as assure the anonymity of the participant. It is possible though that other individuals from the local context, who may read the thesis, might recognise participants based on the description of the case. But the participant will have an opportunity to negotiate the final outcome of the study in form and content with the researcher. I understand that the participation of the participant is completely voluntary. He/she may withdraw from the study at any time. I plan to make the experience

as thoughtful and as interesting as the interaction can be.

NAME:

SIGNED:

RESEARCHER

DATE

NAME:

SIGNED:

PARTICIPANT

DATE