

PASTORAL CARE AND COUNSELLING
FOR MOTHERS WHOSE CHILDREN DEVELOPED
EPILEPSY AND COGNITIVE IMPAIRMENT:
A CHALLENGE TO THE CHURCH

By

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UNIVERSITY OF NATAL**Abstract****PASTORAL CARE AND COUNSELLING FOR MOTHERS WHOSE CHILDREN DEVELOPED EPILEPSY AND COGNITIVE IMPAIRMENT: A CHALLENGE TO THE CHURCH****By ADRI MARIETTE SUTHERLAND**

A dissertation presented on the availability of Pastoral Care and Counselling for mothers whose previously normal, healthy children, developed epilepsy and became intellectually handicapped. The dissertation covers the mothers' reaction to their children's condition, the support they did or did not receive through Pastoral Care and Counselling and the theoretical perspective on pastoral care and counselling. Finally, the dissertation offers a challenge to the Church to seek ways of forming support groups to those suffering from grief.

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DEDICATION

This work is dedicated to Aidan, who restored my belief that God works miracles in big and small ways, and that we just have to stop and look to see them.


DECLARATION

I, Adri Mariette Sutherland, candidate for the Masters in Theology (Ministerial Studies) in the University of Natal, Pietermaritzburg hereby declare that: the whole thesis, except where specifically indicated to the contrary in the text, is my own original work:

Student's Name

Date

As the supervisor, I have agreed to the submission of this thesis.



Supervisor's Name

21-11-2003

Date

GLOSSARY

Aspirate: saliva or vomit that is inhaled into the lungs

Aspiration pneumonia: inflammation of the lungs caused by inhaling own aspirate

EEG: electroencephalogram, which is the recording of the electrical activity of the brain by placing electrodes on the scalp

Encephalitis: inflammation of the brain

Epileptic seizure: a brief electrical storm in the brain that causes unconsciousness and often stiffness followed by muscle twitching

Extubate: to remove the tube supplying oxygen from the ventilator

Febrile convulsion: a seizure that is caused by a very high temperature, and normally occurs in children between six months and four years; the child generally outgrows this condition by five years

Hysterical epilepsy: seizures brought on by external stressors with no clinical origin which also do not respond to anti-convulsants. Generally, when the stressors are removed, seizure activity ceases

Hyperbaric oxygen treatment: administering high doses of oxygen to a person in a high pressure sealed unit or tank to force the body to take up more oxygen

Idiopathic epilepsy: seizures of unknown cause, usually associated with a metabolic disturbance

Interictal: between seizures

Intractable seizures: seizures that cannot be controlled by a minimum of two drugs

Ketogenic diet: introduction of a diet high in fats, which leads to the production of ketones and, for reasons that are unclear, to reduction in seizure frequency

Lennox-Gestaut Syndrome: refers to a variety of clinical seizure types, generally tonic-clonic or myoclonic, associated with an abnormal EEG and generally poor prognosis for normal development, sometimes resulting in total mental retardation

Mono-therapy: epilepsy being treated with one anti-convulsant drug

Post-traumatic stress: a psychological condition characterized by anxiety, withdrawal, depression and a proneness to physical illness that may follow a traumatic experience

Pregnancy-induced hypertension: abnormally high blood pressure brought on by pregnancy

Status epilepticus: seizure activity lasting longer than fifteen to thirty minutes, or recurrent seizures that are so close together that no period of interictal consciousness occurs

Thiopentone: general anaesthetic used to induce a coma to lower brain activity to try and stop seizures

Types of epileptic seizures:

Generalised seizures: involve both hemispheres of the brain, generally manifesting in impaired consciousness

Absence seizures: previously called petit mal, refer to staring spells, usually less than twenty seconds in duration

Atonic: generalized seizures in which the predominant motor manifestation is loss of postural tone, associated with loss of consciousness, usually for several minutes. They are simply a grandmal seizure with limpness, rather than stiffness and repetitive jerking

Myoclonic: single or multiple brief, shock-like jerking movements of the head, trunk, or extremities

Tonic seizures are those in which rigid extension of the body and extremities occurs – the ‘stiff’ part of the grandmal seizure

Clonic seizures include those generalized seizures with repetitive bilateral clonic jerking of the extremities, with the typical alternating stiffening and jerking of the traditional grandmal seizure

Tonic-clonic: tonic and clonic seizures can occur individually, but when a tonic seizure is followed by a clonic seizure, it is called a tonic-clonic seizure, formerly grandmal

Partial seizures: involves the temporal lobe of the brain

Complex partial: impaired consciousness associated with cognitive symptoms (de

ja vu [familiarity], jamais vu [unfamiliarity], 'dreamy states', or affective disturbances such as fear or anger and hallucinations).

Other manifestations are hand wringing movements, lip smacking, or plucking at clothes and clicking sounds

Simple partial: consists primarily of focal motor activity (repetitive jerking of one arm, one leg or side of the face)

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CHAPTER 1

INTRODUCTION

Introduction

During the time of crisis of having a previously healthy child diagnosed with a debilitating condition, the mother goes through various stages of grieving similar to the stages of grief after losing a loved one in death. This grieving process is natural, as the mother has to come to terms with virtually losing a healthy, whole, little person, and having to accept a new child with special needs, and often with a changed personality.

The mother has to deal with the fact that her previously healthy child not only suffers from epilepsy, but is also now intellectually handicapped, or cognitively impaired. In their book “The Intellectually Handicapped Child”, Steenkamp and Steenkamp have the following definition for the term “intellectually handicapped”: “... refers to a general mental endowment which is inadequate to cope with the demands of life unless special assistance is given” (1992: 3).

For the mother to arrive at the point of acceptance, she will need the guidance and assistance of various support bases. Using three case studies, this study investigates the three mothers’ reactions to the realization that their formerly healthy, normal children developed epilepsy and became cognitively impaired. These mothers seem to have experienced similar reactions and emotions to a varying degree, but akin to the emotions experienced when having lost someone in death. In these case studies, all names have been changed to protect the identities of the participants. To avoid the cumbersome writing style of he or she, I will use the masculine pronoun throughout the dissertation where gender is concerned.

During their crisis period, these mothers needed a great deal of support from various support bases, namely from their husbands, their family and relatives, the medical fraternity, their community and community of faith, and especially their parish minister. This study investigates whether these support bases were available, and how effective

they were. This applies especially to the availability of the mothers' parish minister as representative of the community of faith and God's presence and love on earth.

Based on various theorists and their approaches, an attempt is made to define the role and function of the minister in attending to a mother in the crisis of her healthy child becoming epileptic and cognitively impaired.

Motivation

The motivation for this topic of research stems from my personal experience in the area of pastoral care and counselling. I experienced tremendous emotional trauma as a mother whose healthy, normal son contracted encephalitis resulting in him developing epilepsy and becoming cognitively impaired. It made me realise how much I needed support through pastoral care and counselling, as well as guidance from the Church, which was unavailable to me during my time of crisis. I have since decided to research the availability or lack of pastoral care and counselling for mothers whose formerly healthy children developed epilepsy and became cognitively impaired.

During the research painful wounds were opened, as I had to be brutally honest and own the feelings of resentment, embarrassment, anger, blame and guilt that I have experienced on my journey to acceptance. I came to realise that these feelings are normal, but that although one should not suppress them, one should learn to deal with them responsibly and positively in order to grow through the crisis.

Literature

The aim of this study is to find an ideal situation where pastoral care and counselling would be readily available for people in crisis, specifically for these mothers whose healthy, normal children developed epilepsy and became cognitively impaired. In order to facilitate this ideal situation, the contributions and approaches of these various theorists were applied.

I used a form of Pastoral Care and Counselling that uses support group therapy. I therefore used literature that was most succinct and demonstrative of the necessary group therapy needed for parents of children with disabilities. The following theorists support my choice of group therapy.

They are: Carkhuff and Berenson: "Beyond Counseling and Therapy"; Clinebell: "Basic Types of Pastoral Care and Counselling" and "Mental Health through Christian Community"; Egan: "The Skilled Helper"; Rogers as interpreted by Aden: "The New Shape of Pastoral Care and Theology" (edited by Oglesby); Estadt: "Pastoral Counselling"; Blanchette: in Estadt "Pastoral Counseling; Steenkamp and Steenkamp: "The Intellectually Handicapped Child"; Oates: "Grief, Transition and Loss"; Leick and Davidsen-Nielsen: "Healing Pain".

The Research Focus

The Research focus of this study is: What does pastoral care and counselling through the Church offer mothers faced with the crisis of their healthy normal children developing epilepsy and becoming cognitively impaired? An attempt was made to find answers to the following questions:

- ① • Did the mothers find pastoral care and counselling readily available when they encountered trauma in their lives?
- Did these mothers feel that they could approach their community of faith and minister without reservation?
- Is pastoral care and counselling able to answer the questions mothers have as to why their healthy, normal child is afflicted with a debilitating illness?
- ② • Can pastoral care and counselling show that God is still there even when a hurting mother feels her prayers are not being answered?

Regrettably, the answers to some of these questions were no, as the role of pastoral care and counselling was not always being fulfilled by the relevant ministers.

The role of pastoral care and counselling that emerged from this study, is defined as follows:

Pastoral care and counselling is God being there for us in our time of need, through the community of faith and the minister as affirmation and representation of God's love here on earth.

This definition of pastoral care and counselling is based on the pastoral care and counselling functions as outlined by Clinebell, which he in turn based on the findings of Clebsch and Jaekle. These functions are: sustaining and supporting – helping a hurting person to endure and to transcend a circumstance in which restoration to his or her former condition seems impossible; guiding – assisting troubled people to make confident choices, which will positively affect the state of their well being; reconciling – to re-establish broken relationships between a person and God, a person and others, and with self; healing – restoring the person to wholeness and leading him to advance beyond his previous condition; nurturing – to enable people to grow through their crisis and develop their God-given potentialities, throughout the life-journey with all its valleys, peaks and plateaus.

Theoretical Framework

The theoretical framework for this dissertation is contextual in nature, as I am using my own context and experience as locus of interpretation, as participant-observer in the light of the aforementioned theorists, namely Carkhuff and Berenson; Clinebell; Egan; Rogers; Estadt; Blanchette; Steenkamp and Steenkamp; Oates; Leick and Davidsen-Nielsen.

Research Design and Methodology

I have used both literary and oral sources for my research. In the literary research, I have used the abovementioned theorists to compare and identify an ideal pastoral care and counselling approach.

The oral sources were structured into three comparative case studies detailing the experience of three mothers having had healthy, normal boys who developed epilepsy and became cognitively impaired. Therefore, my research will be primarily qualitative, including semi-structured interviews with the three participants. These semi-structured interviews will be based on a predetermined, informal questionnaire. I will compare the three case studies to evaluate the effectiveness of pastoral care and counselling for each of the participants.

The interviews were conducted with people who were identified as having the same problem. The interviews were then conducted on an interpersonal level when the participants were offered trust and confidentiality.

At the time of the study the parish priests were unavailable for interviews. They were either on transfer or abroad. A lack of training in the area of disability and its effect on those concerned also means that the priests are unequipped to deal with the problem.

The Case Study Method

My reason for choosing the case study method as basis for my research is supported by "The Dictionary of Pastoral Care and Counseling", edited by Hunter, that gives the following definition: "The Case Study Method is an organized and systematic way of studying a person, group, family and reporting various crises, using a predetermined outline of questions" (1990: 124).

The Case Study Method has been used by various noted scholars, such as Anton T. Boisen, who developed his Clinical Pastoral Education Model based on the Case Study Method as a form of illustrating and teaching sectors of the community. Erik Erikson used the Case Study Method in explaining the psychosocial development of Martin Luther King and Ghandi

A case study usually deals with a problem of adjustment during a specific period of time. The most frequently used type of case study in pastoral care and counselling is that of the student's own experience (1990: 125):

- I. Background
- II. Description of the event
- III. Evaluation

According to the Dictionary of Pastoral Care and Counseling, "A case study should be theologically provocative in pastoral care" (1990: 126). I hope that I have adequately adhered to these principles.

Models of counselling

Lartey (1997: 57 – 61) discusses the following models of counselling, which have their roots in psychological counselling, which were considered before a final decision on specific models were made for the purpose of this study.

Insight-oriented approaches aim at helping people gain insight into the nature and development of their problems. As the origin of these mothers problems were not really developmental in nature, this model proved insufficient for this study.

Behaviouristic or learning theory-oriented approaches have as a basic premise that all behaviour is learned, and that all learning is the result of reinforced practice. They therefore aim at helping people to change their behaviour through the application of

principles of learning. Once again, this model proved inadequate for the purpose of this study.

Relationship-oriented approaches have the underlying assumption that human beings are relational beings. Through experiencing understanding and acceptance in the counselling setting, the person will be enabled to renew broken relationships with self and others. Due to the nature of these mothers' experiences and the resultant broken relationships with self, others and also with God, this model relates directly to this study and was therefore used to great effect.

Transpersonal or spiritual growth-oriented approaches regard spiritual growth as central and essential in all therapy or counselling, and crucial to the therapeutic process. Viktor Frankl based his therapeutic work on the basis of the human need for meaning and purpose. Jung likened individuation, or selfhood development, to a religious experience. This model greatly relates to the research of this dissertation, and was chosen for that reason.

Critique of Pastoral Counselling

Lartey offers the following critique of pastoral counselling:

On *psychological reductionism**, he quotes Pattison, who argued that pastoral counsellors often prefer using the outdated analytical tools of psychological theorists to current theological or social analysis.

On *social and political apathy*, he says that pastoral counsellors have unfortunately in their theory, not included issues of economic and social power, marginalisation, access and social control, which have a direct bearing on the personal and emotional well-being of people in any society.

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in my case this serious*

*(On a point of style, it is to be noted that throughout the dissertation, all quotations containing italics are the authors' own.)

On the *theological feebleness*, Lartey quotes Lambourne who criticised the pastoral counselling movement for “replacing Christian symbols with psychotherapeutic ones, changing theology into anthropology and idolatrously turning the relationship between counsellor and client into ‘God’” (1997: 80).

Lartey admits that *individualism* is emphasised in the Western forms of pastoral counselling, which stresses the intra-psychic, inner lives of hurting people as the focus of therapy.

Grief-healing Support Group

It is in response to these criticisms of pastoral counselling that I propose a model of a grief-healing group as a vehicle for healing in a group setting. This grief-healing group will be founded on, and grounded in theological and liturgical principles. This will emphasise the Christian faith aspect of the members in the group. The group itself will represent a community of caring and healing to each member, emphasising that they are not alone in their grief and pain, that there is someone who understands what they are going through. Clinebell and Leick and Davidsen-Nielsen are proponents of grief-healing groups as a therapeutic setting.

During a crisis, especially a crisis of self, there is a loss of function. There is symbolic significance relating to earlier losses, which requires self-integration. Adjustments can often be reached more easily in a group setting, as there is mutual support.

The crisis often causes shock, denial, anger and depression, which could lead to isolation of the grieving person. To reintegrate into the community, the person has to find meaning of God’s activity in this particular crisis. A grief-healing group can be the first step to reintegration into the broader community of faith.

Critique of the Grief-healing Support Group Model

Although I wanted to demonstrate to the Church what support and guidance are needed, I had to turn to support groups outside the Church, as there were no such support groups available. This resulted in the Grief-healing Support Group model being an eclectic mix of a grief support model, a parenting support model and a support group facilitated by people who have suffered the effects of physical trauma in their lives.

Chapter Outline

Chapter 2 Sustaining and supporting – helping a hurting mother to endure and to transcend a circumstance in which restoration to her former condition seems impossible

The three case studies are presented, focusing on the three mothers' experiences of their crises. Their children's acquired condition has an emotional, psychological, as well as a spiritual effect on the mothers. The function of pastoral care and counselling these mothers needed at this time, was the function of sustaining and supporting, which helps a hurting person to endure and transcend a circumstance in which restoration to his or her former condition seems impossible.

Chapter 3 Guiding – assisting troubled mothers to make confident choices, which will positively affect the state of their well-being

Faced with the crisis of her healthy, normal child developing epilepsy and becoming cognitively impaired, each mother went through a grieving process similar to that of having lost someone in death. These emotions are, amongst others, anger and blame, frustration, embarrassment and guilt. For the mothers to move through this stage of their crisis more easily, the pastoral care and counselling function of guiding should have been available to them. The function of guiding assists troubled people to make confident choices, which will positively affect their well-being.

Chapter 4 Reconciling – to re-establish broken relationships between the mother and God, the mother and others, and the mother and self

This chapter deals with the various support bases of the mothers during their crises. The pastoral care function of reconciling a person with God could be extended to reconciling a person to people who are supposed to be a support base as well. It is easy to become angry and embittered when support is not forthcoming when it is needed most.

Chapter 5 Healing – restoring the mother to wholeness and leading her to advance beyond her previous condition

In this chapter, the various theorists and their approaches and contributions to pastoral care and counselling are discussed. These theorists, Carkhuff and Berenson, Egan, Rogers, Clinebell, Estadt and Blanchette, propose a view of an ideal counsellor for a person in crisis. A mother experiencing the trauma of her child developing epilepsy and becoming cognitively impaired needs and deserves the care of a sensitive minister to help restore her to wholeness. The pastoral care function of healing - to restore a person to wholeness and leading him to advance beyond his or her previous condition should be expressed in the therapeutic relationship of pastoral counselling.

Chapter 6 Nurturing – to enable the mother to grow through her crisis and develop her God-given potential, throughout the life-journey with all its valleys, peaks and plateaus.

This chapter deals with ways in which the minister can assist a mother in crisis to work through her crisis successfully. Practical ways in which the minister can assist the mother in crisis, are: prayer, home visits, support systems, pastoral counselling in the form of brief counselling, and the formation of Small Grief-healing Groups. The pastoral care function of nurturing – to enable people to grow through their crisis and develop their God-given potentialities, throughout the life-journey with all its valleys, peaks and

plateaus, should be employed by the minister to enable the person to use the crisis as a growth opportunity.

Chapter 7 Conclusion

In this chapter I outline a proposed model for a Grief-healing group. Based on the work of Leick and Davidsen-Nielsen, as well as Clinebell, I have found that a small group to facilitate healing of various types of losses to be the best vehicle to do so.

Conclusion

Being a participant-observer had its limitations. The difficulty I had in writing this dissertation arose because I was wearing two hats: I had to be objective for the sake and purpose of this study, but as participant-observer, a mother whose previously healthy son contracted viral encephalitis resulting in epilepsy and cognitive impairment, I was also subjective. What made it more difficult was the fact that while I was researching and writing this dissertation, I was living with the difficulties I was writing about. Sometimes I would be dealing with acceptance in the dissertation, when my son would start having seizures and/or behavioural problems due to his condition or the change in drug therapy, causing tremendous ambivalence in me emotionally.

However, I feel that I have reached the point of sufficient growth from the crisis I have experienced, that I am able to use my experience to help others. This is what Clinebell describes as “the greatness about human nature is the ability to turn an adversity into an opportunity for growth” (1984: 228).

This was a long and arduous journey, which is by no means completed, but it is a journey for which I have found the strength to cope so that I could be of help to others in a similar situation. At the same time I want to offer a challenge to the Church to assist those in need of help through their grief.

C H A P T E R 2

SUSTAINING AND SUPPORTING – HELPING A HURTING MOTHER TO ENDURE AND TO TRANSCEND A CIRCUMSTANCE IN WHICH RESTORATION TO HER FORMER CONDITON SEEMS IMPOSSIBLE

Introduction

In the following three case studies, three mothers face the trauma of each having had a healthy little boy, who through an illness or from unknown causes, developed epilepsy and became cognitively impaired. The case studies highlight the effect that the children's illness and subsequent handicap have on the mothers. These effects are emotional, psychological and spiritual, according to Steenkamp and Steenkamp (1992), as well as Davis (1991) and Ruggill (in Ferry, Banner and Wolf: 1986) and Leick and Davidsen-Nielsen (1991).

In Case study 1, a healthy, normal little boy contracted encephalitis, which caused status epilepticus and resulted in intractable seizures and cognitive impairment. This had a profound effect on the mother, as will be seen in the discussion below.

2.1 Case study 1

THE CASE OF AMY: FROM DESPAIR TO HOPE

Interviews with Amy on 6 March 2003; 3 April 2003 and 28 April 2003

Three years ago, Amy found her eldest son, James, then 4 ½ years old, early one morning having seizures in bed. She took James' temperature, thinking it might have been a febrile convulsion. His temperature was 35 degrees Celsius, which made her think that the thermometer was faulty, and so incidentally did the general practitioner when she told him. Later she was to learn from the Paediatric Neurologist that extreme temperature fluctuations occur with encephalitis, the disease James had contracted.

At the Medical Centre, James could not be stabilized, even on repeated high doses of Valium. Eventually the paramedics took him to the hospital. The paediatrician at the children's ward also tried in vain to stabilise James. Amy and John had to hear the devastating news that their son was fatally ill and would be transferred to Intensive Care Unit (ICU). When they were allowed to see him in ICU, he looked stable although he was attached to a multitude of tubes and machines. Unbeknown to them, this was the beginning of several gruelling weeks, which taxed them physically and emotionally while their son was fighting for his life. They were told that James had contracted encephalitis resulting in the intractable seizures. He was put on a ventilator, as he could not breathe on his own due to aspiration pneumonia contracted when he inhaled his own aspirate when the seizures started. He subsequently had to have a tracheotomy for fear of infection as he was on the ventilator for so long – every time he was extubated he would stop breathing when the seizures flared up.

After ten days of no change in James' condition and wasting away in front of their eyes, Amy and John requested that a Paediatric Neurologist be called in, feeling that if the worst happened, they as parents had done their best. After examining James, the paediatric neurologist explained to Amy and John that he had been called in late on James' case and that James was very, very ill. He did not want to give them false hope, but he would try his utmost to help them.

The paediatric neurologist put James into an induced coma with thiopentine for twenty-four hours. This was done to try and stop the excessive electrical activity in the brain that was causing the intractable seizures. When the infusion was stopped, the seizures started again. The infusion was resumed for another twelve hours, and when stopped, James went into a natural coma.

When James started to come to, he would just blankly stare ahead of him, not showing any indication that he was aware of his parents, or his surroundings. After several days, Amy walked into the ICU and James turned to look at her. When she held him in her arms, he burst into tears, and so did she. This was the start of a long and painful recovery.

James had to relearn how to walk and talk and he had developed learning disabilities. He had also become incontinent because he was on a catheter for so long while in ICU, and had to be potty trained again. To boost his immunity, he was put on steroids, which made him go from an emaciated little bone-bag to being bloated. With physiotherapy he could walk again by the time he left the hospital.

At home, Amy and John had to take over the role of the nurses. They had to make sure that James had his medication on time, and when he had seizures they had to administer Valium rectally. Despite this, he landed back in hospital twice with status epilepticus.

Now, three years later, the unpredictability of James' seizures still takes a toll on them. His medication has been adjusted numerous times, but to date they have been unable to control the seizure outbreaks.

2.2 Effect of the child's condition on the mother

a. Emotional effect

When her son was hospitalised, it seemed at first that he was not going to recover. However, when James made it through the first day, Amy realised new hope for her son's recovery. There were times during his protracted stay in ICU when her hopes would sometimes flounder, but her husband's steadfast belief that James would recover also made her belief stronger.

It was only when James was discharged and his care rested squarely on her shoulders that the reality sank in. She then realised the gravity of his epilepsy, the condition she took a long time to admit to, and the severity of his intellectual handicap. She was heartbroken at the thought of her previously healthy normal son, becoming a special needs child. At the same time she would rejoice at the progress he was making in his recovery, even his returning to crèche.

James' daily need for care affected Amy's relationship with John. She felt as if he was interrogating her about James' care when he would come home, as if he did not trust her with their son's care. There were days that James would have so many seizures that Amy felt she could not cope with her domestic workload, her sick son and her one-and-a-half year old toddler. The relationship between Amy and John deteriorated to those of polite housemates, with the occasional argument about the state of the house. Conversation centered mainly on the children and James' treatment. There was very little couple time in their marital relationship.

Amy also felt that John was spending a lot of time away from home. People would often call him to come and fix things at their homes and he would oblige without consulting her. She felt that he should inform people about their situation at home and even refuse. He felt that she was being selfish because he was only helping people, whereas she felt that he should help her at home with the children. A severe communication problem was in evidence.

b. Psychological effect

Amy fell pregnant unexpectedly with her third baby who would be born when James was six years, and her second son only thirty months old. Instead of the bonding she and John shared during the previous two pregnancies, they drifted further apart. At the time she found out that she was pregnant, James was readmitted to hospital with status epilepticus.

Amy's precarious emotional state at that time caused her to fall into a deep depression. She barely managed to look after her children and most of the time neglected her home. She could not sleep, and asked the pharmacist for some sleeping tablets. He told her she could not get sleeping tablets without a doctor's prescription. At that, she blurted out her story to him, a perfect stranger. The pharmacist then told her that she was suffering from post-traumatic stress. Relieved that she could now name what she was experiencing, she tried harder to cope on her own, sometimes succeeding, more often not at all.

Amy's self-esteem suffered because she started feeling inadequate as a mother and wife, incapable of performing even the most basic household chores. She started having suicidal thoughts, thinking her family would be better off without her. What stopped her from attempting it was the thought of someone else bringing up her children. Eventually, she realised that she needed psychological counselling.

When she went for her first session, it turned into a double session, because the psychologist felt that she needed it. He also booked her for two more sessions for that week because she was so stressed out. Eventually, she and John also had some joint sessions. This, she feels, saved their marriage. They could both verbalise their true feelings with the mediation of an objective third party. They also learned better coping strategies in dealing with James' condition and care, as well as how to improve their relationship and that of their little family.

The stress Amy was under during her pregnancy took its toll. She landed in hospital with pregnancy-induced hypertension, resulting in an emergency caesarean section delivery of her baby at thirty-four weeks instead of a full term forty weeks. Because she had general anaesthetic and the baby was born at 2 am, Amy only saw the baby at 9 am. When the nurses brought the baby to her, she did not recognize the baby. He did not look like her first two babies and she had to look for familial features to determine whether he was really her child even though his wristband identified him. Whereas she bonded instantly with her first two babies, it took her two weeks of mechanically caring for her baby before she experienced the same overwhelming love for him that she had for the other two at birth.

Amy's second son, now four and a half, was only one and a half years old when James fell ill. She was torn between wanting to be with James at hospital and being with her baby. Even when James was discharged, she felt guilty that she was almost neglecting him because James' care took up so much of her time. She feels that they missed a lot of his growth. She also found that he was now often treated as the eldest, and that they

consciously had to remind themselves that he was only four years old. His crèche teacher told them that he was displaying traumatic behaviour, for example drawing and colouring in hard black crayons. Now they are trying to spend time alone with him. They also allow him to have sleepovers at his older cousins, where he is treated as a little boy, because he is younger than they are.

c. Spiritual effect

Amy feels that God's presence was conveyed to her through her own prayers and those of other people. When James was still in ICU, his name was put on the prayer lists of their own parish, as well as other parishes. Strangers would approach them when visiting relatives in the ICU and told them that they would pray for them and put James' name on their parishes' prayer lists.

When James recovered, Amy jokingly said that God had to let him live because the whole world was praying for him: people leaving for Australia, America and England all said that they were going to put him on their prayer lists, and so did people in Durban, Cape Town and Johannesburg. They even had Hindu and Moslem people approach them, saying that they would be praying for them.

At one stage Amy felt that she could not bear the agony of seeing her son in pain anymore. She found herself crying to God: "Do You know what I am going through?" She then instantly envisioned Mary at the foot of the cross while her Son was suffering on it. She felt that was God's answer to her: that He did understand. As a convert from the Reformed tradition to the Catholic tradition, this was an enlightening moment for Amy. Although she converted to the Catholic Church, she never really paid much attention to the veneration of Mary and the saints. Yet, at her lowest point as a mother, Mary is the person she could identify with, and even ask Mary, 'mother to mother', to intercede for her and her son. The saint she asked to intercede for James when he was critically ill was Saint Anthony, the saint of miracles.

Amy had stopped attending church for a while after James was discharged. This was for two reasons. Firstly, their nights were so unpredictable in terms of James' seizures and insomnia, that she was too tired in the mornings. Secondly, she felt that the church was not there for her during her time of need, particularly the parish priest, that she saw no reason to go to church. However, after a lot of prayer and soul searching, Amy started attending church again.

During times when Amy finds it extremely difficult to cope with James' seizures and the added care he requires during the seizure outbreak, she often feels that she must have done something terrible in order to be punished in this way.

In Case study 2, the little boy was also a healthy, normal child up to the age of three. He suddenly started having seizures, but the doctors could not determine the cause of his seizures and attributed the cause to idiopathic epilepsy. Sandy's son's seizures and cognitive impairment affected Sandy deeply, as will be seen in the discussion below.

2.3 Case study 2

THE CASE OF SANDY: FROM GUILT TO REALIZATION

Interviews with Sandy on 20 May 2003; 29 May 2003 and 5 June 2003

Sandy's eldest son, Ian had a febrile convulsion at sixteen months. He has a history of chronic tonsillitis, which was treated with high doses of medication and antibiotics. At three years, he had a tonsillectomy. Shortly after the tonsillectomy, he had a tonic-clonic seizure at crèche. Sandy witnessed the second tonic-clonic seizure at home, and rushed him to hospital. At hospital Ian was diagnosed with epilepsy. Ian started having multiple seizures, alternating between atonic, myoclonic and tonic-clonic. He sometimes had up to seventy-four seizures per day before adequate medication levels were able to bring the number of seizures down. However, even now, two years later Ian's seizures are still not fully controlled. Ian also developed learning disabilities due to the excessive amount of seizures bombarding his brain.

2.4 Effect of the child's condition on the mother:

a. Emotional effect

Sandy also has another two-year old toddler, and a baby of four months. She had left her husband Mike during her pregnancy with the last baby, but returned to him after the birth. Their relationship was very strained, until recently when Sandy exploded in anger over his treatment of her.

Having moved from Johannesburg to Durban the previous year, Mike was always inviting his family to spend long weekends and school holidays at their home. Sandy used to keep quiet about having to provide meals and accommodation for them, while they did not even help her to cook or clean up afterwards. She found it ironic that his family was not even on speaking terms with her, but could use her home as a “free hotel”. The last long weekend was the last straw, however. She blew her top in anger for the first time, and told Mike exactly how she felt about his treatment of her during their entire marriage. He was stunned, because it was the first time that she had spoken to him in such a manner. However, it does look as if he is taking her seriously, and their relationship seems to be more relaxed of late.

Sandy feels that she has hardly any time for her other children, as she has to concentrate on Ian so much. When she does spend time with the other two children, she feels guilty for neglecting Ian.

b. Psychological effect

Sandy is very concerned about Ian's condition, as she was told that the prognosis was not very good. She was told that he has a diseased brain, which is progressively degenerative. This had a profound effect on her. She is frantically looking for alternative

treatments for Ian. She has tried homeopathy and spiritual healing, which thus far have proven unsuccessful. She is also considering the ketogenic diet and hyperbaric treatment in an attempt to at least control the seizures and stop the degenerative effect. Sandy is focusing so much on Ian and his treatments that she is even considering sending her other two children to live with her mother so that she can concentrate even more on Ian.

Sandy and Mike's relationship is on very rocky grounds, and has been from the onset of their marriage. Both set of parents seemed to have opposed the marriage. Living with her in-laws at the start of their marriage, complicated the relationship between Sandy and Mike, as well as Sandy and her in-laws, with Sandy feeling that Mike sides with his family against her. With Ian's condition causing her so much distress, coupled with taking care of a toddler and a baby, at times Sandy feels that she is unable to cope. She says that sometimes she feels suicidal, which she tells Mike, in an attempt to make him aware of the extent of her feelings. He laughs it off and tells her that he will give her the razors, or asks her why does she not jump out of their seventh floor flat window.

c. Spiritual effect

Sandy is a very spiritual person. She prays daily, especially for Ian's health to improve. To that effect she has taken him for spiritual healing. She also regularly obtains holy water from the Catholic Church for him and says healing prayers over him. Sandy's faith in God has not diminished through her traumatic experience; instead she draws solace from it. She does however feel that Ian's illness is a punishment for her disobeying her parents in marrying Mike. Her frantic efforts to find a cure for Ian's condition seem to be a way of atonement for her disobedience.

In Case study 3, the little boy also having been a normal, healthy child until almost three years, suddenly started having seizures. As in Case study 2, the doctors could also not determine the cause of the seizures and also attributed it to idiopathic seizures. He also became cognitively impaired. Once again, the trauma of Jean's son's condition affected her on various levels.

2.5 Case study 3

THE CASE OF JEAN: FROM DENIAL TO ACCEPTANCE

Interviews with Jean on 30 July 2003; 16 August 2003 and 20 August 2003

Two years ago, Jean's son Liam, started having seizures at 5 AM every Saturday morning. Even after having five seizures in a row, he seemed to be fine afterwards. The staff at the hospital asked her whether there was any change in their weekend routine that might be bringing on the Saturday morning seizures. Jean felt that Liam should be used to his father, Rick, rising early and working at weekends, so she did not feel that he had any reason to feel insecure. The reason the staff was asking these questions was to determine whether Liam was having hysterical epilepsy.

Jean was given Valium to administer to Liam on a Friday evening to try to prevent the seizures. This treatment worked for about three weeks, as his body probably got used to the Valium, and the seizures started again. This pattern continued for approximately six weeks and Liam was put on anticonvulsant treatment.

When his seizures stopped the staff at this particular hospital stopped the anticonvulsant treatment. Because this was done abruptly, it caused Liam to have severe rebound seizures. He had a seizure every half an hour, amounting to eighteen that day, before it was brought under control.

The staff at this hospital was unequipped to handle Liam's case, and he was transferred to a hospital that is more specialized in this area. Liam had to undergo various tests, amongst others, a glandular test and a thyroid test, to determine the cause of his epilepsy. The tests all proved negative, with the doctors identifying his epilepsy as idiopathic, which means that it is caused by a chemical imbalance with no known cause. For the next ten months, Liam suffered approximately thirty seizures per month before the medication was brought to therapeutic levels. His seizures have now been under control for almost two years, and soon he will be weaned off the medication to see if the epilepsy is controlled without medication.

2.6 Effect of the child's condition on the mother

a. Emotional effect

Jean was devastated when Liam was diagnosed with epilepsy. She had stopped smoking shortly before he started having seizures, but this trauma she was experiencing caused her to start smoking again.

Her relationship with her husband, Rick, deteriorated because they were concentrating so much on Liam and his condition. Their intimate relationship became non-existent and they were hardly communicating with each other, not even arguing. She has no idea how Rick feels about Liam's condition, as he does not talk about it.

Jean has an older daughter who was nine at the time Liam started having seizures. Jean feels that she had little time for her daughter, expecting her to look after herself and become more independent, as she was older. She feels that she took out a lot of her frustration about Liam on her daughter. Her daughter's schoolwork deteriorated to such an extent that Jean was called in by her teacher. She had to explain the situation to the teacher. Since Liam's seizures were brought under control, her daughter's schoolwork improved, as well as the mother-daughter relationship.

b. Psychological effect

Jean said that she felt as if her whole world was crumbling and crashing in around her. She had felt suicidal at the time, wanting to walk off a bridge, because she just wanted it all to end. She feels better now that the seizures are under control, but the trauma of what she went through will never leave her. She still gets flashbacks of her traumatic experience. Despite Liam being seizure-free for almost two years, she still expects him to go into a seizure unexpectedly.

c. Spiritual effect

Jean says what baffled her was that a normal, healthy child could have seizures without any cause. The fact that he would scream before a seizure, led her to believe that the cause of his seizures were spiritual. This belief was reinforced when the doctors at the first hospital told her to go for spiritual healing, as they did not know how to treat Liam and could not find the cause of his seizures. Women from her church, the Full Gospel Church, came to pray for the 'bad spirit' her son had fallen under. She believes that somebody was dabbling in 'dirty spiritual matters', when her child was unwittingly in the wrong place at the wrong time.

Her Bible Study class sustains this belief of hers where she learnt that there are two sicknesses that are not 'God-given' – the one is epilepsy and the other is madness. Both are caused by demon-possession. She also believes that it is the devil that made the pattern in which the epilepsy manifested itself.

Jean belongs to the Full Gospel Church, but even prayed a nine-hour Novena that she obtained from a Catholic friend in her desperation to find healing for her child. She also took him to tent crusades and faith healers.

During the time when Liam had uncontrolled seizures, Jean questioned God repeatedly to find out what she had done to deserve to be punished in such a way.

Summary

Their children's acquired condition has an emotional, psychological, as well as spiritual effect on the mothers.

Emotionally, the mother is heartbroken at the thought of her previously healthy child becoming a special needs child. The child's condition also affects the mother's relationship with her other children as well as her husband. Davis confirms this: "Family relationships are central concerns for all, but can be a source of particular worry for parents of children with disabilities. One frequently hears mother's anxieties about neglecting their husbands and especially their other children" (1991: 228). Ruggill found that: "Although not direct victims of the disorder, brothers and sisters of the child with epilepsy may feel particularly helpless. They may feel chronically neglected by their parents who may appear to place the needs of the epileptic child ahead of his brothers or sisters" (Ferry, Banner and Wolf 1986: 203). Ruggill cautions that the normal jealousy between siblings may be increased because of the perceived preference the parents have for the epileptic child. She says that parents should be counselled to expect this reaction and spend special time with the other children.

In the case of Amy, she felt that at times she could not cope with looking after James, her toddler and the subsequent pregnancy. Her relationship with John deteriorated, with a marked communication problem, which was only resolved once they sought psychological counselling. Amy found that her second child displayed anger, which could be a result of him feeling neglected, because of his sickly older brother, as well as the new baby. The typical middle-child syndrome is magnified by his older brother's condition. She and John are trying to pay special attention to him to overcome this feeling of neglect.

Sandy feels guilty when she spends time with her toddler and baby, and on the other hand, she feels that she neglects them when she sees to Ian. Her relationship with Mike is unpredictable, alternating between periods of relative calm and volatile arguments. Jean was concentrating so much on her youngest child, that she neglected her older daughter,

although their relationship has improved of late. Jean's relationship with Rick also deteriorated due to a lack of communication and intimacy. Although their relationship has improved since Liam's seizures stopped, she still does not know how he feels about their son's condition.

Psychologically, their children's condition seemed to have had such a devastating effect on the mothers that their coping abilities proved inadequate at the time. In all three case studies the mothers became very depressed and felt they could not cope any more with their situation. This had such a profound effect on them that they all contemplated suicide at one stage, something that they fortunately did not carry out. Only Amy sought psychological counselling, whereas Sandy and Jean tried to cope on their own. Sandy is experiencing her crisis so acutely, that she wants to send her two youngest children to her mother, so that she can concentrate on Ian only.

Spiritually, the mothers vacillated between deepening their faith in God by relying on Him for comfort and strength to carry their burden; and on the other hand directing anger and blame toward Him for allowing their child's condition. A very important concept that came to the fore is the fact that all three of these mothers felt guilt at their children's condition, as if they could have prevented their children's condition. However, the most profound feeling of guilt was their assumption that they were being punished by God for some sin that they must have committed.

In his book "Why do people suffer", James Jones says that: "One of the commonest reactions to unexpected suffering is that it may be a punishment from God. We inevitably go in search of reasons, or for somebody to blame. These ideas dominate the first thoughts of most of us when we suffer" (1993: 51). This was exactly the reaction of these three mothers when they were experiencing the crisis of their children developing epilepsy. They were convinced that God was punishing them for something they must have done wrong. Amy and Jean could not pinpoint these sins for which they were being punished, whereas Sandy thought she knew what she had done wrong.

This raises the question of the theological origin of human suffering in any form, as God's punishment for human sin.

Human suffering as punishment for sin

According to John Hick, in his book "Evil and the God of Love", the theodicy-tradition teaches that all evil that indwells or afflicts humankind is, according to Augustine, 'either sin or punishment for sin'. This tradition, according to Hicks, has descended from Augustine through Aquinas to the more tradition-governed Catholic theologians of today, as well as in the Reformers and in Protestant orthodoxy (1977: 172). Whether one agrees with this theology or not is irrelevant, as this is the way people often feel when calamity strikes. This is also how these mothers felt when they experienced the trauma of their healthy, normal child developing epilepsy and cognitive impairment.

Hicks argues that to regard an individual's sufferings as divine punishment for his sins, is a very ancient and very natural theory, which tends to appeal both to the conscience of the sufferer and to the judgment of the onlooker. He says that the punitive theory is built into the English language, as 'pain' is derived from the Latin *poena*, which means penalty or punishment. Following the punitive view of suffering is the fact that every sufferer (beyond infancy) is also a sinner, although suffering is not directly related to the degree of his sinfulness. Sometimes the innocent suffer horrifically whilst the wicked seem relatively untroubled.

However, the disparity between guilt and pain does not undermine the Augustinian theodicy, which speaks of the 'actual' sins of individuals as well as the 'original' sin of humanity as a whole, of which the evils afflicting humankind generally, and having to be borne unequally by different individuals, are a divinely appointed consequence. Thus the sufferings of the apparently innocent are met by the doctrine that, properly speaking, no one is innocent – for no one, not even a new born child, is innocent in respect of Adam's crime (1977: 172).

Meaning in suffering

Hicks defines suffering as “that state of mind in which we wish violently that our situation were otherwise. The characteristic elements of human suffering consist of regret and remorse; anxiety and despair; guilt, shame, embarrassment; the loss of someone loved; the sense of rejection, of frustrated wishes, and of failure” (1977: 318). In the next chapter, these emotions will be discussed more fully. It will come to light that these mothers all experienced these emotions to a lesser or greater extent.

Hicks maintains that suffering can be either self-regarding or other-regarding. The violent and obsessive wish that the situation were different may have in view self-interest or the interest of others. It may spring from self-concern or from sympathy. This distinction is relevant to the theological question as to whether Christ, as one who was sinless, can have experienced suffering (1977: 319).

Hicks suggests the following answer

In general our human sufferings are self-regarding; we wish *for our own sake* that our situation were otherwise. Christ’s suffering, on the other hand – as when he wept in sorrow over Jerusalem – was an other-regarding anguish; he grieved, not for himself, but on account of others. We may say, then, not that Christ, as God incarnate, did not suffer, but that he did not suffer egotistically, as we do.

(1977: 319)

Amy, Sandy and Jean all experienced “that state of mind in which we wish violently that our situation were otherwise”. However, their wish for their situation to be otherwise occurs on both levels as proposed by Hicks. They wished for their children’s suffering, as well as their own mental anguish, to be changed. All three of them admit to even praying that they could take their child’s suffering on themselves, instead of watching their child’s suffering. This of course does not put them on the same level as Christ’s suffering, but it gives them an idea of what Christ went through, suffering on behalf of humankind.

Hicks says, that according to Irenaeus, human suffering exists in order for God to complete ‘soul-making’ or character training in the human life. He says that even from the most traumatic tragedy human kindness can abound that makes even the tragedy worthwhile. For example, he says that a selfish spirit may be moved to compassion, a thoughtless person discover life’s depths and be deepened thereby, a proud spirit learn patience and humility, a soft, self-indulgent character be made strong in the fires of adversity. When this fails to happen, instead of ennobling, affliction may crush and wrest from it whatever virtues it possessed (1977: 330 – 331). These mothers learned from their tragedy, not only to care and accept for a virtually new little being, but also to be more compassionate towards other children and people with disabilities, which are often worse than their own children’s.

In the New Testament, suffering is viewed as capable for constructive use. This starts with Jesus’ agonizing pain and suffering, resulting in his death, being viewed as Christ fulfilling the pattern of redemptive suffering for the sake of humankind. In one of the Church’s cardinal doctrines, the judicial murder of Christ was the focus of God’s redemptive work and the turning point of humankind’s salvation. The paradigm of evil is therefore turned into good by the voluntary endurance of pain and suffering as God’s servant and agent (1977: 355).

The members of the early Christian communities continued this view of suffering. The three main themes are: Firstly, there is a rejoicing in the hardships and persecutions of Christian apostleship as a sharing of both the sufferings of Christ and the joy of his redemptive work, for example, Paul states in II Corinthians 1 verse 5: ‘as we share abundantly in Christ’s sufferings, so through Christ we share abundantly in comfort too’. Secondly, there is a vivid expectation of sharing in the joy of Christ’s heavenly Kingdom, for example, Paul states in II Corinthians 4 verses 16 – 17: ‘So we do not lose heart. Though our outer nature is wasting away, our inner nature is being renewed every day. For this slight momentary affliction is preparing for us an eternal weight of glory beyond all comparison...’ Thirdly, there is a sense of ‘soul-making’ significance of suffering, as Paul

states in Romans 5 verses 3 – 4: ‘we rejoice in our sufferings, knowing that suffering produces endurance, and endurance produces character, and character produces hope...’ (American Revised Standard Version: 1952).

The Biblical answer for our own suffering today can be found in the response of Paul in his letter to the Romans. In chapter 8 verse 28, Paul says that ‘in everything God works for good with those who love him’. In verses 38 – 39 he says: ‘neither death, nor life nor angels, nor principalities, nor things present, nor things to come, nor powers, nor height, nor depth, nor anything else in all creation, will be able to separate us from the love of God in Christ Jesus our Lord’ (ARSV: 1952). Hicks says that we do not know how or when God is bringing future good out of our suffering, but we must be assured that He is doing so, and that we can therefore commit ourselves wholly to his providence, as the practical outcome of faith in God’s love and sovereignty as seen in the life, death and resurrection of Christ (1977: 360).

Conclusion

Although these mothers often despaired at their children’s condition, their deep-rooted faith in God helped them to pull through the most traumatic event in their lives. They strongly believed that God was sustaining them through this traumatic time.

The three mothers in the case studies were profoundly affected by their children’s condition. They experienced emotional, psychological and spiritual trauma.

Emotionally, their state of mind and their feelings of inadequacy to cope with their situation, affected their relationships with the rest of their family members. It took time for them to mobilise their coping abilities before they could improve their relationships

Psychologically, Amy, Sandy and Jean felt their coping abilities to be so minimal that all three of them contemplated suicide at one stage. However, they were able to draw on their

inner strength to rise above their feelings of hopelessness and despair to carry on with the task at hand, that of taking care of their little boys who desperately needed their help and care. This was no easy task, made even more difficult having to cope with the care of their other children.

Spiritually, these mothers all had a deep-rooted faith that was sorely put to the test. They all drew on their faith to sustain them during their traumatic times. However, they also felt that they were being punished for some sin they must have committed to deserve punishment by God.

This belief has been handed down throughout church history by the theology of Augustine, and preserved by the Church. However, at the same time the belief that suffering has meaning also has Biblical grounds. Therefore, one can draw solace from the fact that through suffering, one can make a positive change in one's life so God can accomplish the process of 'soul-making'.

CHAPTER 3

GUIDING – ASSISTING TROUBLED MOTHERS TO MAKE CONFIDENT CHOICES, WHICH WILL POSITIVELY AFFECT THE STATE OF THEIR WELL BEING

Introduction

During the time of crisis of having a previously healthy child diagnosed with a debilitating condition, the mother goes through various stages of grieving similar to the stages of grief after losing a loved one in death. This grieving process is natural, as the mother has to come to terms with virtually losing a healthy, whole, little person, and having to accept a new child with special needs, and often with a changed personality.

Hilton Davis says the following:

The sight of an ill or disabled child elicits powerful and complex feelings of alarm, sadness and anger, along with the desire to help, comfort, and protect. An immediate reaction is an urge to make the child better. These are strong feelings for an onlooker, but so much more powerful, even desperate, for the child's parents.

It is essential that parents adapt to their situation before effective help can be made available to the child. If the parents are distressed, have no clear idea of the benefits of what the professional advocates, cannot work with the child for whatever reasons, or do not want to, then all other efforts will be attenuated.

(1991: 223)

As seen in the previous chapter, these mothers do feel overprotective about their children. They even went so far as to wish that they could take their children's suffering on themselves. In a desperate attempt to get their child better, they resorted to means that they normally might not have otherwise considered. Sandy and Jean tried faith healing. Jean even prayed a nine-hour Novena, which is a Catholic prayer, although she belongs

to the Full Gospel Church, which is a Pentecostal Church. Amy delved deeper into the Catholic tradition by enlisting the intercession of Mary and Saint Anthony.

The mother has to deal with the fact that her previously healthy child now not only suffers from epilepsy, but is also now intellectually handicapped. In their book “The Intellectually Handicapped Child”, Steenkamp and Steenkamp have the following definition for the term “intellectually handicapped”: “... refers to a general mental endowment which is inadequate to cope with the demands of life unless special assistance is given.” (1992: 3).

They state the following:

On becoming aware of the problem, the parent is often dazed and unable to think of any way out of the dilemma.

Then follows a state of shock from which various emotions emerge – especially feelings of frustration, loss, sadness and even shame. You want to be proud of your child and then comes the realization that this one is ‘different’ - he does not fulfill parental ambitions; yet he belongs to you and must be accepted and recognized as such; it is yours and yet not yours; a feeling of ambivalence develops – wanting and yet rejecting the child.

Shock may gradually change to ‘*chronic grief*’ or a feeling of loss where the parent will continue thinking of what the child could have been.

Parents of a handicapped child first ask: Why me? Why must I be the one to be punished? Once they become resigned to the fact they ask: Why him? Only then does self-pity change to an attitude of readiness to really support the child in his needs.

(1992: 12)

As seen in the previous chapter, these three mothers have experienced the shock at the diagnosis of their children’s condition, and experienced the emotions of frustration, loss, sadness and embarrassment, which at times made them wish that their situation could be

changed, that their child could be well again as before he became ill. At times the frustration at the child's behaviour gave way to a feeling of resentment and rejection of the child, which lead to feelings of guilt in the mothers.

The mothers' perception that they are being punished has also been discussed in the preceding chapter. It could be seen that the mothers perceived their suffering on two levels: firstly, on the level that they are being punished, which according to Hicks is self-regarding, secondly, they saw their suffering in relation to their child, wanting him to be well again, which according to Hicks is other-regarding (1977: 319). This happened once the mother was able to come to terms with her son's condition, and could accept him as a new little being to be loved and cared for, as his condition has changed his personality, effectively changing him into a new child.

This acceptance is not easy, as Steenkamp and Steenkamp state:

...the extent of acceptance is determined by the parents' temperament, values, faith and even intelligence. The higher the intelligence of the parent, the wider the gap will be between their expectations and the child's potential; the sharper the contrast between him and the other children. Their disappointment will be greater, but the possibility of a more realistic acceptance and approach will be correspondingly greater.

(1992:12)

The acceptance did not come easy, and the child's behaviour sometimes complicates the mother's acceptance. However, the mothers' acceptance of their children was mostly based on their deep faith and belief that God would lead them through their crisis.

Davis also states that:

Learning that there is something wrong with the child is a profound crisis for the parents. Literally this means a point of change, a time for decision. They have to adapt to a sudden occurrence that has serious long-term implications, which are probably far beyond their previous experience.

They begin the process of losing their images of the non-disabled child and start to build a new set of constructs to enable them to anticipate their child's behaviour and the disability (Davis and Cunningham: 1985.) This ongoing process has been conceptualized by various authors as having phases of shock, emotional reaction, adaptation and orientation, which signal the turmoil of change in the parents' understanding of their world.

The process has been likened to bereavement or a grief reaction. That they are similar in involving major upheaval and change is indisputable. That they differ, however, is clear, since the process is not only one of adaptation to loss, but to gaining a child with a disability. One mother ... described the two pictures she continued to hold in her head years later: the one confronting her daily, and the beautiful one from the past that she allowed herself to see when 'depressed and hidden under the bedclothes'.

(1991: 224)

The mothers had to change their mindset of the image they had of their previously healthy child. In time, they had to rebuild their vision of their child based on the new little being he had become, one with a disability. This was, and at times still is, a painful exercise, and it is understandable that the mother would sometimes hanker back to the child who was, the child she had lost.

Ruggill, in Ferry, Banner and Wolf (1986) echoes the fact that when the diagnosis of a seizure disorder is first made, the stunned parents often see it as a catastrophe striking the entire family. Their initial responses may include shock, fear, guilt, anger, confusion, shame and helplessness (1986: 200).

These emotions are also discussed in studies of grieving the loss of someone to death, for example, Colin Murray Parkes: "Bereavement: Studies of Grief in Adult Life" (1981).

Based on the study of Steenkamp and Steenkamp (1991), the emotions a mother might experience when faced with the realization that her child is now intellectually handicapped and suffering from epilepsy, are akin to emotions of grief when losing someone to death.

These emotions will be discussed as follows:

- **Denial:** Refusal to accept the reality of the condition
- **Anger; Blame:** Displaced anger and blame directed at the medical staff and/or God
- **Bargaining:** Promises made to God in return for the child's recuperation
- **Frustration:** Frustration at child's hyperactive behaviour and diminished cognitive ability
- **Sense of loss; Sadness; Chronic grief:** Feelings of grief at the loss of the formerly healthy, normal child
- **Embarrassment; Resentment; Bitterness:** Child being labelled epileptic and cognitively impaired causes feelings of humiliation
- **Guilt:** Feelings of humiliation over the child's behaviour causes feelings of guilt when the mother realizes that the child cannot control his behaviour
- **Hoping for a miracle:** Wishing that the child's condition and subsequently the situation could change
- **Acceptance:** Learning to accept child's condition

(1991: 12 - 13)

Case study 1

Denial

At first when James was discharged from hospital, Amy knew that he had a long way to recovery, as the medical staff in hospital conveyed his condition to her. There was great rejoicing when he would master a new word or skill. Because he was doing so well, and the medical staff was so optimistic about his whole recovery, Amy did not think of James as intellectually handicapped. Nor did she think of him as epileptic. To her he was recovering from encephalitis that caused the seizures, and once fully recovered, the seizures would also disappear.

Anger and Blame

The first sign that everything was not all right was his slowness in learning new words, and the fact that he could not understand a lot of instructions. However, her anger and blame were directed at outsiders. Firstly, she blamed the City Health who gave him the measles vaccination that caused the encephalitis. Secondly, she blamed the first doctors who treated him, whom she found out afterwards did not know how to treat him. They did not call in the paediatric neurologist until the parents requested it and therefore let him suffer more brain damage than he might have had. She also felt anger towards the educational psychologist who identified his regression, as being negative towards his recovery. Amy directed no anger or blame towards God at James contracting encephalitis, but instead managed to deepen her belief in God and increased her prayers to derive comfort from her faith. However, she started getting frustrated and even angry with God when she felt her prayers for James' full recovery from the seizures were not being answered. Every time she felt God had answered her prayers, James would start having seizures again, and her hopes would be extinguished. She feels as if she is on an emotional roller coaster, and this affects her relationship with James and the rest of her family.

She also blames herself for James illness, as she signed the consent form for him to receive the measles vaccination at crèche. They have found that amongst other illnesses, measles can also cause encephalitis. This was the only virus he was in contact with that fits the incubation period of ten days to develop into encephalitis.

James' illness also made Amy paranoid about her other children's health. Her second son had rigors one night due to a high temperature. Amy never slept the entire night, fearing convulsions. When her baby once had an acute asthma attack, she did not sleep a wink, fearing his lungs would collapse like James' almost did when he was in ICU.

Bargaining

The first time Amy started bargaining, was when she was waiting for the paediatrician to stabilise James. She was willing to promise anything to God as long as her son would become well. She was even bargaining with James himself, promising him a bicycle for his fifth birthday instead of their initial decision to get him a 'big-boy' bicycle when he turned eight. By the Grace of God James will be seizure free and get his bicycle on his eighth birthday, as promised three years ago.

Frustration

After the initial excitement of teaching James, came the frustration at his inability to grasp certain words and instructions. The frustration was compounded by the fact that she kept on thinking of him as the same healthy boy he used to be. Amy also had unrealistic expectations of his progress based on the optimistic reports of the medical staff. The paediatric neurologist had told them after James' recovery that he also did not think that James would survive his illness. The fact that the paediatric neurologist called his recovery a miracle led Amy to believe that the miracle would extend to the full recovery of all his capabilities.

Something else that became very frustrating was James' erratic behaviour. Most of the time he would be calm and quiet. At other times he would become hyperactive, aggressive and also insomniac. This could be residual from the encephalitis, but it could also be a side effect of the build-up of the anti-convulsant drugs. During these episodes, he was unable to sleep, and would walk up and down in the house. Amy and John sometimes would be relieved when this behaviour culminated in a tonic-clonic seizure, which means that James at least would sleep due to the post-ictal period, and they would get some sleep too. They discovered that this behaviour could be attributed to two things: it could either be a temporal lobe seizure, or the medication he was on could result in hyperactivity. This is very frustrating, as there is nothing she can do about it but wait for the phase to pass, until the next time...

When Amy discussed this with the paediatric neurologist, he mentioned that it could also be an indication of Lennox-Gestaut syndrome. Having read up on neuropsychology and realising the implication of this, Amy was devastated. However, the paediatric neurologist told her that it could only be determined through clinical testing. Amy felt that James was just given another label that they had to contend with: epileptic, cognitively impaired, and now Lennox-Gestaut syndrome. Amy found it very difficult to get used to her son's behaviour, especially if this happened in public. She knew she had to find help to cope emotionally, as she found it very hard to come to terms with James' behaviour, his condition, and her own feelings of embarrassment, guilt and inadequacy to cope with his condition, her toddler, her unexpected pregnancy and her everyday chores.

Sense of loss, sadness and chronic grief

After realising that her son's condition was long-term, Amy was overcome with a deep sense of loss. She started mourning the son she had lost, and kept on thinking of what James used to be like; the things he used to do and say.

Amy still finds herself thinking of James as how he was before he became ill, but as time passes, these episodes are becoming less frequent. However, she does find that sometimes an event might trigger her memories and the pain then is very acute. Recently, she met the mother of a former crèche playmate of James', who told her that her son was in Grade Two. This brought on an almost physical pain at the memory that her son should have also been in the same class.

Amy also finds the comments and attitudes of other people very hurtful at times. Particularly at the times when James is going through one of his phases, people make comments on his behaviour. She feels as if it is a reflection on her, that she is incapable of controlling her child. She has found that there are times, particularly in the early stages of his recovery, when he could not tolerate being in unfamiliar environments, and he

would become hyperactive. This also contributed to the fact that they would end up staying at home most of the time.

With the doctors experimenting with different anti-epileptic drugs in an effort to find a therapeutic combination, Amy and John could see that different drugs made James react differently. Some made him drowsy most of the time, and some made him insomniac and hyperactive. Though frustrating, through trial and error, they hope that the current paediatric neurologist has finally prescribed a drug that will give proper seizure control without the side effects of the other drugs.

Amy often finds herself thinking back on James' developmental milestones before he became ill. He could walk by nine and a half months. He could talk fluently by the time he was two, even causing his cousin who was a year older to be taken for speech therapy. James' four-year-old brother is at the same age he was when he fell ill, and is starting to surpass him in everything. This is very painful for Amy to observe.

Embarrassment, resentment, bitterness

The feeling of embarrassment came when Amy had to recognize that James was now labelled as epileptic and intellectually handicapped. It was difficult for her to admit that to other people, and in public she tried not to draw attention to him. As he was generally quiet after his illness, she just let people make their own assumptions about him. This was not always possible, as he would become hyperactive in public at times, and people would frown on his behaviour. Most of the time people would think that he was just an ordinary naughty little boy, which to Amy was far more acceptable than people thinking that there was something drastically wrong with him. However, she resented the stares of strangers when he had seizures in public places, instead of them lending a hand.

She started feeling resentful towards him, irrationally blaming him for getting sick. She also started feeling bitter, thinking that she must have done something terrible in order to be punished with an intellectually handicapped child. This resulted in Amy ignoring

James at times, alternating in her shouting at him when he was hyperactive. Her resentment also stemmed from the fact that she could not go back to work, and had to stay at home to look after the children. In a way she feels it was a unilateral decision taken by John, as he did not trust anyone else to take care of James.

Guilt

Amy's thoughts and actions which stemmed from her embarrassment, resentment and bitterness would, in turn, be followed by feelings of guilt, especially when he would have seizures. The turning point came one day when she was shouting at him, and as she went closer, she saw the fear in his eyes. The fact that her son was actually scared of her shocked her into reality. Since then she takes time out when she feels herself building up frustration, and goes for a walk, or sits outside in the garden until she feels better. She had also found that working in the garden relieves her stress, especially as the children play outside around her, and do not nag her as when they are inside the house.

Hoping for a miracle

When James was in ICU Amy was praying daily for a miracle that he would survive his illness. Despite the medical staff expecting the opposite, James recovered. Amy firmly believes that God granted them the miracle of James' life. She, however, also expected the miracle of his full recovery physically and intellectually. At times, she doubts that that will happen. Then when she has glimpses of improvements in his speech and language her hopes soar up again.

Amy will always hope for the miracle of James' seizures to be controlled. Many drugs have been tried, but none has been successful. Amy and John also started looking at alternative treatments. They tried chiropractic treatment, which was not very successful, as they could not keep up with the appointments. They are also looking into hyperbaric treatment, but the medical fraternity do not feel that hyperbaric treatment works for seizures. However this type of treatment seems to aid with cognitive improvement, and

therefore Amy and John are keen to try it. Recently, they found out that the latest drug that the paediatric neurologist wants to prescribe, would be covered by their medical aid. This is the “Rolls Royce” of the anti-epileptic drugs, as the neurologist calls it. This is also the drug recommended by the visiting paediatric neurologist from London who assessed James. The reason they could not try it before, was because it was so expensive and the medical aid might not have paid for it, but because it is not available at the State Hospital, they will now pay for the drug. This brings Amy and John closer to the hope for a miracle.

Acceptance

The compounded factors of James’ illness, his after-care, her unexpected pregnancy caused Amy so much stress that she sought psychological counselling. This helped her to cope better with her circumstances. It also helped her to accept James’ new personality. She was able to accept that he would have to attend a special school, and to put his needs ahead of her ego. She has a much better relationship with James now, as she has learned to accept and love the new little person he has become. What she has not accepted, but has resigned herself to for the time being, are his seizures. She is continuously looking for treatments to better control the seizures.

Sandy went through much the same emotions as Amy did, as will be discussed. Although there are differences in the mothers’ experiences, there are also quite a few similarities.

Case study 2

Denial

Sandy says that when her son was first diagnosed with epilepsy, and subsequently with intellectual disability, she felt as if her world was collapsing. She could not believe the

diagnosis, and even told herself that it was not true. She was in total shock, and did not want to admit that it was true.

Anger and blame

Sandy feels that the medication for Ian's chronic tonsillitis caused the metabolic disturbance. According to her, he was given high doses for his age for the tonsillitis. She also feels that the anaesthetic administered during the tonsillectomy aggravated the metabolic disturbance that subsequently caused the seizures. All this she blamed on the doctors who were treating her son at the time.

Sandy also feels that her estranged marriage to Mike at the time aggravates Ian's seizures, as there was no stability in their family life. When they are together as a family, their relationship is volatile, with a lot of arguing between the parents.

Sandy also blames Ian's condition on herself. She feels that she is to blame for his condition because she married Mike against her parents' wishes, and this is her punishment.

Bargaining

She has been bargaining with God to make her son better, but does not know what to do to control her son's seizures.

Frustration

Her frustration is with Ian's behaviour. He also has hyperactive tendencies at times, alternating with drowsiness. She feels that the anti-epileptic drugs cause this. She tried for a long period to keep him on mono-therapy, but finally had to put him on dual drugs to try to control his seizures better. Even so, Ian still has breakthrough seizures.

Sense of loss, sadness and chronic grief

Sandy feels that she has lost her little boy that she knew and brought up to the age of three. He has had a personality change, which could be due to his condition or it could be a side effect of the drugs. She feels that at times she copes better with her sense of loss, and then there are other times when she just feels overwhelmed with sadness. Through it all she tries to keep a brave face, and be there for Ian.

Embarrassment and bitterness

There are times when Sandy feels embarrassed by Ian's behaviour in public, especially when they are in the supermarket and he starts misbehaving. There is some regression that occurred, so his behaviour sometimes mimics that of his two-year-old brother. Sandy, a qualified lawyer, says that she does not feel resentful towards Ian for having to leave practising law, as he needs her right now.

Guilt

Sandy feels guilty about Ian's condition, thinking that his unstable family environment must have caused it. The feeling of guilt is compounded by the fact that she feels that she brought this on her son by marrying Mike in the first place, against her parents' wishes.

Hoping for a miracle

Sandy still hopes to receive a phone call to say that her son was misdiagnosed. Sandy and Mike are also trying alternative therapies. Sandy tried herbal remedies and also wants to try hyperbaric treatment in the hope that Ian's seizures will be controlled.

Acceptance

Sandy has learned to accept Ian's condition, and is also in the process of looking for school

placement for him. She has become more tolerant of him, and also tries to give him more attention.

Jean's experience of her son's condition also has similar aspects to the first two case studies. The difference is that she has reached her hope for a miracle: Liam has been seizure-free for two years, the accepted period for an epilepsy sufferer to be weaned off the anti-convulsants and declared seizure free.

Case study 3

Denial

Jean did not think that Liam suffered from epilepsy and ascribed his seizures to be of a spiritual cause. The women from her church came to pray for the 'bad spirit' under which her son had fallen. The doctors from the first hospital told her to take Liam for spiritual healing when they failed to diagnose the origin of his seizures and this reinforced this belief.

Anger and blame

Jean was angry with God and had blamed Him for Liam's condition. She thought it unfair that something like that should have happened to her and her son. She also asked God what she had done to deserve what was happening to her.

Jean is also angry with the doctors who stopped his medication abruptly, causing the rebound seizures. She also feels that the medication that he was put on initially, have side effects that outweigh its therapeutic abilities.

Bargaining

Jean also tried to bargain with God, wanting to take her son's suffering on herself, instead of seeing her son suffer.

Frustration

Jean feels that Liam's personality had changed. He became hyperactive and uncontrollable at times. He is also aggressive, wanting to hit and scratch. He also does not like strangers. Her expectations of Liam's abilities are affected as well. She says that his memory is impaired, especially the fact that he cannot remember his colours. At the same time she wants him to go to a regular school and not a school for children with learning disabilities.

Sense of loss, sadness and chronic grief

Jean feels that her son's personality changed. He became hyperactive, aggressive and uncontrollable. He does not listen to her and she has to repeatedly try to make him listen to her.

Embarrassment

Jean finds it embarrassing to go out in public with Liam due to his behavioural problems. She even finds it embarrassing to administer his medicines in public, feeling that people are staring at her and thinking her child to be "cuckoo".

Guilt

Jean wonders what she has done wrong to deserve what was happening to her.

Hoping for a miracle

Jean's miracle had come true: Liam had been seizure-free for two years. Despite this, she still fears that he might have another seizure, putting them back at square one.

Acceptance

Jean seems to find it difficult to accept that Liam's intellectual age is lower than his chronological age of five years. On the one hand she talks about him being unable to remember his colours due to his memory being impaired, and on the other hand she wants to send him to a regular school.

Summary

These three mothers underwent a grieving process similar to that of losing someone in death. Indeed they have suffered a tremendous loss, the loss of their previously healthy normal child. Instead, they have gained a child suffering from epilepsy and who is cognitively impaired.

At first they denied that the diagnosis was accurate. Amy expected the seizures to stop once the encephalitis had healed. Sandy refused to believe that the diagnosis was true, and told herself that it was not true. Jean did not believe that the seizures were due to epilepsy, but rather had a spiritual origin.

When the seizures continued, the mothers directed their anger and blame at the medical fraternity, themselves, and ultimately, God.

All three of these mothers tried to bargain with God to make their children well.

The mothers experienced a great deal of frustration having to come to terms with their children's cognitive impairment and hyperactive behaviour. Amy still thought of James as a healthy little boy and became very frustrated when he could not grasp simple instructions. She also felt very frustrated at his hyperactive behaviour, especially in public. Sandy also gets frustrated at Ian's limited cognitive ability, but more so at his hyperactive behaviour. Jean's frustration stems from the fact that she feels that Liam's personality has changed and

he has become very aggressive and uncontrollable. She also feels that his memory is impaired, as he is not able to memorise his colours.

These mothers feel that they have lost the little boy whom they brought up before the child became ill. Instead they have to accept the little boy with a changed personality. This caused a severe sense of loss, sadness and grief.

The mothers also experienced an acute feeling of embarrassment. The embarrassment stems from the fact that the mothers imagine the attitudes and reactions of other people regarding their children's condition. The reason for the mothers' embarrassment could be that they regard their children's condition as a reflection on them, as if they are unable to control their children's behaviour in public. This causes them to refrain from going out in public. Amy also had feelings of resentment towards James, irrationally blaming him for getting sick.

The feelings of embarrassment and resentment resulted in feelings of guilt in Amy. Sandy's feelings of guilt are caused by self-blame. Jean wonders what she has done wrong to deserve what was happening to her.

Amy and Sandy are still waiting for the miracle of their children being seizure-free. For Jean, this hope has come true already, since Liam has been seizure-free for almost two years.

With psychological counselling, Amy has reached acceptance of James' cognitive impairment, but she cannot accept his continued seizures. For this, she will hope for a miracle until he becomes seizure-free. Sandy feels the same way about Ian's condition. She has accepted his cognitive impairment, but also prays for the miracle of him becoming seizure-free. Both these mothers are trying to find appropriate educational facilities for their children, recognizing that they will need special education. Jean recognizes that Liam has a cognitive impairment, but still wants to enrol him at a regular school. This might mean that she has not fully accepted his cognitive impairment.

These mothers have suffered a tremendous loss, the loss of the healthy little boy they gave birth to. Even though they did not lose their child in death, they had to come to terms with a new little person with a new personality and diminished intellectual abilities. Amy and Sandy still have to cope with their children's seizures, sometimes daily. They are trying to lead as normal a family life as possible, trying to put their initial trauma behind them. This, however, is not possible, as they are painfully reminded of it every time their child has a seizure.

Ruggill in Ferry, Banner and Wolf, says that: "The sadness and mourning over the loss of a previously healthy child may affect every family member and never quite disappear. The frustration that epilepsy is an ongoing disorder and cannot be totally "fixed" gives rise to a predictable sense of helplessness" (1986: 202).

She also says that the parents of the child with seizures may carry the burden of the question, "Why did this happen to my child?" for a lifetime and that it is not rare for parents to become overprotective of the epileptic child, fearing that he may injure himself during a seizure.

It is therefore understandable that these mothers would experience strong emotions during a period of grieving their loss. Among these is guilt at not being able to prevent their children's condition, or the illness that caused it. Stearns recognizes that: "Guilty feelings are almost inevitable in the presence of loss. Whatever the situation, people are apt to blame themselves." (Estadt: 1983: 238). For these mothers, to see their young, innocent children suffer inevitably led them to blame themselves. Then anger followed guilt and blame: anger at the person or persons perceived to have caused the onset of the illness. In their cases the mothers directed their anger at the medical fraternity, who could have and should have foreseen their children's illnesses, and taken preventative measures.

Stearns feels that:

Anger and bitterness can be a good sign. These strong emotions often signal that the healing process is well underway. Once the person is openly angry, many feelings are projected outwardly. Whether the anger is displaced or directed at the one who died or directed toward God, still there is the sense that the bereaved person is mobilizing his or her energy once again. The grieving person is fighting for life and that's a good sign.

(in Estadt 1983: 245)

These mothers have directed their anger outwardly: to the medical fraternity at first and later to God. According to Stearns, healing can take place once the internal anger is directed outward. For these mothers this might just have been the case.

Stearns and Leick and Davidson-Nielsen recognise that grieving is a long-term process. Stearns writes: "When a significant loss has a person in its grip, a minimum of six months to one year is usually required for healing" (Estadt 1983: 236). Leick and Davidsen-Nielsen also feel that "In the case of a serious bereavement, it is a process that may take several years" (1991: 38). This acknowledgement of the varying length of 'grief time' validates the mothers' sense of the significance of their loss. They are not abnormal in grieving for the loss of their children's health and intellectual ability.

According to Stearns: "One of the most difficult realities of grief involves the loss of potential" (Estadt 1983: 237). These three mothers had hopes and dreams for their children when they were born, and as they grew up and displayed certain abilities. These hopes and dreams died a sudden and cruel death when their child was diagnosed with intellectual disabilities. All of a sudden these mothers had to learn to know little strangers with different personalities and different abilities to what they had come to believe in.

Colin Murray Parkes defines the term *Deprivation* as follows: “Deprivation means the absence of those essential ‘supplies’ that were previously provided by the lost person” (1981: 24). These mothers are deprived of the personalities of the children they raised and their intellectual abilities. But more than that, they are also deprived of their own hopes and dreams for their children. They will have to come to terms with that fact, and learn to change their dreams and hopes. In fact, at the moment, Amy’s and Sandy’s hopes and dreams are for their children to be seizure-free so that they will have the chance to learn and benefit from their speech and occupational therapies, and also start school.

It is thus understandable that they would grieve for the loss of their healthy, whole child, but also for the loss of their own hopes and dreams for that child. They had to undergo a grief process, as described by Leick and Davidsen-Nielsen:

In the normal course of grief, the emotions change a lot. During the course of a single day someone may feel a sharp physical pain at one time, a deep sense of loss accompanied by profound sobbing at another, a nagging sense of guilt an hour later, and then anger... Between these strong emotions there may have been periods of relative calm. Over time these emotions help to cleanse and heal the wound. In healthy grief work it is this flexibility that gives the mourner the opportunity to enter into his deeper feelings at certain times and to get a little peace at others, thus gathering strength for the next round. The grieving person thus goes in and out of emotions of grief. It is a hard and exhausting process.

As time goes on, there are longer and longer intervals between the difficult periods, and their intensity wanes. Finally they fade away completely. Left behind is a yearning pain which particularly makes itself felt at anniversaries and festive seasons.

(1991: 38)

These mothers have passed the initial period of grieving, where each day was difficult to endure, when they would vacillate between extreme emotions and feeling as if they were losing their minds. They are now at the place where they would have periods of relative calmness, which would only be disturbed when something triggers a memory.

Amy had the experience where she was going through a period of relative acceptance, when she met a mother whose child is the same age as James. She felt an acute pain when she realized that James would have been in the same grade as that child. She also experienced sadness watching her younger son surpassing his older brother in skills James was able to perform before he became ill. Sandy also experienced this feeling of grief when she witnessed Ian mimicking the behaviour of his younger two-year old brother, instead of the reverse happening. Jean says that the trauma of what she went through will always stay with her, and she still gets flashbacks of that difficult time in her life.

Of this Parkes says the following:

The most characteristic feature of grief is not prolonged depression but acute and episodic 'pangs'. A pang of grief is an episode of severe anxiety and psychological pain. At such a time the lost person is strongly missed and the survivor sobs or cries aloud for him.

At first they are frequent and seem to occur spontaneously but as time passes they become less frequent and take place only when something occurs that brings the loss to mind.

(1981:57)

Parkes says further that "Pangs of grief can be re-evoked even years after a bereavement." (1981: 110). Parkes' observation is significant in the case of these mothers. Even though they experienced other emotions during the course of their grieving, these 'pangs' are what they mostly experience. This can be triggered by various incidents, but especially when observing the development and achievements of children of the same age. These mothers also have younger children, and they experience acute pain at times when their eldest child behaves in a similar way as his younger siblings. The same is true when the mother finds that the siblings are superseding their eldest brother.

For the mother to successfully overcome her initial trauma and grief, she has to undergo the process of grief work.

Parkes describes the process of grief work as follows:

Grief work arises largely from memory although a bereaved person may use his imagination to fill in the gaps – to provide pictures of events that he has forgotten or has never witnessed. At such a time there is a conscious need to ‘get it right’ and getting it right is not just a matter of recalling the traumatic event correctly; it includes the need to ‘make sense’ of what has happened, to explain it, to classify it along with the other comparable events, to make it fit into one’s expectations of the world. Trying out new solutions, searching for clues to explain ‘why did it happen to me?’ and repeatedly, monotonously remembering the sequence of events leading up to the death– these are what make up the process of grief work.”

(1981: 96)

These mothers went through endless times of trying to reconstruct the events leading up to their child’s illness. Amy kept on remembering the first time the crèche teacher told her that James had a fever that day. She and John took him to the doctor who diagnosed a viral infection, not knowing how serious it would become. She kept on reliving the morning she found him having the seizures in bed, the weeks of him being in ICU in a coma. And all the time she kept on wondering what she could have done differently, starting with not signing the consent form for the vaccination. Maybe if she had taken him to the paediatrician where he received all his other vaccinations, he would not have fallen ill. When he got sick, maybe they wasted precious time not taking him straight to hospital instead of the medical centre.

Sandy has the same experience, where she relived the events of Ian’s diagnosis, trying to figure out what she could have done differently. Sandy also tried to reconstruct the events leading up to his first seizure, thinking that maybe if he were not on such high doses of medication for his tonsillitis, the metabolic disturbances would not have occurred. That maybe, if he did not react to the anaesthetic, he would be fine today.

Jean relived the onset of Liam’s seizures, trying to think how he could have contracted them. She is convinced that he was in the wrong place at the wrong time, where someone

was dabbling in 'dirty spiritual matters'. She also feels that if only the doctors did not stop the medication so abruptly the first time, Liam's seizures would not have worsened as they did.

Davis says the following about parents in this situation:

Parental concerns about their children cannot be divorced from their constructions of themselves as people and parents. All actions and decisions in relation to their child reflect upon themselves. The question of their own adaptation is ever present. How they will cope with the child is one of the first questions parents ask themselves. They ponder their ability to cope with their distress, sadness, disappointment, and anxiety. They fear the stresses on them, and question their ability to meet the demands of the child and treatment schedules. Many parents explore their role in the aetiology of the disorder, to see if it was their fault and whether it could have been avoided.

(1991: 227)

This is exactly what these mothers did. They tried to see what they did wrong to cause their children's condition. They also tried to see what they could have done differently to prevent their children's condition.

These mothers had to come to the realisation that there was nothing they could have done differently that could have prevented their sons' illness. The questions they have will never be answered in this life, but by going through the process of grief work, they were able to come to terms with their grief in a healthy way.

Conclusion

All three of these mothers experience a traumatic loss, and underwent a period of grieving. They experience the normal emotions associated with a traumatic loss, and through grief work, manage to work through their grief and come to acceptance of their loss. By accepting their loss and the 'new' child they have, they could move on with their lives. They could also proceed and focus on their children's needs, as reiterated by Steenkamp and Steenkamp: "Parents of a handicapped child first ask: Why me? Why must I be the one to be punished? Once they become resigned to the fact they ask: Why

him? Only then does self-pity change to an attitude of readiness to really support the child in his needs” (1992: 12).

CHAPTER 4

RECONCILING – TO ESTABLISH BROKEN RELATIONSHIPS BETWEEN THE MOTHER AND GOD, THE MOTHER AND OTHERS, AND THE MOTHER AND SELF

Introduction

A mother faced with her child falling ill and then suffering from seizures coupled with a diagnosis of intellectual handicap, needs a lot of support from various support bases. When these support bases are readily available, the mother is able to cope adequately in caring for her child and the rest of the nuclear family. The various support bases will be discussed to see whether the three mothers in the three case studies received the support they needed, and still need.

4.1 Support from husbands

Davis and Fallowfield state the following about support from husbands in the face of their children's disability: "Mothers may complain of the lack of support, physically or emotionally, provided by their husbands" (1991: 229). The husbands' support to the mothers, or lack thereof, will be discussed in the three case studies.

Case study 1

Amy and John drew closer initially when James was hospitalised. They relied on each other for emotional support as they tried to come to terms with the gravity of James' condition. However, there also came a time during his hospitalisation when Amy found that they were drifting apart, because they tried to be strong for each other by concealing their own feelings and emotions. Having read about similar situations before where couples break up when a child gets ill or dies, Amy vowed that she would not allow that to happen. She approached John one evening after returning from hospital, and openly discussed what she

felt was happening to them. She told him how James' condition was affecting her, and how hurt she felt about the two of them drifting apart. This helped him to open up, and they both cried over their son and admitted their need for each other during that traumatic time.

When James was discharged, a great deal of his daily care rested on Amy's shoulders while John was at work. However, when John arrived home, he would take over James' care, and Amy would be able to take a break. Amy coped well in the first couple of months after James was discharged, even though he landed back in hospital with status epilepticus.

However, when she fell pregnant unexpectedly and James was back in hospital the second time she felt her coping mechanisms disintegrating. She felt that she could not cope with John questioning her every day after work about James. Coupled with this were John's absences from home when playing handyman for other people. She felt as if he was neglecting her and the children, even though he played his part in administering John's medicines at night and taking him to the toilet during the night to prevent him bedwetting. When he was home, he spent most of his time with James and their middle son. She felt that he was not there for her emotionally, that he was neglecting her even though they were both so tired that they did not make time for each other. When Amy's depression worsened, so did their relationship, with them alternating between fighting and ignoring each other. Once again, Amy recognized the danger signs threatening their marriage, and this time decided to seek professional help. With the help of the psychologist, Amy and John were able to settle their problems and reconnect emotionally.

Case study 2

Sandy felt that she was getting absolutely no support from Mike. Even before Ian was diagnosed with epilepsy and intellectual disability, their marriage was on a rocky path. Ian's condition just aggravated the pre-existing problems in their marriage.

Even though Mike was looking for treatments on the Internet and exploring the different options available, Sandy felt that he needed to be more physically involved with her and the children. He did not administer medicines to Ian at all, and left the entire daily care of the children to her. She was the one who had to take Ian for his medical appointments and speech and occupational therapy.

Mike had recently started his own business in Durban after working for his brother in Johannesburg. He was working long hours to build up the business, which Sandy understood. She, however, felt that when he had free time he should have spent it with her and the family. Instead, he spent his free time with friends, and always invited visitors over for long weekends and holidays. She felt that he did not want to spend time alone with her and the children.

Sandy would argue with Mike about spending so much time away from home, which he saw as nagging. She said that she used to keep quiet about the constant visitors in their home, but recently she exploded and told him exactly how she felt. He was shocked, as she has never spoken to him like that before. She felt that he seemed to have changed his attitude towards her for the better. Before he used to call her names, which he saw as teasing and she found hurtful, even going as far as jocularly telling her that he would provide the blades when she told him she felt suicidal. After confronting him in front of friends, he seemed to have realised that he was hurting her, even though she had told him so before. Their relationship seemed to be on the mend.

Case study 3

Jean found Rick very supportive. He accompanied her to Liam's hospital appointments. He even took Liam for his EEG when she was working. He spent a lot of time with Liam, playing with him. However, their relationship seemed uncommunicative, as she had no idea how he felt about Liam's condition.

4.2 Family Support

Davis and Fallowfield found that: “Many families are well supported by relatives, neighbours and friends. Others do not have such support or lose it as result of the situation of having the child” (1991: 229). In the following discussion, this finding will be put to the test.

Case Study 1

When James was hospitalised, Amy’s parents had just arrived from the Cape to spend the school holidays with them. Amy was able to spend the greater part of the day at hospital while her parents saw to their house. She had the emotional and physical support she needed at that time from her parents. Amy, who is originally from the Western Cape, has no other relatives in Durban, and has become quite close to John’s family. Amy’s mother-in-law provided babysitting services to her one-and-a-half year old toddler until he got used to her parents.

Amy and John had sold their car prior to James’ illness, and were without transport in getting to the hospital. John’s family and relatives took turns fetching them from hospital in the evenings. At the time when it looked as if James was not going to recover, John’s uncle and aunt called the family together for a prayer meeting to pray for his recovery. John’s family became very supportive of them during James’ hospitalisation.

Amy’s parents left for the Cape again due to commitments while James was still in hospital. Even though Amy understood that and had John’s family’s support, she still wished that her parents could have stayed longer. They do provide emotional support, as she calls them on the telephone when she needs to unload emotionally. Amy is also very close to her sister, who, although living in Cape Town, is just a phone call away. Her other relatives called regularly while James was in hospital, and occasionally afterwards to enquire about his condition. Amy went on holiday to the Cape the first Christmas after

James was discharged and was deeply touched when all her relatives paid her a surprise visit at her parents' home and had an impromptu celebration for them. When her parents and sister come to visit, they pitch in to give Amy a break from her chores and looking after the children.

When James was discharged, John's family continued to be supportive to them. John's uncle and aunt once again called a family prayer meeting in thanksgiving for James' recovery. Amy became even closer to John's family, as they were always willing to lend a listening ear or a helping hand.

Despite this, Amy reached a stage where she felt she needed to become more self-sufficient, even though she still desperately needed their help and support. It was this cutting off of her support base that also sent her into her depression. Working through her emotional problems with the psychologist helped her realise that she can rely on the family for support without feeling as if she is losing her independence. He put it to her in this way: "James is your responsibility, but he is not only your responsibility. He is the whole family's responsibility" (20 May 2001). After this, Amy felt more ready to accept help when it was offered and also to ask for help when needed. The latter sometimes she does with great reluctance due to her constant battle for self-sufficiency.

Case study 2

When Ian was diagnosed, Sandy's family attributed his condition to their estranged marriage. Sandy had left Mike quite a few times while Ian was a baby, which supported her family's view of the cause of Ian's condition. They were very unsupportive, especially since they opposed Sandy's marriage to Mike in the first place. She spent the last Christmas holidays with her family, and for the first time they understood what she was going through. They could see that his behaviour was not intentional, as they had thought before, but that it is a result of his condition and medication. They used to tell her that Ian

was disruptive and hyperactive and that she should control him better. They have become much more supportive of both Sandy and Ian since they spent time together. Mike's family is not supportive at all. Even though she has tried to explain Ian's condition to them, they do not understand. They feel that Ian will outgrow his condition, and that she should just learn to cope better. Sandy's relationship with her in-laws is very strained due to previous problems, and their attitude towards her and Ian is aggravating the situation. They come for holidays from Johannesburg and stay with Sandy and Mike, even though they are not really on speaking terms with her. They also do not lend her a hand with the household chores while staying there; neither do they help her with her children, who are all under five years of age.

Case study 3

Jean finds that she has little support from her family. Her brother sometimes gives her a hand, and so does her father occasionally. She finds that her sister, who also suffered from sudden-onset seizures as a teenager, is not supportive of her at all. She expected her sister, of all people, to be more supportive of her. Jean also finds that her mother, who went through a similar situation with her sister, is the least supportive of her. She is constantly fighting with her mother for telling her that Liam is naughty, and she feels that her mother is constantly picking on Liam. She feels that her mother should be more understanding and supportive of Liam as well, especially since she has experience of young children as she runs a crèche. Jean also says that her cousins, who knew that Liam was in hospital, did not even visit them in hospital, or when he was discharged. She just tried to cope on her own, as she feels that she was being ridiculed, criticised and condemned by those she expected to have been more understanding of her situation.

4.3 Support from the medical fraternity

Davis and Fallowfield state that: “Ironically, a difficulty that parents frequently raise in counselling relates to the behaviour of professionals” (1991: 230). These mothers had varying experiences with those in the medical profession, as will be seen in the following discussion.

Case study 1

Initially when James was hospitalised, Amy felt that the medical staff was very supportive and caring. She would bombard them with questions regarding his condition and the prognosis until she was satisfied with their answers. Most of the time, the doctors were quite willing to answer her questions.

She, however, started feeling frustrated and rightly so, as she would discover afterwards, when James’ condition seemed unchanged after more than a week. After she and John requested that the paediatric neurologist that they learned about be brought onto James’ case, the initial paediatrician’s attitude towards them changed. He gave a very sarcastic answer to a nurse in their presence when she asked whom they should consult on James’ condition.

Amy and John found the nursing care in the ICU of exceptional standard. There was a nurse at his bed round the clock. The nursing staff also arranged for both of them to have three meals per day from the hospital kitchen, where normally only one person was provided for. Initially, the nurses would ask them to leave when they were attending to James. After a while, they recognised Amy and John’s need to be of help to their son, and allowed them to stay and even help when he was being washed and changed.

Amy appreciates the paediatric neurologist's role in saving James' life. When James was discharged, they continued consulting him. However, Amy became increasingly frustrated at her questions being met by an 'I know best, do not question my treatment' attitude. She felt that as the mother living with her child, she needed answers as to why certain treatments were applied.

Amy eventually found another paediatric neurologist with whom she is able to discuss James' treatment. She feels that he values her opinions and observations and he answers her questions without talking down to her. Amy also has a good relationship with her general practitioner and appreciated his comment when she questioned him on the prognosis for James' recovery. He said: "Doctors do not have all the answers, only God does" (August 2000).

Case study 2

Sandy's first experience with doctors treating Ian was not a happy one. She feels that they treated him unnecessarily with high doses of antibiotics and chronic medication for tonsillitis. She feels that this aggravated the metabolic disturbance that caused his seizures. She also feels that the anaesthetic that he had when eventually his tonsils were removed, also contributed to his condition.

Sandy was very upset with the doctor who told her that the faulty neurological problem could have been present at birth. She felt vindicated when a paediatric neurologist told her that it would have been picked up if it were present at birth. The doctor who diagnosed Ian with Lennox-Gestaut syndrome was also very callous when telling Sandy that the prognosis for this condition is very poor and that Ian will end up being a "vegetable". The doctor treating Ian at the moment has encouraged Sandy to try the Ketogenic diet. However, due to the stringency of the diet which has to be kept up for three years, she does not know whether she will be able to cope looking after the two younger children while administering the diet to Ian. Due to this she has considered sending them away to live with her mother in Johannesburg.

Case study 3

Jean was convinced that Liam's condition was not caused by a medical problem, but by a spiritual one. To her this was confirmed when the staff at the first hospital told her to take Liam for spiritual healing. However, she feels that they caused Liam's condition to worsen when they abruptly stopped the medicine, instead of tapering it off. When Liam was transferred to the specialist hospital, she used to approach the doctors whenever she felt the need, until Liam's seizures were brought under control. According to protocol, when a patient has been seizure-free for two years, the medicine is reduced to see whether Liam has outgrown the seizures. However, Jean feels that the doctor is going too fast and she fears that this may cause rebound seizures, which will cause them to start the two-year period again.

4.6 Support from Psychological Counselling

Clinebell states the following: "The loss of someone who has been a significant part of one's world of meanings and satisfactions is a psychological amputation" (1984: 220). He continues by saying: "When death or any severe loss strikes, the usual response is feelings of psychological numbness and shock (nature's anaesthesia) mixed with feelings of unreality..." (1984: 222). Clinebell feels that if pathological grief symptoms, for example severe depression, persist after several months after the loss, the grieving person should consult a competent psychotherapist. In the three case studies, all of the mothers experienced severe depression resulting in suicidal thoughts. Only Amy sought psychological counselling, whereas Sandy and Jean tried to cope on their own.

Case study 1

Amy became very depressed and unable to cope with James' condition when she fell pregnant unexpectedly. This was probably due to delayed shock or post-traumatic stress, caused by unresolved grief over the trauma of James' illness, coupled with the new stress

of her unexpected pregnancy. Her depressive state caused her to neglect her house chores, causing her to barely care for her children, and spending most of her day staring at the ceiling. She lost interest in most of her activities, even neglecting her garden that she usually enjoyed pottering in. She became very concerned about herself when she found that she was having suicidal thoughts and thoughts of leaving John and the children. She decided to seek psychological counselling.

The psychologist was able to let her work through her grief, her depression, her anger and resentment. She was able to learn how to cope when these emotions recurred. She also learned how to cope better with James' condition.

Amy also had joint sessions with John, and they both learned how they were neglecting and affecting each other. Through psychological counselling they were able to work out their problems and heal their relationship.

Case study 2

Sandy has not received any professional psychological counselling. She has admitted that she needs to find some psychological counselling to learn better coping skills to deal with her situation and problems, but as yet has made no attempt to secure an appointment.

Case study 3

Despite the fact that she felt suicidal in the beginning when her trauma was overwhelming her, Jean says that she never found the time to go for much needed counselling, and she had to just go it alone.

4.5 Support from Parishioners/Community

Clinebell states that: "The entire lay caring program of a church should be an outreach ministry to persons in need, in the wider community and the world as well as within the

congregation” (1984:414). Estadt supports this view when he says: “Through empowering the laity, churches can become more nurturing and caring communities in which the love of God is experienced by all, even those members isolated from the mainstream activities of the church” (1983: 135). The mothers received support from their church communities initially, but this eventually dried up at the possible perception that the trauma has been overcome.

Case Study 1

When James was hospitalised, his name was put on the prayer list at their local parish, and fellow parishioners regularly phoned to enquire about his condition. The biggest surprise was that strangers were reaching out to them when discovering their plight. In hospital, people visiting their own relatives would see Amy and John sitting by James’ bed. They would approach them and ask them if they would mind them putting his name on their parishes’ prayer lists. This was even offered by people leaving for overseas. Members of the community also reached out to them.

When James was discharged, enquiries from the parishioners and community dried up, as they all assumed that James was out of the woods. Little did they realise that the ordeal was far from over. Amy and John did not have the energy or the inclination to inform them of this.

However, Amy found that when James would have a seizure in public, there would always be someone to lend a helping hand in the crowd of onlookers. For instance, there was the young woman from the local supermarket, who once took early lunch to carry James home when Amy was pregnant. One day, a stranger stopped his car on the road when he noticed her sitting on the pavement with James after he had a seizure. He took them home, and she has never seen him since. She even wondered if he was not an angel sent by God that day, because there was no other car on the road at the time.

Amy does find that she gets upset with people staring when James has a seizure in public, and also when he behaves hyperactively. Recently they went to an exhibition, and James became agitated by the hustle and bustle of the huge crowd. He also was very upset when he could not see his mother any longer, as Amy and her mother got separated from the others while looking at things of interest to them. When James and John eventually caught up with them, James displayed separation anxiety, and clung to her. He refused to stay with his father for the duration of the exhibition, and wanted to stay with his mother only. He kept on telling those around him he wanted only Mommy. Amy felt a bit embarrassed by this, as she felt people staring at them. He only started calming down when they left, and went to a less crowded environment. He felt so secure then, that he even wandered off on his own and they had to search for him!

Case study 2

Sandy feels very isolated, as she recently moved from Johannesburg to Durban. She does not know a lot of people, and feels that she does not really have anyone to turn to. She has joined a support group and is getting to know other people with children with similar conditions as her own.

Case study 3

Jean had tremendous support from her parishioners. The woman's prayer group came to pray for them regularly in the first few weeks when Liam's seizures started, and she feels that it really helped. She also feels that the Bible study group helps her to stay spiritual. The prayers from her parishioners helped to sustain her emotionally as well as spiritually.

As far as the broader community is concerned, Jean feels that people never understood what she was going through, and even now she feels that people stare at them and ridicule her. Liam also cannot stand crowds and strangers, which affect his behaviour even more. Jean says that when they went to a wedding once, he cried to leave and Rick had to wait

outside the church with him. For this reason, they mostly stay at home, or go out to less crowded public places.

4.6 Support from the parish priest (pastoral care and counselling)

Switzer has this definition of the pastor: “The clergyman is a physical representation of the whole community of faith, of the tradition, of a way of viewing the meaning of life, of the dynamic power of faith, and of God himself” (1974: 23). It is thus understandable that the minister is the first person to whom a person in crisis might turn. It is, however, distressing when the pastor is unavailable when needed most. Estadt says the following about the unavailability of the minister to people in crisis: “When people find themselves abandoned by the Church’s ministers in their time of need, it may well be experienced as abandonment by God” (1983: 134).

Case study 1

The hospital chaplain assigned by the Church visited James while in ICU. Amy and John saw him once or twice, but mostly they missed his visits. Their parish was changing priests at the time of James’ hospitalisation. The priest they knew, even though he was informed of James’ condition, left without visiting them or James. The new priest was hardly at the parish at the time, because he was attending various conferences both locally and abroad. This resulted in Amy and John feeling deserted by the parish, and they subsequently stopped attending the services. It took a long time for them to start attending church again, due to James’ care exhausting them and also their resentment towards the parish priest. It was only when they had done a lot of soul searching and prayer that they started attending church again.

Case study 2

While still in Johannesburg, Sandy approached her local priest about Ian’s condition. He was very supportive of her, and provided pastoral care and counselling to her on a fairly

regular basis. He did this in the form of listening to her and praying for her. He also gave her holy water and oils to use for Ian. When she moved to Durban, she did not have the same kind of support, as she still has to get to know her way around, and get to know the priest.

Case study 3

Jean feels that her pastor was very encouraging to her on the occasions when she did speak to him. However, she did not see him regularly, because there always seemed to be other people ahead of her who wanted to speak to him.

Summary

Case study 1

Amy seemed to have had emotional support from John initially. However, James' condition and care eventually caused a lot of strain on their marriage. His taking on handyman jobs from other people aggravated her perception of him not providing enough emotional support to her once James was discharged. She acknowledged that when he was at home, he spent a lot of time with the children, even though she wanted him to spend time with her as well. Both of them learned to cope better and how to improve their own relationship, after psychological counselling,

Amy seems to have a very good support base in the form of her family, and even more concretely, in John's family who provide emotional and physical support. In this respect she is luckier than a lot of people in a similar situation. Even though she is far from her own family, she has their support emotionally as she can just call them. When they are together, they do provide physical support as well.

Amy had an overall good experience with the medical fraternity. However, the physicians dismissing her observations and questions have marred this. She has now found a physician who takes her comments, questions and observations seriously.

Amy was fortunate to find psychological help when she needed it. The psychologist made her feel at ease, and helped her work through her problems and difficulties. She was able to learn new coping strategies that enabled her to cope with Ian's condition and her family life.

Amy had a good experience with the community supporting her during James' illness. She has continued support, even though she does find the odd person upsetting her with stares and comments.

Amy's biggest let down in her time of crisis was the unavailability of her spiritual leader. This made her feel disappointed and resentful. She is trying to overcome this and has resumed her church attendance, which she neglected because of her grievances towards the priest.

Case study 2

Sandy and Mike's marriage was already on rocky grounds, and this situation was aggravated by Ian's condition. Sandy spent a lot of time with Ian going to hospital, as well as taking him for his therapies. She also has the two younger children to look after. She feels that she is not getting a break and time for herself, as Mike does not help her with the children, not even by administering Ian's medicines. She feels that he needs to play a more active role in their household, which might be difficult for him as he has a traditional view of the roles of men and women in a marriage. However, the quiet Sandy seemed to have made her point when she exploded in anger and told Mike how she felt. She says that it looks as if he is changing his attitude.

Sandy is far from her own, as well as Mike's family. She feels that her family does provide emotional support telephonically and physical support when they are together. The same cannot be said for her in-laws, who do not get on well with her. This makes her feel as if she is in this situation alone. Being in a new city, Sandy feels very isolated from her community. She is trying to make up for this by joining a support group.

Sandy found that her spiritual leader was very supportive of her while she was still in Johannesburg. Moving to Durban changed that and she has to build up a new relationship in her new parish.

Sandy did not find the medical fraternity very supportive. She has received negative comments that discouraged her. However, she has found a doctor now who is supportive of her, and encourages her to try new treatments.

Sandy, though admitting to needing psychological counselling, has never tried going for any treatment. She is still trying to go it alone, concentrating on getting Ian well.

Case study 3

Jean described Rick as very supportive, although they do seem to have a communication problem.

Jean has very little support from her family, although she expected her mother and sister to have been more supportive considering that they had a similar experience.

Jean was very upset with the treatment received from the doctors who initially treated Liam. She felt that they were the cause of his seizures worsening when they stopped his medication abruptly.

Jean said that she never found the time to go for psychological although she felt that she needed it, especially when she became suicidal.

Jean was well supported by her church community, who came to pray at her home regularly.

Although Jean feels that her pastor was supportive when she first approached him, she did not feel at liberty to approach him at a later stage, because there were always other people needing him.

Husbands generally seem to be perceived by their wives as not providing enough support in the face of a child's illness or disability and treatment. Pre-existing marital problems may resurface or be aggravated by the child's condition, as noted by Ferry, Banner and Wolf: "The presence of seizures in a child can exacerbate or aggravate pre-existing marital discord" (1986: 202). This observation is especially evident in the case of Sandy and Mike.

Davis in Davis and Fallowfield (1991) also recognises this. He states the following:

Of particular importance is the relationship between husband and wife. This changes inevitably with the birth of any child, and may change much more in the context of disability. However, there is no simple pattern. Some relationships are strengthened by the crisis, and some are weakened.

... although the problem may not be any greater than in the general population, a substantial number of parents do experience difficulties with their partner. Mothers may complain of the lack of support, physically or emotionally, provided by their husbands. Fathers may complain of their wife's obsessional focus on their child and there may also be sexual problems.

(1991: 228 – 229)

In the first two case studies, Amy and Sandy felt that they were not getting enough support from their husbands, whereas Jean feels that her husband is providing adequate support. Amy felt that John was paying more attention to the children than to her, whereas usually the husband has this complaint about the wife.

Jenny Kander made a similar finding to that of Davis:

Very often previous ways of handling difficulties prove inadequate because so many new and threatening aspects present themselves at once, just when both are feeling vulnerable and at a loss at what to do. The sick child requires more time and attention, the worry is emotionally draining, normal work demands have to be met and, in addition, the other children have to be cared for. All this leaves few reserves of energy for your relationship as a married couple. It often happens that your customary roles cannot be maintained because of all the new problems, and as anxiety, anger and tension mount you and your wife may feel overwhelmed and lose sexual drive. If the financial cost of the child's treatment is high it adds to the stress.

(1983: 3)

It is therefore quite obvious that the sick child can place a huge strain on a marriage. Where the relationship is already on a rocky path, the strain of the child's condition and care can push the marriage over the edge if great care is not taken by the couple to preserve their relationship. The marital relationship can become more strained with the added stress of financial problems. All three of these mothers had to stay at home to take care of their children. This resulted in a loss of a second income, causing financial difficulties for the families. Coupled with this was the high medical expenses incurred by their sick children.

When a child becomes ill or disabled and needs care, relatives and friends usually support the family. It is more the exception than the rule when this does not happen. However, in modern society, with the nuclear family often moving away to new cities, the support system of family and friends is often forfeited in the process. This leads to the nuclear family feeling isolated and bereft of support.

Some families, because of the nature of their children's conditions, tend to keep away from the networks that would and could support them. This is due to the fact that they do not want to impose their child's condition on other people, or they are embarrassed or ashamed by their child, or they have had negative experiences from other people and end up avoiding everybody else. In doing so they lose out on vital support for themselves.

Davis found that:

Many families are well supported by relatives, neighbours and friends. Others do not have such support or lose it as a result of the situation of having the child. ... some parents find it difficult or embarrassing to take their child into public places, particularly, for example, if the child has behavioural problems. These reactions are related to the stigma experienced by people in the context of disease and disability. Parents may perceive people to be reacting differently to the child and themselves. They may feel that people are hostile towards them, and lose self-esteem as a result. ... parents say the problem is exaggerated when their child is disabled, but normal in appearance.

(1991: 229)

We see this in all three case studies. Physically there is nothing wrong with the three children. Then, when the children display behavioural problems, people's reactions change towards them. For these three mothers, it causes acute embarrassment, which results in them avoiding public places with their children.

Doctors normally care well for a sick child in the physical sense. However, most of the time, they tend to ignore the concerns of the parents. Parents often find that doctors talk down to them, or dismiss their observations.

Davis also found this, and notes that:

Ironically, a difficulty that parents frequently raise in counselling relates to the behaviour of professionals. When asked how they (parents) wanted their doctors and others to behave, there was unanimous agreement. They wanted to be treated respectfully, as intelligent adults. They wanted the professional to listen to them, and acknowledge their expertise. They wanted a caring, not a patronizing attitude. They requested knowledge and information to be shared with them in ways that would enable them to be in control and to make informed decisions. They wanted professionals to treat their children respectfully as individuals, and to consider their whole family. They valued honesty encouragement and the time to communicate. It was clear

from these mothers that few of their requests were being met currently.

(1991: 230-231)

This problem seems to be occurring quite frequently, as many parents have this complaint. This problem that doctors have in relating to parents might be better understood in the light of the following:

Jane S. Ruggill describes the problem as follows in Ferry, Banner and Wolf:

We are frequently told how to treat seizures, but no one has written about the frustration of treating a child whose seizures are incompletely controlled...

...the physician understandably becomes frustrated and saddened by his inability to bring the child's seizures under control. At times it is easy to become short tempered with parents... to be unresponsive to phone calls and requests for additional recommendations.

(1986: 204)

Although this explanation does not justify the behaviour of the doctors, one can understand that they are human and they also get frustrated when their best efforts yield no results. Of this, Ruggill makes the following suggestions: "...if we recognize these reactions in ourselves as being natural, it is easier to cope with them and to react realistically to the frustrations of this type of long-term care. We must recognize that some seizures are impossible to control, and in such situations parents can be advised to seek a second opinion elsewhere"(1986: 204).

Ruggill provides some advice on how the family should be treated when faced with their child's diagnosis of epilepsy. She says that parents should be reassured that the physician understands their anxiety and concern and that their feelings are perfectly normal. The family should be told that the physician or someone on his staff would be available to answer any additional questions they may have (1986: 200).

Parents and families may lack medical education and not know the neurophysiology of epilepsy, but they can learn about seizures. Short words and sentences should be used.

The advice and directions should be specific, detailed and focused. The family should be encouraged to ask questions and not made to feel stupid if they do. The nature and purpose of medication should be explained repeatedly. Parents should be told the importance of not discontinuing medication abruptly.

Some families, even highly educated ones, may need elaborate and time consuming discussions to allay their fears. However much time is necessary, the physician managing the child with epilepsy should ensure that this portion of the medical care of the child is undertaken with as much care and caring as the other aspects of his treatment. Ruggill quotes the pioneering epileptologist, Dr William Lennox, who said: "A good physician is concerned not only with turbulent brain waves, but with disturbed emotions and with social injustices, for the epileptic is not just a nerve-muscle preparation; he is a person, in health an integrated combination of the physical, the mental and the spiritual. Disruption of any part can cause or aggravate illness" (1986: 202).

Wayne E. Oates distinguishes three phases of emergency care giving:

- (1) The caregiver moves the situation out of panic, severe alarm, and loss of control into a calmer, steadier, and less terror-stricken state of being.
- (2) The caregiver mobilizes emergency assistance (loved ones and professional help) for stricken persons.
- (3) The caregiver works out plans for the longer term care of the stricken person(s) and provides spiritual support, continuing guidance, and encouragement. In such situations (sudden traumatic grief), the caregiver can communicate the steadfast love of God.

(1989: 15)

These tasks, which Oates assigns to the caregiver, are very important. At a time of crisis, a person often becomes incapable of thinking clearly and making the necessary emergency arrangements themselves. Also, in their time of crisis, the person needs to know that God is there for them and that God does understand what they are going through. Oates says that: "Prayer in times of emergency, when timed accurately is the greatest gift we can share with people in their acute state of being." (1989:18). This is an important act to the mother, as she needs to be reminded that God is there for her, and with her in her time of crisis.

David K. Switzer says the following: "In one way or another, the Christian pastor throughout the centuries has been involved with persons in time of crisis and distress" (1980: 15). It is therefore distressing for a person in need of their spiritual leader to find that he is not available to them in their time of need.

Clinebell describes crisis counselling as follows:

By standing with a person in crisis the minister helps him to mobilize these (latent) inner resources and also to draw on the resources of the religious tradition and community. During stormy crisis periods, a person's sense of selfworth and meaning are temporarily depleted, his world shattered. The support of his pastor can help keep the floundering ship of his life from sinking. Ordinarily, when the storm's fury diminishes, the ship will right itself.

(1965: 223)

This description and analogy are extremely relevant to the experience of mothers faced with the trauma of their previously healthy children becoming special needs children, the term generally used to describe children with disabilities, be it physical or intellectual. The mother, more than anything in her time of crisis, needs her spiritual leader to be available to her, to convey to her the love and presence of God. The mother needs to know that God has not deserted her in her time of need and knows what she is going through.

When people feel unable to cope with their situation, it might be necessary to seek psychological help. Sometimes people might make their own arrangements, at other times they might be referred by their general practitioner or even their minister, if they feel inadequate to cope with the person's problems. Switzer recognizes this: "The decision to refer or transfer is determined by the needs of the person that are relevant to the crisis and the ability of the minister to meet those needs. When he cannot, someone else must be found who can" (1980: 122).

Conclusion

These mothers had varying degrees of support provided by the different support bases. However, the support they sought from their minister seemed to have been inadequate.

The question that arises is: Are ministers trained to deal with the crisis of a mother whose formerly healthy, normal child developed epilepsy and became cognitively impaired? The answer at first seems to be no. Ministers generally do not receive specific training in this area. However, the answer could also be yes. The minister could utilize his training in grief and bereavement counselling, coupled with crisis counselling, to provide adequate care for such a mother. It is therefore up to the minister to discern in which way to help a mother faced with the crisis of losing her healthy, normal child and gaining a child suffering from epilepsy and being cognitively impaired.

Another question could be asked, and that is: Why does the mother not persist in asking for help? This could be answered by the fact that these mothers did indeed approach their ministers, whose response to their crises proved inadequate. They subsequently refrained from returning to their ministers for support. This is an indictment on the clergy, of whom Clinebell states: "One of the most important advantages a minister has is not needing to wait until people ask or come for help. As the professional role of clergy is defined, we are expected to take the initiative in making help available to those who need it but are not ready as yet to ask for help" (1984: 36). Having found inadequate support from their ministers could have added to their crisis, and also prevented these mothers to

work through their crisis sooner. Estadt feels that: "... when people find themselves abandoned by the Church's ministers in their time of need, it may well be experienced as abandonment by God" (1983: 134).

CHAPTER 5

HEALING – RESTORING THE MOTHER TO WHOLENESS AND LEADING HER TO ADVANCE BEYOND HER PREVIOUS CONDITION

Introduction

In order to provide a model for pastoral care and counselling for mothers faced with their previously healthy children as special needs children, we first have to look at the following:

What is pastoral care and counselling? Why pastoral counselling? Who is a pastoral counsellor? Where is pastoral counselling done? How is pastoral counselling done?

In order to answer these questions, one has to look at the theorists of pastoral care and counselling and how they influenced pastoral care and counselling. One also has to look at the theorists from other overlapping disciplines and how they influenced pastoral care and counselling.

The following theorists will be discussed to see what their influence and contribution is to pastoral care and counselling.

5.1 CARKHUFF AND BERENSON

Carkhuff and Berenson call the counselling process the helping process, with the counsellor being the helper, and the client the helpee. They identify four goals of helping in the following sequence: (i) helpee exploration, (ii) helpee understanding, (iii) helpee action, which together constitute (iv) helpee learning. According to them, the first goal of helping is to respond to the helpee's frame of reference in order to facilitate helpee exploration. They feel that the facilitation of exploration is essential if goals are to be defined, changes are to take place, and the goals achieved. Therefore, it is vitally important that "the helper's ability to respond must take him fully enough into the helpee's experience, not only to facilitate helpee exploration but also to teach the helpee how to explore" (1977: 152).

Carkhuff and Berenson see helping as being about human growth, personal responsibility, learning and skills. Through helping comes freedom. Through learning, the growing person obtains the skills that are needed to understand what he did not understand before. Subsequently, the growing person's constant learning and increasing responsibility results in freedom.

Crisis Therapy

Carkhuff and Berenson say that crises are crises because the individual has no defence to deal with the situation. However, each crisis has the ability to lead to constructive change. A crisis compels the person to adopt new skills to adequately respond to his problems. In order for a crisis to lead to physical, emotional and intellectual growth, it requires the input acquired from extensive and intensive exploration, full understanding, and orderly, systematic goal-directed action. According to Carkhuff and Berenson, the question we must ask of each step chosen to free us from a crisis is: does this step get me closer to a growth goal? (1977: 163).

An effective helper's life is well ordered so that he or she can focus fully on another person. The whole helper can enable the helpee to face his or her problems and thus enable the helpee to move forward.

For Carkhuff and Berenson it is crucial that

A whole helper brings his whole person and all of his accumulated knowledge to bear at the crisis point. If the helper is able to "touch" the client, letting him know that he is with him in his deepest moment and that he will do whatever he has to do to free the helpee to choose life, then the closed cycle that disallows action is broken.

(1977: 172)

This is the client's most vulnerable moment, when the heart of the crisis is reached and exposed. It is therefore essential that the counsellor shows the client that he is fully with her in that moment, and that whatever vulnerability is shown, will be treated sensitively. The client then will feel strong enough to move forward from this point, breaking through the crisis that held her back from living life to the fullest.

5.2 EGAN

In his book "The Skilled Helper", Egan has the following ideal of what a helper should be:

Helpers should all be committed to their own growth – physical, intellectual, social-emotional, and spiritual. Helpers have adequate basic intelligence, and have respect for the world of ideas. They have common sense and social intelligence and are at home in their own social-emotional world as well as others'. They are more interested in accomplishments than behaviour. They respond from their clients' frame of reference, respecting their clients and not judging them. They genuinely care for those who came for help. They are non-defensive, spontaneous, and always willing to say what they think and feel, provided it is in their clients' best interests. Good helpers are concrete in their expressions, dealing with actual feelings and actual behavior rather than vague formulations, obscure psychodynamics, or generalities. Their speech, caring and human, is also lean and to the point.

(1982: 27)

Egan sees skilled helpers as integrators, who help clients explore their experiences, feelings, and behaviour. As clients provide information about themselves, skilled helpers help clients to integrate the information so clients can understand themselves and their behaviour. Counsellors willingly share themselves and their experiences if necessary to advance the helping process. They confront clients with care, to help clients place demands on themselves, provided that these demands are based on the clients' experience and not on the helper's needs. They are able to deal openly with their own relationships with their clients to help clients understand their own behavior and interpersonal style and to help them move toward goals and action. They do all this with concern and respect for the client (1982: 27).

Skilled helpers help their clients to set goals and develop action programmes that lead to positive behavioural change. They know that the helping process is complete only when the clients act on their understandings. They enlist all possible resources to enable their clients to achieve their goals, helping their clients to see alternatives. They use a comprehensive helping model, regarding it as a tool to help clients live more efficiently, fully focusing on the client.

Good counsellors are comfortable with individual clients as well as groups. They can get involved in someone's life, no matter how traumatic it is. They can handle crises, because they can draw on their own inner strength, so that they can help others to be competent and confident. They recognize that it is an honour to be allowed into someone else's life, and they value this privilege.

Skilled helpers have their own problems, but they are able to face them. They deal with their own behaviour and are in touch with themselves. Skilled helpers "know what it means to be helped and have deep respect for the helping process and its power. Even though they are living effectively, they also know they are in process, that each stage of life has its own developmental tasks and crises." (1982: 28)

5.3 CARL ROGERS

Leroy Aden finds Carl Rogers' therapeutic approach extremely relevant and important to the religious concerns of pastoral care and counselling. He says that even though "Rogers as a psychologist never develops the latent religious end points of his three ingredients, the formulations that follow emerge out of an attempt to conceptualise my own experiential observations as a Rogerian-oriented pastoral counselor" (in Oglesby 1969: 263).

Carl Rogers identified three therapeutic ingredients crucial or essential to the counselling relationship. He calls them empathic understanding, unconditional positive regard and congruence.

Empathic understanding: This means a sincere honest attempt by the therapist to understand and convey the feelings and experiences of the client as the client himself sees and feels them. Rogers calls it duplicity when a person becomes a divided and disrupted being, living separated from the deeper significance of his existence. Empathic understanding addresses itself to this radical self-alienation. The primary role of empathic understanding is to reverse the individual's defensive stance toward life so that he can become more conscious of his own inner reality, his feelings, attitudes, and desires. At the same time he becomes more conscious of the reality that exists outside himself.

Unconditional Positive Regard: According to Rogers, the individual develops a "need for positive regard", that is, he must feel that his life makes a positive difference in the world of the significant other, that he is respected, cherished, and loved (1969: 267). Consequently, he becomes attentive to the response of others and begins to evaluate his feelings and desires according to their negative or positive reaction. Gradually, according to Rogers, this whole process is internalised so that the individual takes on the values of the significant other and cannot regard himself positively unless his experience is in accord with these introjected values, these "conditions of worth" (1969: 267). Therefore, Rogers maintains that one of the essential ingredients of a healing relationship is unconditional acceptance. Unconditional acceptance by the therapist means that he cares without conditions attached which the client has to meet.

Congruence: Rogers calls the integrity and authenticity of the therapist congruence, which he feels is the most basic of the three conditions. Genuineness, or unconditional authenticity, in the therapist inspires confidence, or unconditional trust, in the client who feels assured that the therapist *is* what he appears to *be* (1969: 271).

5.4 CLINEBELL

Clinebell defines pastoral care and counselling as follows:

Pastoral care is the broad, inclusive ministry of mutual healing and growth within a congregation and its community, through the life cycle. *Pastoral counselling*, one dimension of pastoral care, is the utilization of a variety of healing (therapeutic) methods to help people handle their problems and crises more growthfully and thus experience healing of their brokenness. Pastoral counselling is a reparative function needed when the growth of persons is seriously jeopardized or blocked by crises. People need pastoral care throughout their lives. They may need pastoral counselling at times of severe crises, usually on a short-term basis.

(1984: 26)

Clinebell proposes a model of pastoral care and counselling which he calls the liberation-growth model. For Clinebell the goal of ministry, and of pastoral care and counselling is to liberate people in order to reach their fullest potential. "Liberation includes *liberation from* the limitations in a person's life that prevents full development, *liberation to* a life in all its fullness and *liberation for* life in the Spirit expressed in loving service" (1984: 30).

According to Clinebell people's growth takes place in relationships. Pastoral care and counselling should help people increase their ability to relate in ways that nurture wholeness in themselves and others.

Clinebell says that pastoral care, as understood in the New Testament, is the duty of the whole congregation to be a caring, healing, growth-enabling community. This general ministry should provide a warm, caring interpersonal environment for people experiencing losses and crises, which can help prevent crises from mounting, and enhance the healing effects of crisis counselling and therapy. The clergy's task is to train, coach, inspire, and supervise lay persons in their ministry of caring, while also using the rich resources of their training, professional role, and pastoral office in doing their own caring work (1984: 34)

For Clinebell, one goal of pastoral care and counselling is to enable people to respond to their crises as growth opportunities. This is done by the use of short-term crisis methods, support groups, and lay caring persons and teams. Every crisis should also be regarded as a spiritual growth opportunity. Pastoral counselling aims at helping persons deal constructively with their immediate problems, make decisions, face responsibilities, and make amends for self-other hurting behaviour, as well as expressing, experiencing, and eventually resolving growth-blocking feelings, attitudes, and self-perceptions. The aim of counselling is to help people improve and implement their potential coping skills, and in the process they gain strength, competence, esteem, and hope to cope with future crises.

To be fully effective, pastoral care and counselling needs to use the insights and methods of a variety of growth-centred therapies. However, says Clinebell, although it is important that pastoral counsellors should learn from current sources, they should remember that their identity is based on the tradition of shepherding.

Clinebell refers to Clebsch and Jaekle who identified four essential pastoral care functions in the history of the church:

- 1) Healing – restoring the person to wholeness and leading him to advance beyond his previous condition
- 2) Sustaining – Helping a hurting person to endure and to transcend a circumstance in which restoration to his former condition seems impossible
- 3) Guiding – assisting troubled people to make confident choices, which will positively affect the state of their well being.
- 4) Reconciling – to re-establish broken relationships between a person and God..

Clinebell adds a fifth function:

- 5) Nurturing – to enable people to develop their God-given potentialities, throughout the life-journey with all its valleys, peaks and plateaus.

(1984: 42)

“An effective caring and counselling relationship thus becomes a part of the continuing incarnation of the Spirit of creating God in the lives of hurting, hoping people” (1984: 50).

Clinebell bases his “growth formula” on the fact that “growth takes place in every relationship when accepting love and honest confrontation are present. When someone speaks the truth to us in love, it constitutes healing love, which is essential in all pastoral care and counselling” (1984: 56). Clinebell says that Jesus’ way of relating to people embodied this formula. He cared deeply for all kinds of people, but with confronting honesty. He related to them in terms of what they could become as well as what they were. He saw them through the glasses of growth and thus helped them grow (1984: 56)

Ministers need to understand their uniqueness as counselors, vis-à-vis other professionals who do counselling and therapy, so that they can maximize their special contributions to helping the troubled. *The heart of our uniqueness is our theological and pastoral heritage, orientation, resources, and awareness.* This is our frame of reference and the area of our expertise. The awareness that the transpersonal Spirit of God that is the core of all reality, should influence profoundly everything we do including our counselling.

(1984: 67)

Clinebell reiterates that the counselling pastor’s working premise that “*spiritual growth is an essential objective in all caring and counselling* is unique among the helping professions. A minister’s expertise is to nurture spiritual wholeness as the centre of the whole-person growth”(1984: 67). They are also expected to use the resources of their religious tradition as an integral part of their counselling. “Ministers counsel within an ecclesial setting where established, trustful relationships often provide a solid foundation for crisis counselling, allowing persons to be helped in much less time than would be required to start from scratch with an unknown counselor” (1984: 67).

The role of pastors in crisis ministry

Clinebell stresses the fact of the uniqueness of the pastoral counsellor when he says: “Their unique function, as spiritual growth-enablers, is to help crisis-stricken people to discover the ultimate meaningfulness of life lived in relationship with God whose steadfast love is always available, even in the midst of terrible tragedy” (1984: 184). This underscores the fact that ultimately, the person in crisis must be made aware that God loves them and that He cares about them in the midst of their crisis.

For Clinebell, a minister’s aid to people experiencing crises and losses has four aspects – the general ministry of pastoral care; informal crisis counselling; short-term (one to five sessions) formal crisis counselling; and longer-term counselling and therapy to help persons repair the psychological and/or consequences of severe crises. The general ministry of pastoral caring is a ministry of presence, listening, warmth and practical support. Trained lay carers can and should share responsibility for this important and demanding ministry. Short-term crisis counselling, informal or formal, is needed by persons whose coping skills are more easily obtained, who can manage their crises better and for whom effective approaches to the new situation created by the crisis can be planned. Those who are so distraught and debilitated by overwhelming losses or multiple crises need formal longer-term counselling. The minister, if unequipped to deal with the situation, should refer persons whose lives have been so devastated to psychotherapists (pastoral or secular) who have the time and training to do the reconstructive psychotherapy needed (1984: 184)

The core experience in both crises and grief is that of loss. A loss or the threat of a loss is always involved in crises. Feelings of grief are a part of all major life changes, transitions and crises. In most crises and losses, there is separation anxiety, feelings of identity confusion, and the necessity of developing new ways to meet one’s basic emotional needs (1984: 185).

In crisis and bereavement counselling, the original root of the word “religion” – religio, to bind together – has dynamic significance. When devastating loss overwhelms one’s life, deep-rooted religion may help bind it together, imparting some sense of coherence and meaning. The awareness to some people in their crisis that their faith is deficient or obsolete can open them to the growth process of changing and renewing their spiritual lives. “A renewed faith usually develops only after one has finished much of one’s painful grief work and is able to reflect on and learn from the painful loss. A pastor’s skills in facilitating spiritual growth may help grieving people enlarge their faith and revitalize their relationship with God” (1984: 225).

Clinebell is specific in what he believes about the role of pastoral counsellors in crisis and grief counselling:

Whatever your crisis counselling and bereavement skills, their ultimate usefulness will depend on how you cope with your own crises and losses, and what you learn about yourself, life, people, and God from those unwelcome intruders. People who feel shattered need your supportive strength, but they also need to sense that you know something about how it feels to be shattered. They need your faith and hope, but they may also need to sense that you have known doubt and despair firsthand. In short, they need to experience the strength in you that comes from admitting your weaknesses and failures, from accepting your vulnerability and your deep need for others.

(1984: 239)

5.5 ESTADT

Estadt has the following definition of the pastoral counsellor: “a religiously integrated person who approaches others with a sense of mystery along with an ability to enter into communion with others in a therapeutic alliance with the goal of reconciliation and personal religious integration” (1983: 1). This definition echoes the view of the pastoral counsellor by Clinebell.

Estadt expounds this definition by relating his own personal experience as a religious person to his personal experience of loss. Estadt, relating the experience of watching his father on his deathbed and his own feeling of helplessness, says the following: “Through this experience I came to understand that a lack of control does not equal a lack of potency”(1983: 3). This he discovered when his father thanked him for supporting him during the time of his illness. Although he felt helpless in the face of his father’s suffering, his father found strength and encouragement in him just being there. Estadt describes that he can “reflect, in reverence, on the special *awareness of the holy* which I have experienced in the midst of helplessness” (1983: 3). As a pastoral counsellor, Estadt recognises the presence of God in the midst of his loss, and is aware of the fact that God was with him during the time of his loss.

Estadt says that we have a “need to work toward an acceptance of the mystery of the divine plan as it unfolds in our lives, full well realizing that it may be necessary for acceptance to precede understanding” (1983: 3). With this, Estadt emphasizes that as humans, we have to accept events occur in our lives, even though we do not understand why God is allowing them to happen.

Estadt’s experience of God in his relationship with his father and other clients “was rooted in a *faith that transcends the here and now* together with a *personal capacity to trust*” (1983: 4). It is obvious that he found strength during his crisis in the fact that his faith was beyond his earthly experience of loss, and that he trusted God that there was a reason for it happening. Estadt finds a connection in Jesus’ suffering, as Jesus experienced the same human suffering that humans experience. This knowledge gave him the strength to face his crisis and loss.

According to Estadt, the pastoral counsellor has to understand the pain and struggle of those needing help by entering into their experience. However, he cautions that the counsellor should not get caught up in the person’s pain himself, because “If the counselor gets caught up in the client’s confusion, hurt, and anger, the counselor can hardly be a confident voice communicating faith and trust” (1983: 5)

He continues by saying:

To be sensitive to the suffering of persons in the midst of intense struggle without being drawn into the struggle itself requires an advanced level of personal religious integration. It requires, a sense of personal finiteness, an awareness of the holy, a faith that transcends the here and now, a personal capacity to trust, and what I would term: a grateful acceptance of one's personal pilgrimage.

(1983: 5)

Once again Estadt relates his own personal experience, this time in the light of his mother's death. He could not accept her suffering on her deathbed and reacted in anger to God. It was only when he envisioned Jesus on the cross, with John and Mary at the foot of the cross that he came to an understanding and acceptance of his mother's suffering and death. He understood his mother's suffering and death in the light of Jesus' suffering and death, and he understood: "that Jesus came, not to change the human condition but to embrace it" (1983: 6)

As pastoral counsellors, according to Estadt, "We are interested in the intrapsychic processes of our clients and in their successes and failures in relating to others" (1983: 7) To enable people to meet life's challenges, the pastoral counsellor uses various therapeutic approaches. "What is unique in pastoral counseling, however, is the fact that we are instinctively interested in and sensitive to the transcendent strivings of our clients" (1983: 7). This ties in with Clinebell's belief that the uniqueness of the pastoral counsellor to that of other counsellors, is the fact that the pastoral counsellor is interested in the spiritual growth of the client. Estadt also recognises that the pastoral counsellor has to meet people at their respective stage of development and facilitate growth in a way that is consistent with the person's goals.

Estadt firmly believes that however strongly the pastoral counsellor might feel about his own personal faith and Christian tradition, he should not superimpose his own set of values on the client through subtle forms of proselytising. He also maintains that

despite the fact that the pastoral counsellor and the client are *copilgrims* on life's journey, the pastoral counsellor should keep his professionalism during counselling.

He also says that as pastoral counsellors, we share with other counselling professionals the concern for personal integration in our preparation for the counselling ministry. In addition, however, the pastoral counsellor, being a minister of the church, is expected to have achieved a level of personal *religious integration*.

Estadt feels that pastoral counselling has to bring about reconciliation, which has to occur in a three-fold manner: with self, with others, and with God.

Reconciliation with self: The counseling process leads clients to a continuing, truthful self-evaluation as they are able to acknowledge and to accept even the "shadow side" of their character. Increased openness toward the client's own flaws results in increased freedom. "As pastoral counselors, we help to free our clients so that they can enter more fully and more authentically into the process of living. Increased freedom carries with it both risk and responsibility. Growth forward requires courage, will, and choice" (1983: 12).

Reconciliation with others: Clients have to scrutinize their present and past relationships in order to determine future prospects. They need to get to the heart of their relationship by chipping away all superfluous elements that obscure the relationship. Sometimes the reconciliation deals with significant persons who are deceased, often involving acute emotion as anger toward the deceased person is released.

Reconciliation with God: Sometimes anger at God is related to deep religious questioning about God's perceived lack of concern about human suffering and leads people to question the very existence of God.

5.6 BLANCHETTE

Melvin Blanchette, in Estadt's book "Pastoral Counseling", states the following: "What is needed for the pastoral counselor would include a knowledge of normal as well as abnormal behavior, technical skill and competence derived from study and supervision, and an in-depth appreciation of the theological, philosophical and psychological issues involved in the mystery of becoming human" (1983: 21) For Blanchette, the most important quality of the pastoral counsellor is to be a person who can be with others. The pastoral counsellor is someone who can be with another who struggles with the unfinished business of becoming human. However, the pastoral counselor does not make decisions for the person. The pastoral counsellor's task is to help people devise and analyse the accuracy of their decisions. Solutions to problems must be accepted with a clear view toward the significance of values. "These values are the silent and hidden potentials of behavior which take the form of questions we ask of life" (1983: 24)

The function of pastoral care and counselling: Blanchette defines two functions that pastoral counselling can fulfill: (1) to enable a person to become free in order to be responsible, and (2) to enable a person to deal with pain. Pain is caused by our reaction to the expectations placed upon us. Growth is the result of dealing with the stresses involved in living. Pain becomes a strong motivation for change. The two biggest barriers blocking happiness and causing pain are anxiety and depression. We all know depression caused over a loss, and have felt the debilitating grip depression can have, and the resulting sense of powerlessness. "Pain becomes an all-important call to growth. It is the tension element in life, the situation in which a person comes face to face with the power of life and the power of love. ... for it is only at the cost of pain that one becomes the best" (1983: 25).

The foundations of pastoral care and counselling: The texts of scripture shed light on what it means to be a genuine pastor by taking an understandable image and associating it with God's care. As the shepherds cannot do the grazing or drinking for the sheep, so too pastoral counsellors are limited in what they can do for their clients; they can only be with those who have entrusted to them the depths of their lives. "The work of the pastoral

counsellor flows from the life of the pastoral counsellor, a life rooted in faith. Pastoral counsellors have come to grips with their own lives because of the faith stance that they share. They themselves have been able to experience the healing of God and the way to becoming fully human” (1983: 25 – 26).

Blanchette holds that the faith stance of the pastoral counselor enables the counselor to understand self as an image of God, which enables the counselor to approach clients with the awareness that the clients, too, live in the very same likeness of God. Therefore, as a living exemplar, the counselor may be understood as a brother or sister who serves another so that the other may experience life to the fullest. Based on the example of Jesus, the counselor understands that he does not stand among people as a master but as a friend.

For Blanchette, the proclamation of reconciliation by people of faith goes hand in hand with pastoral counselling. This gives concrete form to the process of reconciliation. “The people who enter into the pastoral counselling process need that love of God to touch them. The client in pastoral counseling faces a set of challenges and beliefs. By getting in touch with the love of God, the client is assisted in making loving choices for him or herself; the developing love of self is itself a freeing experience” (1983: 34).

Blanchette holds that Pastoral counseling is a process of liberation based on the ministry of Jesus. He concludes:

Liberation means that human persons are freed to see themselves as a people who share in a new life; the radical transformation of the world which the Gospel envisions begins now with the transformation of individuals who are willing and ready to make healthy and loving decisions. In such transformation, the process of pastoral counseling finds its roots

(1983: 35)

CONCLUSION

As seen before, the mother confronted with her previously healthy, normal child developing epilepsy and becoming cognitively impaired, needs and deserves the care of a sensitive minister to help restore her to wholeness, beyond her condition of grief and despair. These mothers would have to honestly explore their feelings, with the help of a sensitive and caring helper.

This process can be facilitated by the three therapeutic ingredients, as proposed by Carl Rogers (Oglesby [ed] 1969: 263). This therapeutic approach would be very helpful to the mother who is already feeling guilty about her feelings about her situation and her feelings towards her child. The fact that she will be regarded non-judgmentally would mean that she would readily express her feelings to the therapist.

According to Clinebell, in using the insights and methods of other caring professions, the minister should remember that an important aspect of crisis is to convey the surety that God is present in the midst of our despair. Although these mothers seemed to have been aware of this, there were times when despair and doubt occurred, and it would have been comforting to have the minister convey the assurance of God's love and presence.

For Estadt, reconciliation occurs in a three-fold manner: with self, with others, and with God. Relating to the case studies, firstly they have to reconcile themselves with God by letting go of the anger and blame they might feel about their children's condition. Secondly, they have to reconcile and accept their children with their new personalities, behavioural difficulties and diminished cognitive abilities, and they also have to reconcile themselves with the people they feel angry with for being unsupportive. Thirdly, these mothers have to reconcile their feelings about their situation to come to acceptance within themselves.

The pastoral care function of healing, to restore a person to wholeness and leading him to advance beyond his previous condition, finds fulfilment in the therapeutic relationship of pastoral counselling. It would mean a great deal to a mother confronted with her normal, healthy child becoming epileptic and cognitively impaired, to have this function of pastoral care available to her.

CHAPTER 6

NURTURING – TO ENABLE THE MOTHER TO GROW THROUGH HER CRISIS AND TO DEVELOP HER GOD-GIVEN POTENTIAL, THROUGHOUT THE LIFE-JOURNEY WITH ALL ITS VALLEYS, PEAKS AND PLATEAUS

Introduction

Paul W. Pruyser in his book “The Minister as Diagnostician” poses the following question: “Why do problem-laden people in such large numbers turn to their pastors first in seeking help?” (1976: 46). He gives the following answer: “I am convinced that a great many persons who turn to their pastor for help in solving personal problems seek assistance in some kind of religious or moral self-evaluation. They want to see some criteria of their faith applied to themselves” (1976: 49).

A mother confronted with the sudden crisis of her child contracting a debilitating illness, needs the presence and care of her minister. The first question is: is the minister readily available to provide the pastoral care the mother needs at the onset of the crisis, and in which ways will he provide pastoral care? The second question is: is the minister equipped to deal with the mother faced with her previously whole, healthy, normal child who emerged from his initial illness epileptic and cognitively impaired? Coupled with the second question is the question whether the minister will recognise that the mother has suffered a loss – the loss of her previously healthy, normal child – and therefore is undergoing a process of grief.

Applying Case Study 1, an attempt will be made to provide possible ways in which the minister can be of significant help to the grieving mother, enabling her to move out of her grief and finding ways to cope and embrace her ‘new’ child, whom she, in effect, has to get to know from scratch as his personality has changed due to his illness, but who is in desperate need of her love and care to become whole again.

The focus here will be on the ideal situation: how Pastoral Care and Counselling should be able to provide support and support systems during and after traumatic events in people's lives, with special reference to Case Study 1.

6.1 Pastoral care at the onset of the crisis

Crises are categorised under the broad labels of developmental and situational or accidental. According to Clinebell, developmental crises are the normal occurrences happening throughout a person's lifespan, for example: birth, weaning, starting school, adolescence, leaving school, entering a vocation, marriage, pregnancy, parenthood, the mid-life crisis, loss of parents, menopause, retirement, death of spouse, death of friends, and eventually one's own dying. Situational or accidental crises are precipitated by unexpected losses of what one regards as essential sources of need satisfaction. These include, among others, illness, unexpected death, war, natural disaster, job loss and mental and physical handicap (1984: 187).

Based on the definition of situational or accidental crisis, which is a crisis precipitated by an unexpected loss of what one regards as essential source of need satisfaction, it is clear that this is the crisis that Amy faced. Her healthy, normal son contracted a debilitating illness, from which he emerged epileptic and cognitively impaired. Initially, Amy had to cope with the uncertainty of whether her son would survive his illness, which was a crisis situation in itself. When James did survive, he was not the same little boy she had raised until then. His illness was not only traumatic for her, but also had a traumatic effect on him. Her boisterous, assertive and extrovert son had become a fearful, quiet and withdrawn little boy. The expectations Amy had of him recovering fully and quickly once released from hospital, were destroyed once she realised the full extent of the damage caused by his illness. He could not understand the simplest instructions and he had to relearn vocabulary and skills, which sometimes were beyond his grasp. Amy felt that she could still deal with that, even though it was very difficult at times to see how her son was struggling with the most basic concepts. What she found almost impossible to handle was his behavioural change.

Callahan states that the situational crisis most frequently encountered by the minister is the crisis of illness. Ministers by role definition are expected to visit the sick members of the parish. When there is a serious illness in a family, both the patient and the other family members are going to be physically and emotionally depleted. Serious illness often demands a major realignment in family roles and in the provision of both material and emotional support. The family is faced with fears, upset, and anxiety. They may find themselves expressing unusual feelings of anger, often targeted at the doctor or the medical staff. In many hospitals there is a pastoral care team who are attentive to working with these feelings. This presence does not diminish the need for the pastoral care of a person's own minister, and the minister needs to be aware of the fears and feelings that are present (Estadt: 1983: 141).

Amy found that, even though the parish priest at that time was notified of James' illness and hospitalisation, he did not find the time to visit the family either at hospital or at home. This was in part due to the fact that he was leaving the parish. Due to commitments outside the parish and even abroad, his successor was never long enough at the parish for Amy to even establish a relationship. The fact that her spiritual leader was unavailable at such a traumatic time left quite a void in Amy. The hospital chaplain did stop by to pray for James, but most of the time he came by when Amy and John were not present. Ministers from other denominations who were visiting their parishioners stopped by to pray for James, which Amy and John gratefully accepted. John's uncle, Brian, called a prayer meeting at their home, fulfilling a spiritual role and duty much needed at the time. The current priest came for a home visit when called out late one evening when James had contracted bronchitis, and the antibiotic clashed with his anti-convulsant medication. He spent quite some time with the family, encouraging them and saying a prayer before he left.

Amy did feel that the doctors were not doing enough when James' condition was still unchanged after ten days. They felt vindicated when the paediatric neurologist

immediately proceeded with aggressive treatment, while the original team was following a wait-and-see approach.

Oates' three phases of emergency care giving come into play at the onset of crisis, where the pastor, when approached by his parishioner in distress, has to do the following: he has to bring calmness into the traumatic situation, he has to arrange for immediate help for the traumatised persons, if necessary, he has to provide spiritual support, continuing guidance, and encouragement, also conveying God's unfaltering love. He also has to make arrangements for the longer term care of the traumatised person(s) (1989: 15).

These tasks Oates assigns to the caregiver, are very important. At a time of crisis, a person often becomes incapable of thinking clearly and making the necessary emergency arrangements themselves. Also, in their time of crisis, the person needs to know that God is there for them and that God does understand what they are going through. Oates says that: "Prayer in times of emergency, when timed accurately is the greatest gift we can share with people in their acute state of being" (1989:18). This is an important act to the mother, as she needs to be reminded that God is there for her, and with her in her time of crisis.

Amy had no assistance from her parish priest during her initial crisis of James' hospitalisation. This made her reluctant to contact him afterwards when she experienced the crisis of not being able to cope with her situation. She even stopped attending church services due to the resentment felt towards the parish priest. It was only after she worked through and resolved her feelings of resentment that she resumed her church attendance. Incidentally, by then a new parish priest had taken over, one who did come to their home when called upon.

According to Clinebell, the general ministry of pastoral caring is a ministry of presence, listening, warmth and practical support. Trained lay carers can and should share responsibility for this important and demanding ministry.

Amy received caring from the laity in the person of Brian, John's uncle. He called to ask whether they would like to have a prayer meeting when there seemed to have been no

change in James' condition. It was also Brian whom they called upon to lead a thanksgiving prayer meeting when James was released from hospital, and again for his fifth birthday. Brian was also the one who brought the new parish priest when James had adverse effects due to the antibiotic treating his bronchitis.

Pastoral care: practical ways in which the minister can provide assistance to those in crisis:

In order for the minister to provide proper support to a person in crisis, he has to meet the following criteria, according to Switzer (1980: 66 – 67). These criteria are: i) location – the church provides a visible location for the person in distress; ii) availability – the minister needs to be available **at the time of crisis** (emphasis mine), and not long after the crisis has passed, or worse, escalated; iii) mobility – the conscientious and dedicated minister takes the initiative to intervene by going to persons wherever they are and whenever he has reason to believe that there is a need; iv) flexibility – the minister should accept people for immediate counselling when they walk into the church, as well as do telephone counselling.

At the onset of a crisis, it is most important that the minister be available and is present to the persons in distress. Practical ways of how the minister can provide assistance at the time of crisis are:

Prayer (Oates 1989: 16)

This is by far the most important aspect of conveying care and God's love and presence to the person in distress. Saying a heartfelt prayer puts the whole crisis into God's hands and brings the presence of God in Jesus Christ into vivid awareness. This is probably the most calming act the minister can perform. For example, the minister can say a prayer, asking God to strengthen the mother during her crisis.

Home visits (Oates 1989: 17)

According to Oates, the minister should go to the scene of the crisis immediately, as soon as he has heard of it. The minister can provide practical support by listening to the person in crisis, and reassuring them of God's love and presence.

Support systems (Oates 1989: 18)

The minister should ensure that the person in crisis has adequate support in the form of family, friends or even fellow parishioners. After the initial crisis wears off, the support system seems to disintegrate as people resume their daily activities. This often leaves the person isolated and lonely. According to Oates, the wise caregiver will telephone the person regularly and assess their situation as they do so. Oates also says that: "A prayer over the telephone is appropriate and gives an eternal context for the day-to-day working through the losses or new burdens the person is experiencing" (1989:18).

6.2 Pastoral counselling

Pastoral counselling could take place in the form of short-term or brief counselling for the mother to work through her grief of having lost a healthy, normal child and having to accept a child with epilepsy and cognitive impairment. Brief counselling, according to Howard Stone in "Strategies for Brief Pastoral counselling" takes for granted that people have many strengths and resources of their own and will use them to continue the process of change (2001: 16). The purpose of brief counselling is to mobilise these strengths and resources within themselves so that they can cope with their current crisis, but also that they may be able to cope with any future crisis. Brief counselling, then, can be used as a vehicle for crisis counselling, which has the same goal. This is supported by Switzer, who states that the goal of crisis counselling is "the quickest possible relief of the internal and external symptoms of the crisis and a return to that particular person's usual level of functioning" (1974: 58).

If the mother who is grieving the loss of her healthy, normal child is unable to work through her grief during brief counselling, or display symptoms of pathological grief, the minister should refer her to a therapist equipped to deal with this problem.

As Amy did not feel free to approach her minister for counselling, she went for counselling to a secular psychologist. The counselling was in the form of brief counselling. At the end of eight sessions, the psychologist asked Amy whether she would like to continue to come for counselling or whether she would like to see how she could cope on her own. She chose the latter, which proved tough at times, but her faith in God provided the crutch she needed. This coincides with the view of Stone and Switzer about brief counselling and crisis counselling: that “the person has their own resources to fall back on and that counselling is only there to move the person into the right direction to uncover those strengths that might be temporarily immobilized” (1974: 58).

Wayne E. Oates calls living with a disabled child “no end” grief. He says that: “This kind of grief could as well be called “the death of a dream”. Oates says that being a pastor to such persons and families is being in a pilgrimage with them, where ministry consists of them periodically bringing you up to date, you asking God for endurance for them to live their life one day at a time, asking for strength each day (1997: 21).

Estadt echoes this sentiment when he says that pastoral support is one of the services that persons committed to the church have the right to expect. He sees supportive pastoral counselling as a relationship in which the minister assists the client in dealing with the difficulties, frustrations, and tragedies of life. Frequently people do not need further insight:

They understand only too well the reality of their situations. What they do need is the strength to carry on. Estadt relates the case of him supplying supportive pastoral counselling to a young mother whose five-year-old son had leukaemia. Every time a new

drug was administered, the mother's surge of hope was followed by the depressing anticipation of loss as the temporary effects of each drug wore off. Through weekly supportive counselling sessions, Estadt was able to help the mother to call on her religious values for strength to carry on and sustain her faith, knowing that she was not alone in her suffering. Estadt says that it was important to himself, as well as the mother to remember that Jesus said: "Come to me, you who are burdened and I will *refresh* you", and that Jesus did not say: "I will *take away* your burden" (1983: 132).

Amy had a similar experience with James. Suffering from intractable seizures caused by the initial encephalitis, the doctors tried every available anti-convulsant drug available. Every time a new drug regime was started, Amy's hopes went up that this time the seizures would finally be controlled. When the drug would fail to control, and the seizures started up again, Amy would feel deeply depressed, until the promise of the next drug. She felt as if she was on a constant emotional roller coaster, with her feeling that her emotional state was directly dependent on James' periods of being seizure-free or not. Her faith was severely tested during the these times, when she would beseech God as to why the therapy was not working, and why her hopes would be shattered once again. At the moment, James has been started on the latest anti-convulsant drug, and this time Amy really hopes that it will bring his seizures under control, because there is no other drug after this.

According to Leick and Davidsen-Nielsen (1991), the mother will experience a sense of grief or loss throughout the different developmental phases of the child. In order for the mother to reach acceptance of her child's condition, she will have to work through her grief processes in a healthy way. Leick and Davidsen-Nielsen describes the four tasks of grief work as follows: The first task is accepting that the loss is a reality, which is done on the intellectual level. The second task is entering into the emotions of grief on a relatively shallow level. The third task is to acquire new skills. The grieving person moves in and out these three tasks repetitively, and at different levels of intensity. When the grieving person has reached clarification over the loss after some time of grieving, the fourth task can be started, which is to reinvest one's energy in new ways (1991: 161).

Many parents of handicapped children are threatened by pathological grief. The parents' grief is often complicated by guilt and shame towards the child, so they deny that there is any loss. Leick and Davidsen-Nielsen quote the Swedish psychologist Gerti Fyhr who calls the grief over having a handicapped child the 'forbidden grief' (1991: 161). The mother needs help to face up to her loss. She had lost the normal child and instead her child became epileptic and cognitively impaired. If this grief work is not lived through, the relationship between mother and child is unnecessarily complicated. The mother could be asked to write about the child she had dreamed of, and that can become for her the start of feeling her grief.

The goal of the four tasks is to be able to 'greet' (that is to receive) one's handicapped child in a way that makes it possible to develop realistic hopes about the child, even though she has to live with an ongoing grief throughout the child's development.

The mother needs help with the 'primary grief work' involved in recognising that she does not have a healthy child anymore. According to Leick and Davidsen-Nielsen, Gerti Fyhr calls this the loss of the dream child (1991: 161). By working through the primary loss, the way is opened up for going in and out of the grief feelings in the ongoing grief in a natural and so more life-giving way. The first grief work in connection with the handicapped child is, in other words, the turning point that means that one can live with the ongoing grief.

According to Leick and Davidsen-Nielsen parents of handicapped children have to go through grief work of various magnitudes at various points in the child's life. They lose one hope the day they are told that the child cannot go to a normal school, which for a number of parents symbolises the loss of having a handicapped child, and can cause a dramatic crisis situation (1991: 161).

Leick and Davidsen-Nielsen feel that if someone can go in and out of the emotions of grief, she is able to bid farewell to a hope that was shattered, and later acquire a new, realistic hope. Parents with chronic or avoided grief do not have the same flexibility. They therefore find it hard to reach a relationship with the child in which there is room for hope and joy as well as disappointment and grief (1991: 161).

Leick and Davidsen-Nielsen hold that “Therapists should become more aware about identifying a pathological grief development. ... if parents of handicapped children display symptoms like fear, depression, a tendency to isolation and bitterness or overcompensation in relation to the loss/trauma, it is worth investigating whether the person has worked through his grief” (1991: 162)

Clinebell (1984: 223 – 226) lists five tasks of grief work that the minister has to help the mother work through in the setting of brief pastoral counselling. Case Study 1 is applied to these tasks to see how ideally the mother could have benefited from pastoral counselling, which she was unable to secure when she needed it.

The first task: Moving from shock and denial of the traumatic event to gradually accepting the loss. Amy did not accept at first that the encephalitis had caused James to become epileptic and cognitively impaired. She was convinced that he only needed time to recover from the effects of the encephalitis and then he would be fine. When she realised that her son’s condition was not as superficial as she had thought, Amy felt a deep sense of loss. According to Clinebell, the ministry required during this task is that of caring and presence, practical help, and spiritual comfort.

The second task: Experiencing, expressing and working through painful feelings and emotions – for example, guilt, remorse, apathy, anger, resentment, yearning, despair, anxiety, emptiness, depression, loneliness, panic, disorientation, loss of clear identity,

physical symptoms, etc. Amy experienced most of these emotions, as the loss of her healthy, normal son was akin to losing him to death, and she went through the process of grieving for the little boy and his abilities that she had lost. Moreover, she also mourned the dreams and hopes she had held for him since the day he was born. For Clinebell, the ministry required during this task is that of caring, and responsive listening to encourage full catharsis.

The third task: Gradual acceptance of the loss and putting one's life back together minus what was lost, making decisions and coping with the new reality; unlearning old ways of satisfying one's needs and learning new ways to satisfy these needs. Saying "goodbye" and re-investing one's life energy in other relationships. Amy had to go for psychological counselling in order for her to come to acceptance of her loss, as well as learning how to cope with her new situation of caring for James. She had to learn to accept her 'new' son, and try and be there for him, and giving him the care that he needed. She had to accept that James was not the same child with the same abilities and skills as before his illness, and had to try and help him relearn his skills as best as he could. Clinebell states that the ministry required during this task is that of crisis care and counselling, facilitating reality testing, and support in the difficult tasks of rebuilding one's life.

The fourth task: Putting one's loss in a wider context of meaning and faith; learning from the loss. Amy derived much comfort from her faith in God during James' illness. However, her faith was severely tested with the emotional upheaval she experienced when the anticonvulsant therapy proved unsuccessful time after time. Amy is, however, grateful that God has granted her the miracle of a second chance with James, even though it was, and still is, difficult at times. According to Clinebell, the ministry required during this task is that of facilitating spiritual growth.

The fifth task: Reaching out to others experiencing similar losses for mutual help. Amy found that she has become much more sympathetic toward other parents of children with

disabilities, at times feeling that she has nothing to complain about when she sees children who are severely handicapped. When James was still in hospital, the matron told Amy that maybe one day she would be able to use her experience of loss as a tool to help other people. Joining a support group has made Amy remember those words, as she can empathise with other parents and share with them her coping skills that she had obtained. According to Clinebell, the ministry required during this task is that of enabling outreach to others.

6.3 Pastoral care and counselling in a support group setting

Leick and Davidsen-Nielsen quote the old adage 'A joy shared is a double joy, a sorrow shared is half a sorrow', which expresses the essence of grief work in a group. To be able to share one's feelings with others is crucial for all personal growth. So there can hardly be any doubt that many grieving people could benefit from being in a grief group for a while. They also state that they have experienced that the most difficult and most vulnerable time after a 'loss' comes after three to four months. This coincides with the person's support network beginning to withdraw, because the new 'everyday life' has begun. A grief group can be a great help at this point (1991: 91). This observation of Leick and Davidsen-Nielsen emphasises Amy's experience. She started feeling unable to cope with her situation months after she thought she was coping well under the circumstances. However, her situation was exacerbated by her unexpected pregnancy, and unresolved feelings of grief. Callahan calls this a masked crisis, when the feeling of being unable to cope seems to be the problem, when in actual fact it is an accumulation of events that causes a crisis and subsequent feelings of inadequacy (Estadt 1983: 139).

As stated before, the ministry of pastoral care and counselling should provide a warm, caring interpersonal environment for people experiencing losses and crises, which can help prevent crises from mounting, and enhance the healing effects of crisis counselling and therapy. Based on this premise that it is the duty of the whole congregation to provide a caring environment for the grieving person, or the person in crisis, it is

therefore appropriate that the minister should appoint trained laypersons to facilitate in a support group for crisis and normal grief.

According to Estadt, every congregation has people who are ready to become involved in a caring ministry. What many need is training, guidance, and the call from the parish to become involved. Pastoral counsellors have unique skills for training volunteers to share in the pastoral care mission of the church. With training, lay volunteers can reach out to the bereaved and many more. In empowering lay volunteers, the pastor and the pastoral counselling staff not only multiply their ministry, but also they invite volunteers to experience the “priesthood of all believers” as they share both in the burdens and joys of ministering to and with people. Through empowering the laity, churches can become more nurturing and caring communities in which all experience the love of God, even those members isolated from the mainstream of the activities of the church. The counselling minister is especially prepared by disposition and training to be a catalyst in fostering the ongoing personal and ministerial growth of lay ministers (1983: 135).

Clinebell divides the strategy to effectively minister to the bereaved into three parts:

- 1) To inform the congregation, through sermons and adult education programmes, about the nature and importance of grief work, and how they can enable this healing in themselves, their families and friends
- 2) To train a carefully selected lay-caring team to carry out much of the load of supportive caring of persons with normal grief in the congregation
- 3) To set up and lead (or co-lead) a grief healing group

The Small Grief-healing Support Group

Clinebell states that a grief-healing group can efficiently deepen the grief ministry of a congregation and effectively train a lay crisis and grief team. Participating in a grief-

healing group can help to complete one's own grief work and learn to help other grieving persons. Providing regular opportunities for grieving people to participate in a grief-healing group would provide a great healing impact on them (1984: 228).

One of the great abilities of being human is using crises and losses as challenges to grow. The two transformational experiences of being in relationships of mutual caring and finding spiritual meaning in the loss, can occur in grief healing groups. It is helpful to have people in a group with similar losses to give each other the special empathy that comes from people who know each other's loss personally, e.g., divorce, death, disability, etc (1984: 228).

CONCLUSION

Estadt proposes that a pastoral counselor be included on the ministry team. According to him there is a growing number of ordained clergy, religious brothers and sisters, and lay men and women who are graduating from degree programmes that focus specifically on pastoral counselling. This is valid for many parishes in Kwazulu Natal, as over the past seven years more than eighty Theology students have specialized in pastoral counselling through the School of Theology in Pietermaritzburg.

For Estadt, the counselling service in the parish setting is a powerful symbol of the Church's concern for the well being of its members. This indicates that someone on the church's staff is able and willing to hear the parishioners' personal story. When the church, in the person of the pastoral counselor, can communicate acceptance, concern, respect, and love to a person at a time of deep personal struggle, that individual will experience something of God's abiding love. Conversely, when people find themselves abandoned by the Church's ministers in their time of need, they may well experience it as abandonment by God. A resident pastoral counselor can free the minister who is more gifted in other areas of ministry or whose responsibilities make regular counselling sessions almost impossible. Referral to the parish-based centre is beneficial to both the minister and the

parishioner. The minister has the satisfaction that the church is meeting the person's need; the client experiences the care of the local church (1983: 134).

In an ideal situation, Estadt's vision of a resident pastoral counselor would have been a source of great comfort to Amy. She might have been able to work through her grief work sooner, and she might have experienced the care of the church during her crisis in a profound way. Instead, she felt deserted by the parish priest during her crisis. She did however, feel that the presence and love of God were conveyed by lay ministers, especially in the form of Brian, John's uncle, as well as the prayers of people from various other denominations.

The most important aspect of pastoral care and counselling is that the love and presence of God be conveyed to the person in crisis. Oates proposes the practical ways in which this can be done, as follows: through prayer, home visits and support systems.

As Clinebell states: the minister helps people in crisis to mobilize their inner resources and also draw on the resources of the religious community

Pastoral counselling in the form of brief counselling can be used to great effect to help the mother in crisis who is trying to overcome her feelings of grief and loss. The mother would be able to rediscover her latent strengths and resources that she was unable to access due to the severity of the crisis.

To reach the point of moving in and out of grief in a healthy way throughout her child's developmental phases, the mother first had to have worked through the grief process in a healthy way. This can be achieved with the minister assisting her by completing the grief work tasks by ministering to her in appropriate ways during the different tasks.

Support groups can play an important role in the facilitation of grief and crisis resolution. With the church taking the initiative of implementing Grief-healing Support Groups, as well as training lay group facilitators, a message is sent that the church cares about its members in crisis and is willing to help them overcome their loss, hurt and grief.

In Chapter 7, I have offered a model for Grief-healing Support Groups with a plan for further training in which the church can practically express their concern for the grief-stricken in the parish.

Estadt quotes the prayer of Saint Francis of Assisi, which eloquently describes the role of the pastoral counselor:

Lord, make me an instrument of Your peace;
 where there is hatred, let me sow love;
 where there is injury, pardon;
 where there is doubt, faith;
 where there is despair, hope;
 where there is darkness, light;
 and where there is sadness, joy.
 Grant that I may not so much seek
 to be consoled as to console;
 To be understood as to understand;
 To be loved as to love
 For it is in giving that we receive;
 It is in pardoning that we are pardoned;
 It is in dying that we are born to eternal life.

(1983: 136)

CHAPTER 7

CONCLUSION

Introduction

Based on the findings of Clebsch and Jaekle and illustrated by Clinebell, pastoral care and counselling has five important functions in the church. These functions are crucial for the spiritual and emotional well being of mothers faced with the devastating crisis of their once healthy, normal child developing epilepsy and becoming cognitively impaired. What came to light in this study was that these functions were not always available when the mothers needed them. Where the functions were available, they were not always as well established in the church parish for the mother to comfortably make use of them. This study made an attempt to provide guidelines of how pastoral care and counselling could be made more readily available to mothers having to come to terms with the trauma of accepting that their once healthy, normal children are now epileptic and cognitively impaired.

The first function of pastoral care and counseling: Sustaining and supporting – Helping a hurting mother to endure and to transcend a circumstance in which restoration to her former condition seems impossible.

Here we have seen that the mothers are really hurting at the onset of their children's condition. Their children's acquired condition has an emotional, psychological, as well as spiritual effect on the mothers.

Emotionally, the mother is heartbroken at the thought of her previously healthy child becoming a special needs child. The child's condition also affects the mother's relationship with her other children as well as with her husband.

Psychologically, their children's condition seemed to have had such a devastating effect on the mothers that their coping abilities proved inadequate at the time. In all three case

studies the mothers became very depressed and even suicidal. As seen, only one of the mothers sought psychological counseling, whereas the other two mothers tried to cope on their own.

Spiritually, the mothers vacillated between deepening their faith in God by relying on Him for comfort and strength to carry their burden; and on the other hand directing anger and blame toward Him for allowing their children's condition. A very important concept that came to the fore is the fact that all three these mothers felt guilt at their children's condition and that they were being punished for something that they must have done. Augustine's theology of original sin had so permeated the church, that even if one intellectually disagrees with his theology, at the onset of a crisis, most people seem to revert to it, as these mothers had done.

The pastoral care and counseling function of sustaining and supporting a hurting mother to endure and transcend a circumstance in which restoration to her former condition seems impossible, was much needed at the onset of these mothers' crises. These mothers experienced this function to an extent through the prayers and visits of fellow parishioners, a role that Clinebell assigns to the laity. However, the sustaining function on the part of the ministers themselves seemed to have been minimal.

Guiding – assisting troubled mothers to make confident choices, which will positively affect the state of their well being.

This study has shown that when a mother is faced with her formerly healthy, normal child developing epilepsy and becoming cognitively impaired, she goes through a grieving period similar to that of having lost someone in death. In order for her to accept her child with his new personality and diminished intellectual abilities, she has to be allowed to undergo this period of grieving and experience the emotions that are part of the grieving process. She has to realise that these emotions are normal, and that she should not feel guilty for experiencing them. The emotions that are strongly in the foreground in these case studies are especially anger and blame; frustration; embarrassment and guilt.

The pastoral care function of guiding troubled people to make confident choices, which will positively affect the state of their well being, should have been available to the mothers to help them work through their emotions and bring them to acceptance of their situation and their children's condition.

Reconciling – to re-establish broken relationships between the mother and God, the mother and others, and the mother and self.

Anger and blame directed towards God can lead to a broken relationship with God. The minister, if he accompanied the mother through her crisis, would have been aware if this was the case. The mothers in the three case studies, however, experienced ambivalent feelings toward God: on the one hand feeling anger and blame at God for allowing their child's condition, and on the other hand, feeling utterly dependent on God to sustain them spiritually and giving them the strength to carry their burden. As Estadt argues, it is important to remember that Jesus said: "Come to me, you who are burdened and I will *refresh* you", and that Jesus did not say: "I will *take away* your burden" (1983: 132).

When support from the mothers' various support bases was lacking, it lead to broken relationships with those people. These include support from husbands, family and relatives, the medical fraternity, psychological counselling, parishioners and the parish priest. The need for reconciling the mothers to those people therefore arose, especially with husbands and family.

The pastoral care function of reconciling a person with God could be extended to reconciling a person to the people who are supposed to be a support base as well. It is easy to become angry and embittered when support is not forthcoming, as Jean says that if her relatives' children would get sick, she would also not be supportive of them. For the function of reconciling to properly operate, the pastor needs to be available and aware that there is a problem.

Healing – restoring the person to wholeness and leading him to advance beyond his previous condition

The mother confronted with her previously healthy, normal child developing epilepsy and becoming cognitively impaired, suffers a tremendous blow psychologically and spiritually. She questions the fairness of what has happened to her and to her child. She sees what has happened to her child as a reflection and extension of herself. Whatever the questions might be, the mother needs and deserves the care of a sensitive minister to help restore her to wholeness, beyond her condition of grief and despair.

For Carkhuff and Berenson, the first goal of helping is to respond to the helpee's frame of reference in order to facilitate helpee exploration (1977: 152). In the case of these mothers, their frame of reference would be their experience of having lost a healthy, normal little boy who now is epileptic and cognitively impaired. These mothers would have to honestly explore their feelings, with the help of a sensitive and caring helper.

This ties in with Egan's view of skilled helpers, whom he sees as "integrators, who help clients explore their experiences, feelings, and behaviour. As clients provide information about themselves, skilled helpers help clients to integrate the information so clients can understand themselves and their behaviour (1981: 28). The mother should therefore be guided by a skilled helper to explore her feelings about her situation and her son's condition, in order to understand her feelings and behaviour so that she can accept her situation and change her behaviour.

This process can be facilitated by the three therapeutic ingredients, as proposed by Carl Rogers. This therapeutic approach would be very helpful to the mother who is already feeling guilty about her feelings about her situation and her feelings towards her child. The fact that she will be regarded non-judgmentally would mean that she would readily express her feelings to the therapist.

According to Clinebell, the minister should convey the surety that God is present in the midst of our despair. Although these mothers seemed to have been aware of this, there were times when despair and doubt occurred, and it would have been comforting to have the minister convey the assurance of God's love and presence.

For Estadt, reconciliation occurs in a three-fold manner: with self, with others, and with God. Relating to the case studies, firstly these mothers have to reconcile themselves with God by letting go of the anger and blame they might feel about their children's condition. Secondly, they have to reconcile and accept their children with their new personalities, behavioural difficulties and diminished cognitive abilities, and they also have to reconcile themselves with the people they feel angry with for being unsupportive. Thirdly, they have to reconcile their feelings about their situation to come to acceptance within themselves.

According to Blanchette, by getting in touch with the love of God, the client is assisted in making loving choices for him or herself, which leads to acceptance of self and others.

The pastoral care function of healing, to restore a person to wholeness and leading him to advance beyond his previous condition, finds fulfilment in the therapeutic relationship of pastoral counselling. It would mean a lot to a mother confronted with her normal, healthy child becoming epileptic and cognitively impaired, to have this function of pastoral care available to her.

Nurturing – to enable people to develop their God-given potentialities, throughout the life-journey with all its valleys, peaks and plateaus.

In brief counselling the mother would be able to rediscover her latent strengths and resources that were they were unable to access due to the severity of the crisis of her formerly healthy child developing epilepsy and cognitive impairment. Brief counselling can then make way to supportive counselling, where the mother can bring the minister up

to date with her situation from time to time, and the minister in turn can encourage her and pray for strength to sustain her faith.

The minister has to help the mother work through these grief processes or tasks in the setting of brief pastoral counselling. Another helpful setting in which the mother would be able to work through the grief tasks, are Grief-healing Support Groups.

Support groups

To be able to share one's feelings with others is crucial for all personal growth. Many grieving people could benefit from being in a grief group for a while. Leick and Davidsen-Nielsen (1991: 91). have found that the most difficult and most vulnerable time after a 'loss' comes after three to four months. This coincides with the person's support network beginning to withdraw, because the new 'everyday life' has begun. A grief group can be a great help at this point.

Support groups can play an important role in the facilitation of grief and crisis resolution. With the church taking the initiative of implementing Grief-healing Support Groups, as well as training lay group leaders, a message is sent that the church cares about its members in crisis and is willing to help them overcome their loss, hurt and grief.

An attempt is made to provide a workable model for the formation and implementation of a Grief-healing Support Group:

Model for a Grief-healing Support Group

1. Informing the congregation

The congregation should be informed of the formation of the Grief-healing Support Group, which could be done in the parish newsletter, as well as by the priest at the services. Applications should be invited for lay ministers to be trained as facilitators of the Grief-healing Support Groups.

2. Training the facilitators

The diocese will be approached to train the facilitators. The training ideally could take place over two to three weekends followed by the Initiation the following weekend.

3. Initiation of the Facilitators

Initiation will take place at a Worship Service in front of the whole parish.

The Liturgy will be as follows:

Opening Hymn

Opening Prayer

Gospel Reading

Homily

Lighting of candles

Communion

Induction Ceremony

The priest will ask the lay ministers the following questions

- i) Do you accept the mandate as minister of grief-healing facilitation?
- ii) Do you promise to treat the members of your group with caring, compassion and respect?
- iii) Do you promise to treat all information that is divulged in the group as confidential?
- iv) Do you promise to seek help for a member who seems to need professional intervention?

Following each question, the lay ministers will individually answer: "I do".

The priest will then confer on the lay ministers the ministry of grief-healing facilitation, and present them to the congregation.

Closing prayer

Closing hymn

4. The Grief-healing Support Group meetings

4a) The first meeting

Opening Prayer

The facilitators (two per group) should introduce themselves.

The facilitators then will present the aims of the Grief-healing Support Group.

The members will then introduce themselves through icebreakers.

Closing Prayer

4b) The second meeting

Opening prayer

Members should each be allocated time to share their own stories.

The members should be given the task of writing a letter about their loss.

Closing Prayer: should be in the form of a healing prayer for the losses suffered by the members.

4c) Subsequent Meetings

The five tasks of grief as presented by Clinebell should be worked through, one per meeting. Should the members feel that one task was not sufficiently covered by one meeting, that particular task may be continued in a subsequent meeting.

5. Completion of the grief tasks

The task could be given to the members to write a letter of how they have worked through their grief.

Closing Prayer: should be in the form of a thanksgiving prayer.

Ideally, the group should consist of no more than ten to fifteen members to function optimally to all members' benefit. The group should meet once a week for two hours.

Conclusion

It is evident that the functions of pastoral care were not always present when the mothers needed them when they were confronted with their previously healthy, normal children having developed epilepsy and cognitively impairment. In an ideal situation, these functions would be readily available in the church. However, an attempt at making pastoral care and counselling available to such mothers is provided by the creation of a workable model.

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RECOMMENDED READING

Books:

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