NARRATIVE PASTORAL PRACTICE AT A PRIMARY SCHOOL

by

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ABSTRACT

South African schools provide an enormous challenge for transformation towards inclusive and caring communities of learners, facilitators and caregivers. This qualitative study conducted at a primary school used narrative pastoral therapy-as-research and participatory action research-as-therapy to develop inclusive and caring practices. Co-authoring conversations with learners and caregivers from diverse cultural and religious traditions and collaborating with facilitators challenged me to develop pastoral care as political care. This paved a way for future transformation of a school as a multi-religious community of care and respect. I engaged with participants in finding alternative ways of dealing with loss due to death of loved ones or separation from caregivers. Children with chronic illness challenged their experiences of rejection and marginalisation at school by writing and producing a play while those whose voices were silenced chose other ways to inform learners and facilitators about their illness.

Key terms

Cultural and religious inclusivity; Eco-spirituality; Pastoral care as political care; Loss; ‘School-desk theology’; Childhood chronic illness; Respectful listening; Transformation; Narrative pastoral therapy; Primary school; Commitment; Understanding; Acceptance; Collaboration; Co-author; Co-search; Co-create.
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CONTENTS

ABSTRACT

ACKNOWLEDGEMENTS

CHAPTER 1

IN THE BEGINNING

1.1 AND THEN THERE WERE CHILDREN... 1
1.2 ONCE UPON A TIME, THERE WAS A TEACHER 1
1.3 POVERTY HAS MORE THAN ITS FAIR SHARE... 2
1.4 CONTEXTUAL AND FEMINIST THEOLOGY 4
1.5 RESEARCH WITH CHILDREN 5
   1.5.1 Introduction 5
   1.5.2 Research as Hundreds and Thousands 6
   1.5.3 Listening to children's voices in therapy and research 6
   1.5.4 Research as commitment, care and transformation 8
   1.5.5 Power-sharing 10
   1.5.6 Valid research 11
   1.5.7 Research as stories, stories as research 11
   1.5.8 Research as ethical praxis 13
1.6 RESEARCH QUESTIONS AND AIMS 14
   1.6.1 Research curiosity 14
   1.6.2 Research aims 14
1.7 REPORT WRITING 15
1.8 OUTLINE OF THE STUDY 17
CHAPTER 2

PASTORAL CARE AND COUNSELLING AT A PRIMARY SCHOOL

2.1 INTRODUCTION
   2.1.1 Pastoral care and counselling 18
   2.1.2 Diversity of pastoral care at school 18
   2.1.3 Children in pastoral care and counselling 19
   2.1.4 Pastoral care as commitment and transformation 19

2.2 DEVELOPING INCLUSIVE AND CARING PRACTICES IN DIVERSE CULTURAL AND RELIGIOUS TRADITIONS 20
   2.2.1 Introduction 20
   2.2.2 Doing spirituality 20
   2.2.3 Religious pluralism 21

2.3 CO-AUTHORING WITH CHILDREN AND CAREGIVERS TOWARDS RELIGIOUS INCLUSIVITY 21
   2.3.1 Introduction 21
   2.3.2 Judaism 22
   2.3.3 Islam 24
   2.3.4 Hinduism 25
   2.3.5 Buddhism 26
   2.3.6 African Independent Churches 26
   2.3.7 Minority Christian groups and children from agnostic and atheist backgrounds 28
2.4 PASTORAL CARE AND THERAPY IN A MULTI-RELIGIOUS SCHOOL COMMUNITY 28

2.5 AN ADDITIONAL AIM DEVELOPS 29

2.5.1 Touching the earth – eco-spirituality as a practice of pastoral care 29

2.5.1.1 In the beginning 29
2.5.1.2 Earthloving and earthkeeping – a person who plants a tree plants hope 29
2.5.1.3 From ‘dominion over nature’ to ‘custodians of nature’ 30
2.5.1.4 School environmental policy 30
2.5.1.5 Earth summit 30
2.5.1.6 Ways of nurturing an ecological spirituality 31
2.5.1.7 Earth caring practices 31
2.5.1.8 Finding ways of indirectly challenging environmental destruction 32
2.5.1.9 Children teach adults 32
2.5.1.10 Eco-education 33
2.5.1.11 Beginnings of children’s spirituality 33

2.6 REFLECTIONS 34

CHAPTER 3

COUNSELLING CHILDREN DEALING WITH LOSS

3.1 INTRODUCTION 35
3.2 LOSS AND HOPE 35
3.3 TOWARDS SETTLED STORIES 37
3.4 PETER’S STORY – THE LOSS OF A BROTHER  37
  3.4.1 A car accident  37
  3.4.2 Silence speaks out  38
  3.4.3 Honouring grief, talking future  39
  3.4.4 Images of God: inviting spiritual-talk  41
3.5 RAAMA LOSES A MOTHER  42
  3.5.1 A shooting takes away a mother  42
  3.5.2 Keeping farm animals safe  44
  3.5.3 Grandparents hold a hand  45
  3.5.4 A pilgrimage from pain to hope  46
  3.5.6 Learners for Learners Caring Club  48
  3.5.7 Time to say good bye  48
3.6 SANDILE GOES BAREFOOT  48
  3.6.1 Away from home - a better education  48
  3.6.2 At the doll’s house  49
  3.6.3 ‘My footez get angry’  50
  3.6.4 Doing hope with Sandile  51
3.7 REFLECTIONS  51

CHAPTER 4

CHALLENGING THE EFFECTS OF CHRONIC ILLNESS IN CHILDREN

4.1 INTRODUCTION  53
4.2 THE VOICE OF ILLNESS  53
4.3 DIABETES  54
  4.3.1 Travelling with Sue  54
  4.3.2 Regulatory sign: unpredictability of diabetes  55
Chapter 4

4.3.3 Information sign: diabetes informs a therapist
4.3.4 Information sign: learners teach facilitators
4.3.5 Warning sign: label jars, not children
4.3.6 Information sign: God-talk
4.3.7 Warning sign: chaos’ narratives
4.3.8 Warning sign: Diabetes the chairperson
4.3.9 Information sign: co-creating visibility
4.3.10 Warning sign: the hospital ‘gaze’
4.3.11 Information sign: Diabetes takes a backseat
4.3.12 The checkered flag

4.4 THE SILENCE OF HIV/AIDS
4.4.1 Introduction
4.4.2 Co-searching ways of breaking the silence

4.5 CO-CREATING NARRATIVES
4.5.1 Background

4.6 INTRODUCING DIABETES, EPILEPSY AND HIV/AIDS
4.6.1 Spotlight on Diabetes
4.6.2 Epilepsy takes centre stage
4.6.3 Interviewing HIV/AIDS

4.7 REFLECTION

Chapter 5

FARE WELL, BUT NOT GOODBYE

5.1 FARE WELL – NOT TO RESEARCH
5.2 MULTIPLE REFLECTIONS ON MULTIPLE REFLECTIONS
5.3 PASTORAL PRAXIS AS POLITICAL CARE TOWARDS ETHICAL TRANSFORMATION

5.3.1 School desk theology 78
5.3.2 Consciousness raising 79
5.3.3 Politics of cultural and religious inclusivity 80

5.4 CO-SEARCH WITH CHILDREN 82

5.4.1 Introduction 82
5.4.2 Reflecting on narrative pastoral practices with children 82
5.4.3 Accountability and transparency 83
5.4.4 Power sharing practices 84
5.4.5 Honouring local knowledges 85

5.5 ACTION RESEARCH AND REFLECTIONS 86

5.6 TALKING TO YOU IS LIKE HUNDREDS AND THOUSANDS 88

5.7 SPRINKLINGS OF HUNDREDS AND THOUSANDS 89

5.8 COMMITMENT, CARE AND TRANSFORMATION 90

5.9 HUNDREDS AND THOUSANDS ON MY TONGUE 91

5.10 CARING FOR CHILDREN, CARING FOR THE FUTURE 93

BIBLIOGRAPHY 96
CHAPTER 1

IN THE BEGINNING

1.1 AND THEN THERE WERE CHILDREN...

...and Jesus said: 'let the little children come to me; do not stop them'. Then he took the children in his arms, placed his hands on each of them, and blessed them.

(Mk 10:14,16)

'Jesus placed a child at the centre of the circle' (Mk 9:36). Anderson and Johnson (1994:131) argue that the faithfulness of a church's witnessing to Jesus can be measured by how it regards children. When we honour this notion we will not 'wield power over others, valorize violence, practice discrimination, teach hate, destroy the environment, or preach materialism or indifference toward anyone' (131). Compassion for children can be described as a 'life-sign. With it we take our pulse as humanity' (131). I regard Anderson and Johnson's (1994:21) warning not to rule over children, but rather to grant them dignity and worth in the midst of the community as a contribution that I can bring to the children at the school where I am employed as a pastoral therapist.

The African proverb 'it takes a village to raise a child' reflects the interdependence of all life because it takes more than a family to raise a child (Anderson & Johnson 1994:91). I find this proverb applicable to the work I do at school as a pastoral therapist because I aspire to involve the school in 'doing co-responsibility', in educating and caring for children. My vision is that schools will create sanctuaries for their children.

The words of an Igbo proverb captures the essence of my vision: 'there is nothing greater than a child' (Anderson & Johnson 1994:21). As Pais (1991:6) has observed, it is the 'deeper truth of the gospel of God the Child which requires us to place the highest value on children and to treat them with ultimate seriousness and respect'.

1.2 ONCE UPON A TIME, THERE WAS A TEACHER

After twenty years of being the principal of a nursery school, I embarked on a journey of pastoral therapy studies. At present I am employed as a pastoral therapist and have been involved at one specific primary

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1 The terms learners and children are used interchangeably in this study. Pseudonyms protect the identity of children

2 For the sake of confidentiality the school is not identified. The school is a co-educational primary school in a historically white area. At present the school is racially and culturally integrated, and is moving towards multi-religious integration.
school for two and a half years. The school accommodates about one thousand three hundred learners and follows an Outcomes Based Education approach.

As I have noted previously (Basson & Kaiser 2001:15): ‘The real need for care and support for South African learners became a ‘moment of insertion’ (Cochrane, De Gruchy & Petersen 1991:18) for me, when, after I had only been employed a few months, over three hundred learners requested counselling’.

The children’s desire to speak in confidence to someone was so great that they waited to consult me even before school started in the morning. Their problems varied from learners being in child-headed households, poverty, a lack of adult supervision, loss because of distance from caregivers\(^3\), the death or divorce of caregivers, the death of siblings, domestic violence and crime to learners living with various chronic illnesses such as diabetes, epilepsy and HIV/AIDS. These problems overshadowed other concerns such as stealing, cheating, bullying and lying (see Basson & Kaiser 2001:15).

Political, social and economic discourses play a role in the difficulties experienced by facilitators\(^4\) and learners such as large class sizes, language and cultural barriers. Facilitators are frequently challenged by poverty-related concerns surrounding the children, severe compression of time and minimal resources to address problems. In my school, facilitators and I collaborate with learners, discussing ways of addressing these issues.

Facilitators experience a distance between themselves and the Education Department (De Jager 2001:2-15). Abrahams (1996:226) cites Hargreaves and MacMillan who make comments similar to those of De Jager (2001:15), saying that facilitators today are increasingly experiencing ‘feelings of disengagement and exclusion’ with regard to educational authorities.

1.3 POVERTY HAS MORE THAN ITS FAIR SHARE...

Couture (2000:16) states that 23% of the children in the United States are poor (and many more in the countries of the southern hemisphere). Pieterse (2001:350) refers to May and Govender, whose findings indicate that the percentage of poor children in South Africa varies from 20% percent in Gauteng to over 77% in the Eastern Cape. Couture (2000:16) challenges adults in theological schools and churches to become involved. Although she refers to the United States, Couture’s (:16) comments are even more applicable to South Africa, especially her claim that we have not conducted our lives in ways that allow

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3 To respect the children who do not live with their biological parents the term caregivers is used throughout the study.
4 The term facilitators is used by the Gauteng Education Department for teachers.
children ‘to grow in love and grace’, because even the basic needs of many ‘for shelter, food, multiple stable adult relationships, medical care, and education’ have not been met. We have neglected to solve one of the biggest problems of our time, the jeopardy in which a generation of children lives.

Most children living in poverty live without adequate food, health care, education, or parental and community support. Couture (2000:14) distinguishes between two overlapping categories of children’s poverty: ‘material poverty and the poverty of tenuous connections’ where tenuous relationships refer to the situation of ‘invisible’ groups of poor children whose ‘social disconnection’ results in massive child poverty (:29). These ‘invisible’ groups are children who are homeless, live in foster homes, group homes and institutions. The poverties I engage with at school include both material poverty and the poverty of tenuous connections. The results of material poverty range from children being hungry and cold, physically and medically neglected, to an absence of stationery, incorrect school uniforms and a lack of transport. However, it is my experience that the results of emotional poverty as an aspect of ‘social disconnection’ (:29), such as domestic violence, alcohol abuse by parents, divorce, child-headed households and a lack of parental interest and support both scholastically and personally in children, far outweigh the problems of material poverty. ‘Children’s poverty must be overcome by building relationships with vulnerable children’ (:14).

Through pastoral care, the church can genuinely transform itself and influence society and culture. Such transformation depends upon the ‘church’s capacity to intervene at every structural level of society and culture. Everyone can participate in the shared responsibility...’ (Couture 2000:15). The pastoral care I offer at school is a means of ‘doing spirituality’ (Kotzé & Kotzé 2001:1).

The extent to which they have to deal with these issues daily can take its toll in the lives of pastoral therapists. I identify with Couture (2000:23) when she says that pastoral care regarding children’s poverties can become ‘intellectually overwhelming’ and ‘existentially draining’. This drain is an occupational hazard for pastoral and other therapists:

As therapists we witness and are confronted with the pain and suffering of many people. Daily encounters with suffering, hunger, malnutrition, unemployment, rage and anger, crime attacks, violence, rape – all these issues are not extraordinary but ordinary to many counsellors, caregivers, and pastoral therapists in South Africa.

(Kotzé & Kotzé 2001:2)

There was an aspect of my practice that needed serious attention so that secondary traumatic stress would not overwhelm my life (see Figley 1995) (see Chapter 5). Although I met regularly with my study supervisors and my work was acknowledged at school, at times I experienced secondary traumatic stress.
Couture (2000:37) cites Garbarino, who describes the ‘school as refuge’ in a violent community. Schools may be the most influential institution in the life of a child, since the child spends most of his or her time away from the family at school. I agree with Garbarino when he says that the school’s roles in caring relationships are those of ‘the principal agent of change and source of support’ (:37). I believe that it is my duty to ensure that the school principal, facilitators and myself are constantly aware of and take responsibility for the enormous task which we face and for which we should be held accountable.

I confirm and practise Couture’s (2000:37) stance that ‘a school that provides security in the midst of community violence is proactive in its concern for children’s safety’. Referring to the duty of churches in South Africa, Maiuleke (1993:21) states that ‘whenever a person responds in love to the needs of others, providing food, clothing or shelter, safety, welcome dignity, self-respect or chance to grow, God is present in this action’. Pastoral therapists at schools can play a central role in meeting this challenge. One can only imagine the impact it would have on the lives of learners, caregivers and facilitators if schools and churches united in accepting responsibility for the needs of their communities.

The view of Pieterse (2001:80) that preachers and pastoral therapists who ‘work in a context of poverty have the task of verbalising that perspective’ is especially relevant for my pastoral therapy practice at school. I realise that I have not experienced the world of the poor existentially, but this does not absolve me from my responsibility as a pastoral therapist to try to put myself in their position and to understand their situation and perspective (:80). I believe that it is my duty to ensure that the voices of the poor are acknowledged and respected in ways that honour their experiences and knowledges of poverty and that decisions regarding poverty are not made on their behalf.

Positioning myself on the side of those who suffer means that I can develop ‘the power of empathy and compassion, of delight in otherness, and strength in the solidarity of listening to others, bearing together stories of pain and resistance’ (Welch 1990:135). I therefore chose to invite contextual theology as a companion on the therapy-as-research journey. My commitment to a just society was informed by feminist pastoral practices that are liberating because they seek ‘justice, peace, healing and wholeness for all in partnership’ (Ackermann 1991:96). Feminist theology was the other companion that travelled at my side.

1.4 CONTEXTUAL AND FEMINIST THEOLOGY

My pastoral therapy practice and research was formed and informed by feminist and contextual theological stances. These theologies are concerned with liberating praxis, ‘giving voice to the voiceless; supporting the oppressed...introducing new values’ (Isherwood & McEwan 1993:87). These theologies may never be
‘armchair’ occupations because they are always involved with people ‘on the ground’ (Ackermann 1994:202), and, in this case, children struggling against discrimination, violence, poverty and oppression. Both feminist and contextual theology are actively involved with people at a grass-roots level. I was challenged to ‘do pastoral care as participatory ethical care...not to care for but to care with people who are in need of care’ (Kotzé & Kotzé 2001:7). De Gruchy’s (1994:2) comment that ‘doing theology’ means engaging oneself with people in particular contexts and situations is of particular relevance in feminist and contextual theology. The emphasis on ‘doing theology’ is confirmed by Bosch’s (1991:424) stance that doing is more important than knowing or speaking. Contextual theology (439) and some forms of feminist theologies are regarded as theologies from below and grow from self-other participation and not from a privileged position of knowing. I was challenged to displace my ‘expert’ knowledge to really listen and be guided by the voices at school.

Feminist theology uses a wide and holistic perspective and informs itself from ‘scripture, tradition and the Spirit but also from social theory, economic analysis and psychology’ (Isherwood & McEwan 1993:10), as well as from any other relevant science.

Feminist contributions also include challenging patriarchy with regard to children. So, for example, Bell (1993:3) shows how feminists have revealed incest to mirror the ‘gendered power dynamics of the society in which we exist’. Feminists address incest as a political matter, looking at the relations of power between men and women and between men and children, particularly within the institution of the family.

Feminist theology also challenges traditional theology for its sexism, racism, and classism. To this I would like to add ageism (see Isherwood & McEwan 1993:78). This led me to take up the ideas and values of contextual (Bosch 1991, Cochrane et al 1991) and feminist theology (Ackermann 1991; Isherwood & McEwan 1993) as companions on my research journey. Their views invited me to make a commitment (Cochrane et al 1991) to pastoral therapy and caring for the community at school.

The above-mentioned paradigms guided the participatory research methodology that I will now discuss.

1.5 RESEARCH WITH CHILDREN

1.5.1 Introduction

Inviting children and where possible caregivers to become research participants is a challenging, exciting and rewarding experience that richly contributed to my praxis. Vignettes of the research approach are introduced below.
1.5.2 Research as Hundreds and Thousands

I agree with Clandinin and Connelly (1994:421), who claim that journal writing is a powerful way for people to give accounts of their experience. Clandinin and Connelly (421) quote Sarton, who says:

"Journals are a way of finding out where I really am. They have to do with encounters with people who come here, who talk to me, ... They sort of make me feel that the fabric of my life has a meaning."

Clandinin and Connelly (421) also cite Carr, who refers to her journal entries as 'made up of scraps of nothing'. She compares her journal entries to the small English candies called Hundreds and Thousands, often used to decorate cakes, 'so small that separately they are not worth eating'. However, she adds that

"It was these tiny things that, collectively, taught me how to live. Too insignificant to have been considered individually, but like the Hundreds and Thousands lapped up and sticking to our moist tongues, the little scraps of nothingness of my life have made a definite pattern."

My research accounts looked for the patterns (like Carr's Hundreds and Thousands), narrative threads, tensions, and themes in the research narrative tapestry. I was tempted to view this overall process as a series of steps. Because collaboration occurred from the beginning to end, the plot outline was continuously revised as children's narratives developed.

1.5.3 Listening to children's voices in therapy and research

Heshusius (1995:121) emphasises that listening to children can temporarily 'dissolve the boundaries of the self, making complete attentiveness to other possible and, in turn opening access in new and unanticipated ways'. This listening and getting to know a person resonates with connected knowing described by Belenky, Clinchy, Goldberger and Tarule (1986). Elbow (in Bishop 1996:214) speaks about connected knowing as a situation where the 'knower is attached to the known' so that there is common understanding and a common basis for such an understanding.

Deeply implicated in the very foundations of feminist research lies the question of voice and, by implication, of the research the account. This question concerns how the voices of participants (in this case, children) are to be heard. Feminist researchers are highly aware of the absence of 'women's voices, distortions, and the charge that preparing [a research] account in the usual social science modes only replicates hierarchical conditions found in the parent discipline, where women are outside the account' (Smith in Olesen 1994:167). Smith's argument is even more applicable in a situation where children are concerned.
Finding ways to represent children's conversations 'can be tricky at times. Conversations with children are often not straightforward and may not follow a clear path' (Morgan 1999:vii). Children's interests and concentration levels fluctuate constantly and the question remains about what to represent and how to represent their knowledges. Respecting children's 'local knowledges' (see Andersen 1993) became a challenge during this research as well as during the therapy as research.

Heshusius (1995:122) states that when adults connect with children 'it is in the space that exists between the having in common and the not having in common that the possibility for true dialogue can occur and the generative conditions for real listening, talking, and learning can exist'. Heshusius (1:121) continues to explain the different intentions behind listening: 'There are times, of course, when it is necessary to listen for specific purposes...it is important to understand the difference between listening with a specific purpose and listening without a specific purpose, that is, listening without wanting anything from it'. Bosch (1991:426-427) confirms that the challenge in contextual theology is to maintain dialogue among all participants. In listening to the participants' local knowledges, I was made aware of the importance of their lived experience.

Participatory action research reflects the real lived experience of people. Janesick (1994:210) expounds this by adding that a social setting is studied to understand the meaning of participants' lives in the participants' own terms. Thus, in participatory action research, the knowledge and experience of the marginalised (in this research, children) – is directly honoured and valued. By working full-time as a pastoral therapist at a school and being involved in other areas of school life as well, I was given the opportunity of understanding more fully the multifaceted aspects of the participants' lives (Janesick 1994:210). Denzin and Lincoln (1994:102) confirm that '[l]ived experience is central to qualitative inquiry and the criteria of evaluation in qualitative research are based on an ethics of caring, personal responsibility, and open dialogue'. This challenge guided me to recognise the centrality of an 'expressive collaborative model' (Walker 1998:7), where care is 'interpersonal and...negotiated by all participants' (Kotzé & Kotzé 2001:8).

Authentic participation in research can be identified by a co-constructed agenda, the participation in the telling and re-telling of the narratives and both the participants and the researchers having a voice regarding the outcome of the research report (see Grundy 1997:127). This refers to participatory action research and also applies when I engage in therapy with children at school. During our therapy sessions, I encourage children to decide what they wish to talk about and allow them to direct the journey of the therapy. They are free to express themselves and narrate their stories as they like. So, for example, they choose whether to attend therapy individually or invite their peers, whether to join a group or both. They are
at liberty at any time to read what I have recorded, to question it and to ensure that I have understood them correctly. They decorate their files and make decisions about what activities, as well as about the stationery to be used.

Letters play an important role in reflecting conversations to a learner (White & Epston 1990; Epston 1994; Clandinin & Connelly 1994). I respect children's voices in the telling and re-telling of narratives (Freedman & Combs 1996; Swim 1995:100-118). The storying of their narratives includes conversations, puppet shows, writing their own plays and raps, artwork, play therapy and so forth (see Chapter 4). With regard to art, Eisner (1993:5) believes that the process of crafting images can help children discover a part of themselves, revealing dimensions of which they were previously unaware.

Children contribute in deciding how, when and whether caregivers and facilitators should be involved in therapy or feedback. It remains their choice whether or not and in what ways outcomes should be made available to other children, caregivers and facilitators. This way, therapy can simultaneously be regarded as participatory action research.

1.5.4 Research as commitment, care and transformation

Fals-Borda and Rahman (in Reason 1994:328) believe that '[t]hose who adopted PAR [Participatory Action Research] have tried to practice with a radical commitment that has gone beyond usual institutional boundaries'.

Within the frame of contextual practical theology, commitment is understood by Cochrane et al (1991:16,17) as 'a particular way of being in the world'. This commitment presupposes the existence of self-awareness, self-criticism and opening oneself up to the questioning of others. Commitment becomes fundamental when engaging with the marginalised and oppressed. I believe that without this commitment to the children, my research as therapy and therapy as research would not have been possible.

The urgency of pastoral therapy and care becomes a 'moment of insertion' (being inserted into or directly confronted with these moments) that challenges pastoral therapists to begin in the context with a commitment (Cochrane et al 1991:18). Such moments of insertion introduce trauma as well as challenges for pastoral therapists. Pastoral therapists cannot but take a position when engaging with children in pain and suffering.

Ethically, this position means a commitment to transformation, positioning oneself on the side of those suffering and against all oppressive or exploitative discourses and practices: 'Particular stories call us to
accountability ... they call those of us who are ... complicit in structures of control to join in resistance and transformation’ (Welch 1990:139). ‘Care through personal presence and meaningful conversation may be irrelevant unless we care with others by attending to care and hope through transforming institutions and communities’ (Couture 2000:92).

Stringer (1999:204-205) draws on an ethic of caring when advocating a feminist communitarian moral ethic for research. He propagates commitment to the common good as well as solidarity with research. He emphasises human dignity, care, justice and interpersonal respect, as well as the role of research participants as collaborators in the research process.

Research as care has been described by Dixon (1999:232). I agree with her (:233) when she says that we cannot carry out research on people’s lives without caring about the difference we are going to make to those lives.

Transformation occurs when one feels the pain of another person who is oppressed, examines the different standards of justice, acknowledges one’s own pain and finds joy in listening to others, challenges meanings and ‘experiences delight in the complexity of what emerges’ (Welch 1990:135). Speaking daily with many young people at school provides the opportunity for the kind of transformation that is described above by Welch (:135).

Pastoral care should not involve a patronising, objective self-other distinction. Bruwer (in Pieterse 2001:114) argues that the basic cry of the marginalised (in this case, the learners) is for human dignity and that the pastoral care extended to marginalised children should be circumspect, humble and respectful. Heshusius (1994:17) refers to a participatory consciousness in which relational selves do not come to knowledge by means of separation but by way of care and love. She calls this relationship the ‘self-other’, a relationship that requires an attitude of openness and receptivity to create a greater wholeness. In the training practices we follow, we (trainers, students and people requesting counselling) are all continuously changed through the experience of self-other relationships.

I agree with Reason (1994:324) who believes and hopes for a new worldview, more holistic, pluralist and egalitarian, one that is essentially participative. A participative worldview is at the heart of inquiry methodologies that emphasise participation as a core research practice.

Grundy (1997:127) applies McTaggart’s principles of participatory action research by commenting that this kind of research is different from types of research that are done on people. Participatory action research engages people in an entirely different relationship: ‘... (researchers and participants) are joined by a
thematic concern – a commitment to inform and improve a particular practice.’ I regard this as particularly relevant to my research aim of developing inclusive and caring practices at school (see 1.6.2). Grundy (1997:127) expounds McTaggart’s sentiments by saying that participatory action research concerns itself not only with changing individuals but also with changing ‘the culture of the groups, institutions and societies to which they belong’.

1.5.5 Power-sharing

Gergen and Gergen (1991:86) comment on the sharing of power between researcher and participants in order to construct meaning. When ‘subjects’ become participants, the ‘number of interpretations (or theoretical possibilities) generated by the research is expanded rather than frozen’.

I support the stance adopted by Law and Madigan (1994:6) that, if power forms part of the central metaphor for therapy [and research], it invites therapists [and/or researchers] to be accountable for the power of their position and for its effects.

With regard to narrative counselling in schools, Winslade and Monk (1999:30,31) reiterate that the power-sharing practice is relevant for counselling in schools. They describe the negotiating of a power-sharing relationship as ‘a co-authorship’ in the counselling partnership. Narrative pastoral conversations should include shared contributions that result in the recreation of stories. Continuous permission-seeking, consulting with and respecting children’s ideas and knowledges formed the basis of my narrative pastoral therapy practice. Power sharing and participation with children as research and therapy participants is even more challenging than with adults, because of a hierarchical and power differential that needs to be acknowledged.

The inherent power imbalance in the relationships between adults and children raises dilemmas in both therapy and research. When therapists and researchers engage with children, it is necessary to remain active in minimising the negative effects of this power imbalance. I agree with Morgan (1999:231), who says: ‘Although we cannot make this imbalance go away, how can we as therapists [and/or researchers] make it visible and attempt to recognise, acknowledge and counteract its negative effects?’ One way of acknowledging a power imbalance is to counter what White (1995b:51-56) refers to as ‘ageism’. Ageism occurs when children are routinely excluded from the interpretation of the actions and the events of their own lives because they are ‘too young’ or ‘not adult’. As therapists and researchers, we need to include

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5 In this study, the plural ‘knowledges’ is used to emphasise the notion that each individual’s experiences translate to knowledge.
children in discussions that determine the kinds of personal hope and desire that are communicated in these evaluations of their actions (White 1995b:53).

1.5.6 Valid research

Kvale (1996) raises the issue of the validity of qualitative research. I agree with Dixon (1999:238) that by validity we do not mean the positivist notion of the truth, or the correctness of a statement. Instead, I endorse Kvale’s (.241) stance, defining validity as ‘craftsmanship, communication and action’. He argues that ‘validation comes to depend on the quality of craftsmanship during the investigation, continually checking, questioning, and theoretically interpreting the findings’ (.241). I believe that validity (as defined above) was present in this research. The ‘attitudes I brought into the room’ (Winslade & Monk 1999:28-30) included tempered optimism and respect for the client, passionate curiosity and a willingness to ask questions to which I genuinely did not know the answers, respectful persistence, respect for the children’s knowledges and negotiated co-authorship (see Chapter 5).

Heron (in Lather 1991:55-56) illustrates the notion of Winslade and Monk (1999:28-30) when he says:

[Persons] as autonomous beings, have a moral right to participate in decisions that claim to generate knowledge about them. Such a right ... protects them ... from being managed and manipulated ... [the] moral principle of respect for persons is most fully honored when power is shared not only in the application ... but also in the generation of knowledge.

I agree with this and see it as a prerequisite especially for pastoral therapy or research with children as research-participants. I believe that participatory action research can have the benefit of transforming children’s lives as well as those of parents, families, peers at school and also facilitators and practices at school. Stringer (1999:177) reminds us that as a ‘participatory approach to investigation, community-based action research therefore confronts ethical issues rarely acknowledged in other types of study’.

1.5.7 Research as stories, stories as research

With regard to stories, White and Epston (1990:12) state that:

If we accept that persons organize and give meaning to their experience through the storying of experience, and that in the performance of these stories they express selected aspects of their lived experience, then it follows that these stories are constitutive — shaping lives and relationships.
Stringer (1999:179) suggests that story-telling is more appropriate to action-oriented, participatory research. Story-telling endeavours to capture and reflect experiences more directly by focusing on events that have a significant impact on people’s lives.

Ballard (1994:298) cites Ferguson, Ferguson and Taylor as using the idea of research as stories and stories as research as part of a post-positivist paradigm of research. He (Ballard 1994:298,299) is of the opinion that research as stories uncovers the many experiences of a person, but cautions us to remember that a critical appraisal of methods and findings ‘is an essential part of research practice’. Ballard (.300) believes that one way of critically evaluating whether stories can be used as the basis for action is to assess a story in terms of the values therapists/researchers hold regarding human needs and rights and suggests that even one instance of injustice necessitates correction.

With regard to disability/illness he (Ballard 1994:300) believes that change is not prescriptive but should rather be a dynamic process engaging both researchers and the community in mutual learning and problem-solving (see Chapter 4). Ballard (.302) refers to Donmoyer who says that stories, ‘oral accounts [and] written narratives – are powerful ways of learning’. Because stories communicate knowledge about the reality of the difficulty of human issues, they extend our understanding of other people and our feeling of community.

I also adopt Ballard’s (.302) stance that the position of people’s stories as research is not intended for particular, technical solutions to be extended across similar situations. Instead, these stories enhance the ‘range of interpretations, the range of knowledge, and the range of experiences’ at hand for someone who wishes to use research to inform action.

As humans, we are active participants in the social interpretation of our world. Morgan (2000:5,6) argues that ‘[t]he stories we have about our lives are created through linking certain events together in a particular sequence across a time period, and finding a way of explaining or making sense of them’. What we experience as real is determined by things such as our culture, values, beliefs and gender. I support Gergen and Gergen’s (1991:88) view that while there is no principled endpoint to research, the hope remains that, with each new encounter, there is an increase in the laminations of understanding – ‘to expand and enrich the vocabulary of understanding’.

A narrative approach to therapy opens up opportunities for children to story their lives in the presence of a witness. Therapeutic conversations open up possibilities for children to be consulted about their own solution knowledges and how these can be applied to the events of their lives (While 2000:21).
I believe, that in this research, research as stories played a pivotal role regarding children's illness narratives (Chapter 4). By relating their illness narratives, using research as stories, children with chronic illnesses were given an opportunity, some for the first time, to express their experience of illness, and to extend their knowledges in the form of plays to the rest of their class, to those who had no real understanding of what it is like to have a chronic illness. Similarly, with regards to children's experiences of different kinds of loss through death, research as stories, was fundamental to my research project (Chapter 3).

Graham (in Reinharz 1992:30) encourages her interviewees to tell stories so that interpretation and analysis do not remain the prerogative of the investigator:

> In stories, data and interpretation are fused, the story-line providing the interpretive framework through which the data are constructed. The story, moreover, marks the boundaries of what the individual is prepared to tell ... It is a method, too, consistent with a feminist research programme which seeks to include people in the faithful recording of their experiences.

Similarly, in the narrative pastoral therapy I provide at school, children are encouraged to tell their stories in ways that will create the space necessary for moving from 'thin descriptions' of problem-saturated stories, or the dominant story, to rich and thick descriptions of the alternative story (Morgan 2000; Freedman & Combs 1996; White & Epston 1990).

1.5.8 Research as ethical praxis

For praxis to be possible, theory must illuminate lived experiences as well as the struggles of people, or, as defined in narrative literature, the dominant story or problem-saturated story and the alternative story or unique outcome (White & Epston 1990; Morgan 2000; Freedman & Combs 1996). Madigan and Law (1998:vii) explain the dialogic interface of theory and practice as 'inter-textuality' and a 'recursive union' of theory, discourse, feminism, narrative and post-structuralism when they talk about their praxis and how accountable, ethical and transparent practices are sustained.

I join Lather (1991:57) in arguing that 'we must go beyond the concern for more and better data to a concern for research as praxis'. Lather (:57) suggests that research be consciously used to help participants understand and change their situations. She explains how theory must speak to and be grounded in everyday life (:55): 'Theory adequate to the task of changing the world must be open-ended, nondogmatic, speaking to and grounded in the circumstances of everyday life.'
Regarding accountability and the pragmatics of a research methodology, McTaggart (1996:245) states: ‘Action researchers must simply ask regularly whether things are a little more rational (or reasonable), coherent, just, humane and satisfying for participants and others than they were.’ 

‘Action research is not a “method” or “procedure” for research but a series of commitments’ (McTaggart 1996:248). This notion of commitment is extended by Lather (1991:53) when she says that, by regarding research as praxis, we are ‘committed to the development of a change-enhancing, interactive, contextualised approach to knowledge-building’.

In regarding research as ethical praxis, I was encouraged by McNay (1992:92) who says that ‘[a] feminist ethics is based on a responsiveness to others and a respect for the particular which leads to moral concerns connected to providing care, preventing harm and maintaining relationships’ (:92).

1.6 RESEARCH QUESTIONS AND AIDS

Challenging ideas regarding research with children guided my narrative pastoral practice as well as this research project at a primary school. Recent political, cultural and social changes in the country necessitate a process of transformation. A pastoral therapist trained in facilitating these transformations can make a valuable contribution in this regard (Graham 1996).

In view of what inspired me and the commitment I made, I present my ‘research curiosity’. By curiosity I mean my focused and genuine concern with children’s lives (see Grobbelaar, Kotzé & Kotzé 2001:170).

1.6.1 Research curiosity

My research curiosity was invited by the following question:

How can narrative pastoral practice at a primary school enhance transformation towards an inclusive and caring community?

1.6.2 Research aims

In order to assist my research of the question in a primary school setting, I formulated the following research aims:

• to develop inclusive and caring practices among the culturally and religiously diverse community of learners, as well as between them and the facilitators; and

• to explore and co-author creative ways of doing narrative pastoral practice.
While formulating the research question and aims, I was aware that learners, caregivers and facilitators had not been involved in my formulation of the questions and research aims. Thus, at the initial stage, the research was not a fully participatory research project where questions, aims and ways to reach the aims would be shared, as described in Bishop (1996). I was therefore aware that I would have to address these issues so that what Bishop (:228) refers to as a blurring of the boundaries between ‘researcher’ and ‘researched’ would be facilitated and so that a participatory research project would be encouraged.

I did not generate more specific aims at this stage because I chose to negotiate further learner-initiated aims by listening to the children’s voices. I included these as they evolved.

After I have completed this research, I plan to make a report available to the school’s governing body and the Gauteng Education Department to reflect on and comment on the contributions that pastoral therapists can make in a school community in transition. These recommendations, however, will not be included in this research report.

I pursued these research aims by transcribing individual and group therapy sessions; inviting learners to assist me in developing a practice that they could benefit from as well as ensuring that their voices and preferences were adhered to. Reflexive conversations invited the participating learners to challenge and change my interpretations and correct misunderstandings or misconceptions I might have had about their lived experience (White & Epston 1990:46). I also encouraged learners struggling with chronic illness to write and produce a play and to present it to all the Grade 6 and 7 classes.

I consulted with caregivers on their input and views regarding chronic illness, loss and their preferred spirituality or religion. I attempted to collaborate with facilitators to develop new interpretations of loss and to overcome the implications of child-headed households. Through this research, facilitators were given an opportunity to encounter and engage with the dilemmas of chronic illness. This exercise will also serve as preliminary preparation for inclusive education (mainstreaming learners with disabilities) when the policy is implemented by our school in the future.

1.7 REPORT WRITING

Richardson (1994:522) includes drama as a way of shaping an experience without losing the experience and includes this as a method of inquiry and a form of evocative writing. 'When the material to be displayed is intractable, unruly, multisited, and emotionally laden, drama is more likely to recapture the experience than is standard writing' (:522, also see Chapter 4). I believe that the plays written and produced by the
learners on diabetes, epilepsy and HIV/AIDS illuminated their understanding and perception of these chronic illnesses and that the plays provided a vehicle for this to occur (see Chapter 4).

Both Davies (1996:249) and Morgan (1999:vii) experienced similar difficulties and dilemmas to the ones I experienced in attempting to represent the complexity of what happens in therapy sessions with children when writing up interviews. Morgan (vii) suggests that one way of ensuring a richer description of the work is to include children’s words verbatim. However, Davies (249) cautions that ‘[t]here is a very real danger, too, that the voice of those who are less powerful will be transcribed phonetically and with ‘flaws’ intact while the author and other hegemonic speakers will appear as if they always speak with ‘correct’ pronunciation signalled by dictionary spelling’. Representing children’s voices by quoting their words verbatim in this research project was done to include the spirit of the meetings and the joy of the language used at particular ages and not to expect children to be more ‘adult’ in their ways of speaking (Morgan 1999:vii).

When answering the question as to whom action research reports are written for, I agree with Winter (1996: 26-27) that there are three audiences, all of equal importance. First, there are colleagues, learners and caregivers with whom I have collaborated in working on this research project and with whom I will continue my practice. Secondly, there are interested facilitators and therapists at other schools. The third audience is myself, engaged in a learning experience witnessing what I have learned.

The consent of participants was an aspect of my accountability in this research-as-therapy process. I was given consent from the school principal and the governing body to conduct the research while providing a therapy service to the school community. I consulted with the caregivers of the participating children and received permission for their children to participate in this research project as well as receiving permission from the children themselves. Children, caregivers and facilitators who participated in this study did so voluntarily and with the understanding that she/he was participating in a therapeutic journey as well as a research project. I asked the participants’ consent to take notes during our conversations and also asked permission to use their own words at times for the purposes of this study. I invited them to change and edit the written recordings of our therapy sessions if I had not accurately reflected their words, experiences or feelings. When I had completed the research process, I made the preliminary drafts of this paper, of which we (the participants and I) are the authors, available to the children, caregivers and facilitators who had participated in the study, for their comments, changes and suggestions which have been incorporated into this research report. I resonate with the stance held by Cochrane et al (1991:16) that to make things explicit to oneself is not only to become self-aware, but also to allow for being self-critical, and to open oneself up to questioning from others.
A chapter outline is given below to briefly indicate how this collaborative process evolved in the following chapters.

1.8 OUTLINE OF THE STUDY

Chapter 2 discusses the diversity of religious traditions, the implications thereof for inclusive education and the work of pastoral therapists in a culturally and religious diverse school community. An eco-theology that sees caring for the earth as a priority in taking care of God's creation also forms part of this chapter.

In Chapter 3, I focus my attention of therapy with children who have experienced loss due to death of a loved one. The dilemmas of cultural transitions and the problems of child-headed households, as well as separation from parents or adult caregivers are also touched upon in Chapter 3.

Chapter 4 challenges the effects of a chronic illness in the life of a young person with diabetes. Children addressing diabetes, epilepsy and HIV/AIDS in an informative way also forms part of this chapter.

Chapter 5 closes the research report with reflections. Learners were given an opportunity to reflect on their experiences. Facilitators and caregivers were asked for their opinions on the therapy and research process. Self-reflection and recommendations for narrative pastoral therapy is included.
CHAPTER 2

PASTORAL CARE AND COUNSELLING AT A PRIMARY SCHOOL

2.1 INTRODUCTION

In this chapter I discuss the diversity of religious traditions among learners and caregivers and the implications of this for pastoral care and counselling in a multicultural and religious school community. An eco-spirituality that discusses care for God’s creation, is an aspect of this chapter.

2.1.1 Pastoral care and counselling

Gerkin (1997:88) comments that the primary focus of pastoral care needs to be the care of all people through the ups and downs of everyday life, creating caring environments where all people can grow and develop to their fullest potential. However, whereas all people need the nurture and support of a caring environment, not all need pastoral counselling. Hunter (1990:845) refers to pastoral care in much the same manner, saying that it embraces ‘all pastoral work concerned with the support and nurturance of persons and interpersonal relationships’, including everyday expressions of care and concern.

Gerkin (1997:88) encourages pastoral counsellors to endeavour to join with people in ways that promote what the theologian Richard Niebuhr calls ‘moments of revelation’. Narrative pastoral therapy provides me with a vehicle for engaging with people, especially children, so that they are encouraged to tell new stories, co-creating new possibilities for relationships and new futures, while communicating the inner meaning of their religious tradition.

Pastoral counselling has become increasingly specialised. Under the influence of psychotherapy, pastoral counselling has become more available to the affluent middle and upper classes – to those who can afford it. However, Gerkin (1997:89) reminds us that pastoral counsellors are commissioned to care for neglected or overlooked persons. Pastoral therapists are therefore urged to pursue ‘those whose needs are great while their ability to seek out the care they need is small’ (89). Ways of caring and counselling with marginalised children are important aspects of my work.

2.1.2 Diversity of pastoral care at school

I believe that pastoral care and therapy should be visible not only in the context of the therapy office, but in various practical and everyday levels. Providing for the material needs of learners and popping into the sick
room and having a chat while holding the hand of a sick child is a contribution on one level. Pastoral care on another level occurs when I write letters to facilitators who have consulted with me about their own personal issues.

Likewise, I negotiate with facilitators about the difficulties some learners experience when completing their homework by candlelight; not having the correct school uniform when the only breadwinner in the family has been retrenched; when homework is not as neat as it could be because a family of four are living in a garage and the homework is being done on a mattress on the floor; when children cannot concentrate in class because they are hungry and have no food at home. This leaves me in the challenging position of translating and interpreting difficult circumstances of learners to facilitators and being identified as a ‘go-between’ in teaching and caring practices.

Sevenhuijzen (1998:147) cautions pastoral therapists to consider an ethics of care as a form of political ethics, mutual commitment and a caring solidarity, which I regard as pivotal; this is necessary ‘because everyone in different ways and to different degrees needs care at some point in their lives’.

2.1.3 Children in pastoral care and counselling

With regard to a child’s formative years, I agree with Griffin (1989:124) who says: ‘We are shaped in our formative years not only by the general features of the culture, which are widely embodied, but also by the particularities of the crucial people in our lives.’ He adds that a crucial person could be a parent, friend, teacher, pastor, priest or rabbi who directs a significant influence and opens opportunities that would otherwise remain closed. He distinguishes between direct and indirect encounters with divine grace. Sometimes a person can have a direct encounter with the divine reality indirectly through another person.

2.1.4 Pastoral care as commitment and transformation

My beliefs resonate with those of Kotzé and Kotzé (2001:2) who say:

As therapists we witness and are confronted with the pain and suffering of many people. Daily encounters with suffering, hunger, malnutrition, unemployment, rage and anger, crime attacks, violence, rape—all these issues are not extraordinary but ordinary to many counsellors, caregivers, and pastoral therapists in South Africa.

These moments of insertion (Cochrane, De Gruchy & Petersen 1991) call upon a pastoral counsellor not to become desensitised to the extent and severity of continuous trauma but to remain actively challenged. A delicate balance needs to be maintained between ‘moments of insertion’ that summon pastoral therapists
to begin within the context with a commitment, and guarding against secondary trauma or compassion fatigue (Figley 1995).

Cochrane et al (1991:18) refer to moments of insertion as 'the basic point of departure for a holistic practical theology which refuses to reduce its concerns to the atomized individual or family'. Similar moments of insertion are described by Weingarten (2000:394), who says:

It is the moment when we know we are struggling to descend into the abyss, to see it, to render it, to share this with another equally dedicated soul, and to emerge in some relation to the effort more sad, more sober, and, yes, more free.

Engaging with people in pain and suffering necessitates that pastoral therapists take a position. Graham (1996:172) comments that, ethically, this position requires a commitment to transformation. It is insufficient for me to adopt the stance of 'a lonely bird on the rooftop' (Barth 1933:4). Instead, a commitment to transformation means a positioning of myself on the side of those suffering and against all oppressive or exploitative discourses and practices (Bosch 1991:424-484). It involves trying to feel and understand the pain experienced by learners and caregivers regarding chronic illness, loss through death and separation and trying to develop an inclusive religious policy by co-constructing the different standards of justice, recognising my own pain and challenging meanings together with participants paved the way for a transforming journey (Welch 1990:135).

2.2 DEVELOPING INCLUSIVE AND CARING PRACTICES IN DIVERSE CULTURAL AND RELIGIOUS TRADITIONS

2.2.1 Introduction

In this section I describe how learners, caregivers and myself collaborated in developing cultural and religious inclusivity and caring practices at school (see 1.6.2).

2.2.2 Doing spirituality

Because of the diverse ethnic, cultural and religious groups within the school where I practise, I prefer to use the term 'spirituality' rather than 'theology'. When speaking with children and families, I am encouraged by Luke (Bosch 1991:86) who emphasises love and acceptance, justice and fairness in relationships. Sharing and community, what Bosch (1991:104) refers to as a 'communism of love', is a central thread in Acts. In counselling and care I try to initiate a 'communism of love' or, as White (1995b:51-66) calls it, a community of acknowledgement, or communities of concern (Winslade & Monk 1999:100-103). Peace-
making (Ford in Bosch 1991:118) or aspects of a harassment-free and violent-free school system (Lewis & Cheshire 1998:3-32) include finding ways to address non-violent resistance to evil (Poling 1996).

2.2.3 Religious pluralism

Lubbe (1995:165) refers to religious pluralism as more than mere religious plurality. It implies 'the energetic engagement with that diversity' including reciprocity, the search for mutual understanding, and a conspicuous encounter of religious commitments. My duty and accountability is to appeal to learners and facilitators to give religious pluralism the place it deserves in our school. I want to contribute in a small but meaningful way to a relationship between ecumenism and the 'theology of religions' (Bosch 1991:474). Knitter (1985:166) argues that religious plurality should be free from mutually exclusive claims or indifference. Instead, interreligious dialogue should be based on personal religious experience and firm truth-claims without suggesting that any partner in the encounter possesses the final, definitive, irrefutable truth (:207 & 211). Interreligious dialogue allows one to return with new insight to one's own culture, way of life and religion. Knitter (:xiv) captures the essence of working within a multi-religious environment when he says that such an approach should 'allow Christians to be fully committed to Jesus and fully open to other ways'. Knitter (:222) believes that the counselling experience should 'make the Christian a better Christian and the Buddhist a better Buddhist'.

Christians are challenged to endorse an honest interreligious, intercultural dialogue that will permit all partners genuinely to search for and discover Truth in its inexhaustible richness and to unite in eliminating the suffering, human and ecological, that is destroying the planet (Knitter 1995:29).

2.3 CO-AUTHORING WITH CHILDREN AND CAREGIVERS TOWARDS RELIGIOUS INCLUSIVITY

2.3.1 Introduction

Most of the children and caregivers at the school in the study come from a Protestant Christian background, but the school increasingly has to accommodate children from other backgrounds. In the previous dispensation in South Africa, only Christian religious education was taught at school while other religions were subjugated. For the purpose of this study therefore, I will focus on minority faiths to help me challenge myself in this regard. A brief overview of Judaism, Islam, Hinduism, Buddhism and the African Independent Churches is therefore discussed below, as well as aspects of pastoral care in these religions. Relevant conversations with children and parents are included. Children from minority Christian groups as
well as children from atheist and agnostic backgrounds were also acknowledged. Augsburger (1986:19,20), while speaking about cross-cultural counsellors, comments:

The ability to join another in his or her culture [and religion] while fully owning one’s own requires a broadened vision of the task of facilitating human growth and healing. Clinical skills within a culture are not sufficient. Cultural skills that transcend and thus can participate in transforming culture are equally crucial.

2.3.2 Judaism

Jewish seminaries have only recently begun to include pastoral care, also referred to as counselling and human relations in core curricula. Only lately has counselling been a feature of the rabbinic ministry (as confirmed in conversation with rabbis from both the reformed and orthodox traditions.)

Unlike Christian pastors, who have the model of Jesus the Good Shepherd, the Pastor, it is not in the nature of Judaism to exalt a single person as the focus of theology. The Torah contains the essence of the faith that is central, energising, and formative. Instead of emulating a charismatic person, Jews follow the principle of imitatio Dei. To emulate God is incumbent upon all Jews, lay or rabbinic (Katz 1987:18).

Grollman (1990) believes the family provides stability within Jewish tradition. The home is the centre of ritual, and the parents, by their example, are the primary teachers of the faith. ‘[T]he family is the germinal cell from whence come the spiritual and ethical values to shape the Jewish character’ (601). Jewish families I spoke with confirmed the centrality of the family, saying that they believe that this focus helps resist many of the disruptive influences of modern life.

While rabbis have traditionally been teachers of the Torah, there has always been, within their interpretation of the law, much psychological wisdom. Two movements within Judaism can be identified (Katz 1987:71). First, there was the musar movement founded by Salanter in the nineteenth century and, second, there was the Hasidic movement. The musar movement used certain psychological techniques, usually in a group setting, to bring about moral change in individuals.

Katz (1987:75) comments on parallels with the modern person-centred approach to counselling in the second movement within Judaism. The Hasidic movement grew out of the persecution and ostracism of the Jews in eighteenth-century Eastern Europe. This movement tried to acknowledge the needs of ordinary Jews with a theology that helped them make sense of their intolerable position. Jews were taught that in the midst of despair there were more immediate ways to God than through great learning and long prayers (Mills 1990:495). The essence of the Hasidic movement is encapsulated by Mills (495), who says:
What was brought to a dispirited people was a hope of a life unified in all its parts, personal, interpersonal and metaphysical. By utilising classical mystical concepts, he insisted that the separations they experienced between good and evil, rich and poor, male and female, mercy and judgement, all their inner and outer contradictions contained holy sparks separated from their true source in God. The task of the Hasidic master or rebbbe was to gather up these fallen sparks everywhere.

Central to this movement was a meeting or yehidut between rebbbe and disciple that was remarkably similar to a modern counselling relationship. Whereas the sages of the Talmud were concerned with the encounters as vehicles for teaching, the Hasidic movement was involved in a therapeutic system (Katz 1987:73). Although the rebbbe’s advice was mostly based on biblical and rabbinic wisdom, the goal was salvific. A relationship of care develops between a charismatic personality and a Jew who has the freedom to ask for personal help with any problem related to life.

The model of the Christian pastor has influenced the Jewish clergy (Katz 1987:196). Rabbis from both the orthodox and reformed traditions I spoke to, confirmed that they had completed courses in counselling as part of their studies. However, they were reluctant to affirm that the model of the Christian pastor was significant.

Jewish families at school endorsed the importance of seeking counselling with their rabbi when necessary. They believed that if it were necessary for their children to have counselling outside the school environment, they would be more inclined to consult with Jewish therapists or counsellors. However, they do not object to their children receiving counselling at school. They appreciate the fact that I take the trouble to introduce myself to them first, either telephonically or personally, before speaking with their children. The fact that I advocate inclusive religious and caring practices at school resulted in an offer from parents to assist me in any way they could.

Parents and children remarked positively on my interest in Jewish culture and the posters and souvenirs from Israel in my office. I wonder whether this in some way contributed to the easy rapport I experienced with the parents and children. Children appeared to extend the existing acknowledgement of Jewish culture in my office and added religious symbols. These included a Menorah (the seven- branched candlestick), a prayer shawl or tallit, and a mezuzah (containing the words of the Shema recited by Jews as a reiteration of faith). They believed that making Judaism visible in the counselling room would contribute to the extension and practice of religious inclusivity at school. I introduced group narrative pastoral care to provide an opportunity for children of different religions to explain the meaning and significance of their religious symbols.
2.3.3 Islam

Islam finds its pastoral guidelines in its sacred scriptures. Sunni Muslims, the largest group within Islam, express their faith through conformity to the will of Allah as stipulated in the Shari'a, the body of texts that constitutes Islamic law. The most important of these are the Quran and the Sunna, deeds and teachings of the Prophet Mohammed (according to Muslim parents I spoke to in 2001).

Matters of doctrine, worship, personal hygiene, family life, commercial affairs, and government are all treated in the Shari'a. It lays out a totalistic scheme for living as well as the elements of religion. In principle, therefore, believers who conform to its dictates both achieve merit in eternity and remove obstacles to their prosperity in this world. Within such a system pastoral care is embedded in the prescribed duties incumbent upon all Muslims.

(Gaffney 1990:596)

Gaffney (596) points out that, while Islam rejects the notion of a clergy, a distinctively pastoral authority has been entrusted to certain scholars because of their superior knowledge of the law. As well as presiding at rituals and preaching, they also reprove, issue opinions and respond to situations of particular trouble or distress.

Traditional pastoral practice is based on conformity with the law. When I spoke separately with Muslim mothers and Grade 7 girls and boys, they agreed that should they need advice, guidance or counselling relating to religious, personal or other issues, they would not turn to the priest at their local mosque. When I asked whether it would be respectful of me to enquire why not, they said that they questioned the role of confidentiality. They said that should they need therapy or counselling, they would prefer to consult with a non-Muslim therapist. However, they preferred to confer with their grandmothers, mothers, aunts or with other respected senior women in the community on problems pertaining to marriage, health, children and life in general. They commented that a very special and close bond exists between women in their community and they wondered whether this was also the same in other religious communities. Junior learners said that should they need counselling they would speak to the priest about their problems because they trusted him.

Muslim parents trusted me to consult with their children after they had made sure that I was someone who respected their religion. They knew that I would not try to convince their children differently with regard to their religious and cultural beliefs. They expressed gratitude when I collaborated with them about different ways of attaining religious and cultural inclusivity at school (see Chapter 5).
2.3.4 Hinduism

Lyall (1995:46) alerts us to the fact that ‘a major barrier to transcultural dialogue is to try and understand one culture in terms of the thought categories of one’s own’. He comments that nowhere is this more true than in comparing the psychologies and psychotherapies of East and West.

Among the traditional features of Hindu culture and religion have been the caste system, a belief in reincarnation and the idea of karma or moral causation (Lyall 1995:46). While Western psychotherapies tend to help individuals to assert their independence in relation to this world, Eastern psychologies require the renunciation of individuality. The concept of salvation or moksha signifies emancipation from the bonds of present existence. In this process, a guru or spiritual master plays a special role. Through meditation or yoga, a guru enables a disciple to give up illusions about the realities of this world. The culture is essentially patriarchal, women attaining moksha as they are reborn as males (46).

Gallup (1992:70) takes the view that counselling should seek to reinforce rather than undermine Hindu cultural values. Gallup (70) reminds us that in all counselling, cultural values and belief systems need to be taken seriously. Troeltsch (in Bosch 1991:481,482) confirms that there is ‘an intimate bond between a given religion and its own culture’ and that for non-Christians, cultures and traditional religions hold equally unconditional validity.

Gallup (1992:70) describes a case of physical and emotional abuse towards a wife. Because a divorced or separated Hindu woman is unacceptable, counselling needs to encourage her to win her husband over to a more responsible and thoughtful way of relating to her and the children.

When speaking with Hindu mothers I enquired whether pastoral counselling in this manner would be appropriate at present. They confirmed Gallup’s stance (1992:70) as still reflecting the preferred approach in Hindu culture. They added that, although it was now a decade since Gallup’s comments and much had changed with regard to their independence as women, some things remained the same, particularly relating to Hindu religion. The focus in Hindu pastoral counselling, according to them, is still the search for wholeness.

My experience with Hindu learners in counselling was that they were willing to contribute to my understanding and knowledge of their religion. They often brought me suitable literature from home, as well as pictures and small statuettes of various deities such as Parvati, Lakshmi, Ganesh and Krishna. They believed that these statuettes brought kindness and gentleness, good fortune, sustenance, justice and love to my work (Bahree 1984:14; Breuilly & Palmer 1993:22). Hindu learners remarked that my office was the
only place at school where they felt their religion was recognised and respected. They commented that because Bible Education classes were from a Christian perspective they were not asked to contribute. Although Hinduism was never criticised at our school, it was never acknowledged in any way either. The voices I heard affirmed that it was especially in the counselling context that their religious beliefs were strengthened and validated. Together we explored ways of extending and validating Hinduism beyond the perimeter of the therapy office (see Chapter 5).

2.3.5 Buddhism

The parents for only two families at school who followed a Buddhist tradition had not been born into Buddhist families themselves, but had converted from Christianity as adults. They said that, although their children were not in counselling, they would allow them to consult with me if necessary, on condition that I would not question any of their religious practices.

Lyall (1995:47) explains that for Buddhism ‘the problem is not sin but suffering which results not from guilt as understood by Christians but simply as part of the “givenness” of life’. To avoid being held in the grip of the sufferings of life that creates a force called karma, it is necessary to eliminate desire and to acquire complete detachment or freedom known as nirvana (Breuilly & Palmer 1993:7). This becomes possible through meditation, during which a clear awareness of what is going on inside oneself is cultivated and this can be of therapeutic value. At the heart of Buddha’s teachings, recorded in the Pali Canon, is the idea of not causing harm to any other living being.

The parents and children who spoke with me said that the concept of pastoral therapy or counselling was not familiar to them. By regular meditation, every Buddhist hopes to reach nirvana. With regard to pastoral therapy or counselling, one Buddhist father explained: ‘You see, it’s like this, it’s not that we criticise or judge other religions. It’s just that we don’t consider pastoral therapy or counselling necessary because we are able to deal with our problems ourselves by meditating, reducing karma and trying to achieve nirvana’. No Buddhist learner has as yet been referred for pastoral therapy, and none has sought therapy of his/her own accord. I believe that if this occurred and I consulted with and introduced myself first to the caregivers, as is my practice, then I would be given consent to continue therapy with the child.

2.3.6 African Independent Churches

African Independent Churches or African Indigenous Churches, also known by the acronym AIC’s, a term preferred by many scholars, in recent years has come to be referred to as African Initiated Churches by the World Council of Churches (Daneel 1999:xiii).
According to Cochrane et al (1991:38-39), the 1980 South African Government census indicates that of the more than twenty-two million persons who claim to be Christians, 19.9% percent belong to AIC’s. The phenomenal growth of these churches has led to their becoming the body of churches with the largest membership in South Africa (42). These churches historically originated in the Ethiopian movement as a protest against colonialisation and denomination within the ecclesia, and thus they may truly be called ‘churches of the people’ (43). They are South Africa’s equivalent to the base communities of Latin America and elsewhere (43, 90-92). Daneel (1999:xiii) confirms the sentiments of Cochrane et al (1991) when he says that ‘African Initiated Churches are churches begun by Africans in Africa primarily for Africans’.

It was only after starting to work as a pastoral therapist at the school and meeting with many AIC parents that I realised something of the intricacies of ‘dual membership’; frequently a person belongs to a mainline church such as the Anglican Church while simultaneously being a member of an indigenous church, without the knowledge of the authorities of the Anglican Church. Cochrane et al (1991:43) confirm this, saying ‘[m]istrust is strong, even though virtually every black clergy person knows that this kind of dual membership exists’. Parents indicated that although they live in so-called ‘white areas’ and were happy to attend mainline churches in those areas ‘certain aspects of our culture and religious beliefs cannot and will never be provided for in mainline churches’. According to them, it is only the AIC’s that understand the centrality of ancestral worship and can provide the necessary pastoral support they need.

The essence of what parents shared with me is captured by Masamba ma Mpolo (1994:16), who says that ‘the African sees life as one integral whole. Every profession and event has a spiritual dimension. Though distinguishable from one another...they are inseparable one from the other...each...an integral part of religion’. Healey (1981:14) extends this understanding of African religion by saying that ‘[t]o the African, religion is like the skin that you carry along with you wherever you are, not like the cloth that you wear now and discard...the next moment’. The effect of this is that most people seek answers to their different problems in terms of their traditional spirituality.

Parents and senior learners made it clear that the place occupied by spirits and ancestors as well as by rituals and symbols is a part of African spirituality that has to be considered in pastoral care and counselling and the other pastoral activities of the church. It is their belief that God, as the creator of life and the power that plans and controls the world, communicates and is disclosed in and through ancestors, spirits and deities. Muller and Ritz-Muller (1999:122) confirm the supremacy of the ancestors by saying that ‘[t]he cult of the ancestors can be regarded as the basis of African religiousness. All African peoples have a vital interest in living harmoniously with their powerful though departed relatives’. Nelson Mandela (1994:12) speaks about his father who did not have to be ordained in order to preside over and officiate at rituals,
because 'traditional religion ... is characterised by a cosmic wholeness, so that there is little distinction between the sacred and the secular, between the natural and the supernatural'.

Parents said that because ancestral worship was unacceptable in mainline churches, it meant that they were compelled to consult with and receive guidance, pastoral counselling and care in the AICs. I witness their desire and need to facilitate openness in inter-cultural dialogue. Larrey, Nwachukwu and wa Kasongo (1994:155) extend this by saying that inter-cultural dialogue should include 'psycho-sociological and psychotherapeutic insights together with theological, ethical and spiritual matters in a quest for renewed relationships in pastoral care and counselling'.

2.3.7 Minority Christian groups and children from agnostic and atheist backgrounds

A small group of children in the school are Jehovah's Witnesses and Seventh Day Adventists. Some of the children have mentioned that because of an agnostic or atheist background, their parents preferred them not to receive any religious or spiritual teaching. These children were in the minority and sometimes felt marginalised because of negative remarks made to them in class. It was my responsibility to ensure that when they were referred for pastoral therapy these children were made to feel as welcome and appreciated as any other child. I tried to counter negative remarks made to them by bringing these remarks to the attention of their class facilitators and speaking with those who had made remarks.

2.4 PASTORAL CARE AND THERAPY IN A MULTI-RELIGIOUS SCHOOL COMMUNITY

Knowing about the religions of others and practising pastoral therapy and care in a multi-religious school community requires more than being cognisant with details of the various religious traditions. Instead, it involves getting inside the skins of learners of different religions, walking in their shoes, seeing the world in some sense as they do. It also requires a certain amount of diplomacy and collaboration on the part of the pastoral therapist when, sometimes, caregivers of a particular religion express concern and surprise that I offer an inclusive pastoral care and therapy service at school.

Merton (1968:141) comments 'If I affirm myself as a Catholic, merely by denying all that is Muslim, Jewish, Protestant, Hindu, Buddhist, etc., in the end I will find that there is not much left for me to affirm as a Catholic; and certainly no breath of the Spirit with which to affirm it.'
2.5 AN ADDITIONAL AIM DEVELOPS

While co-creating aspects of inclusive caring and religious practices with the children, caregivers and facilitators described above, an additional research aim evolved. Children began to consider spirituality and the environment in a different way. At that stage I therefore included an additional research aim: the development of an eco-spirituality as a practice of pastoral care, where caring for the earth is consistent with caring for people. This notion of care resonates with an eco-spirituality.

2.5.1 Touching the earth – eco-spirituality as a practice of pastoral care

An ecological spirituality is created in the reciprocity between our receiving nurture from nature and nurturing nature in return (Clinebell 1996:63). Included in this understanding of an eco-spirituality is people-caring.

2.5.1.1 In the beginning

How can you buy or sell the sky, the warmth of the land? The idea is strange to us. If we do not own the freshness of the air and the sparkle of the water, how can you buy them? Every part of this earth is sacred to my people. Every shining pine needle, every sandy shore, every mist in the dark woods, every clear and humbling insect is holy in the memory and experience of my people...We are part of the earth and it is part of us. The perfumed flowers are our sisters; the deer, the horse, the great eagle, these are our brothers. The rocky crests, the juices in the meadows, the body heat of the pony, and man – all belong to the same family.

The above is attributed to Chief Seattle in 1854 by hooks (1993:176). I agree with hooks (1993:175), who says: 'When we love the earth we are able to love ourselves more fully.' I would extend this notion by adding that because of this we can reach out in love to care for others.

2.5.1.2 Earthloving and earthkeeping – a person who plants a tree plants hope

The AIC in Zimbabwe has adopted a practical prophetic call to earthloving or earthkeeping. They joined forces with practitioners of traditional African religions – the chiefs, headmen, spirit mediums and excombatants of Zimbabwe's political liberation struggle – and established their own Christian wing of the green army (Daneel 1999:3). Within a decade, this body of churches has grown to include one hundred and fifty member churches with a total membership of two million adherents (:3).

In addition to nursery development and the planting of millions of trees, they have also introduced new earthkeeping rituals. Sermons and sacramentally related green activities signify the development of a
grassroots eco-theology. Daneel (1999:39) cites Bishop Kindiam Wapendama who believes that, because deliverance resides in the trees, we as followers of Jesus are expected to continue His healing ministry by clothing the earth with trees. Regular indigenous tree planting ceremonies are held at school, where I work as part of nurturing nature.

2.5.1.3 From ‘dominion over nature’ to ‘custodians of nature’

Ackermann’s words (1991:111) regarding feminist spirituality resonate with my understanding that:

[a] feminist spirituality is ecologically orientated, in the belief that violations of the eco-system mean the destruction of our life-support systems and that these violations are a product of the western theological tradition, of an hierarchical chain of being and chain of command, and of the socialization of people into dominant and subordinate social roles.

I agree with Ackermann (1991:111) that we need to change our attitude from one of believing that we have ‘dominion over’ creation to a view and understanding that we as human beings are instead ‘the custodians of nature’. With regards to caregiving, as in ecotherapy, Clinebell (1996:108) quotes Graham who says that we must ‘replace our current philosophies of domination of nature with ecosystemic philosophers of partnership and bondedness with nature’. I regard pastoral care and therapy at school as well as my involvement in the eco-venture club¹ as vehicles for assisting learners to realise the importance of ‘partnership and bondedness’ with nature. Chief Seattle in Morgan (1991:Foreword) aptly captures the difference between controlling and owning the earth or nature as opposed to respecting and nurturing it when he says: ‘Man did not weave the web of life, he is merely a strand in it. Whatever he does to the web, he does to himself’.

2.5.1.4 School environmental policy

In keeping with the Gauteng Education Department’s requirements regarding environmental issues at schools, an environmental policy was drawn up and has been implemented at school. My responsibility is to assist children and facilitators in realising that caring for nature should also be consistent with caring for human beings.

2.5.1.5 Earth summit

Agenda 21, the report from the United Nations Conference on the Environment and Development (UNCED 1992), commonly known as the Earth Summit, links care for the earth with care for children and youth. In

¹ The eco-venture club is offered as an extra-mural activity at school. It is described as ‘Learning about nature in nature.’

30
projects that attend to the environment and development, the concerns of youth and children must not be lost. Care for youth and children, is a significant part of what constitutes sustainable development. The report emphasises the voices of young people as important in decision-making regarding the environment and development. It recommends, as a part of sustainable development, that governments promote youth education, employment, and involvement in the United Nations, and that governments fight human rights abuses against youth. It recognises that sustainable development promotes a healthy social ecology in which children can develop. It recommends that governments reach child-related goals of the 1990s in areas of environment and development, especially in health, nutrition, literacy, and poverty alleviation. Governments should encourage primary environmental care activities that address the basic needs of communities and improve the environment in households and communities for children. The report recommends mobilising children in the activities outlined above. These activities can be guided by government enforcement of the guidelines set out in the Convention on the Rights of the Child, a treaty that is consistent with sustainable development.

2.5.1.6 Ways of nurturing an ecological spirituality

Clinebell (1996:63) suggests that an ecological spirituality is sustained and given new energy by three principles that guide the practices of eco-education and ecotherapy by becoming: '(1) more fully, intentionally, and regularly nurtured by nature; (2) more aware of the larger meaning of [our] place in nature and in the universe (ecological spirituality); and (3) more involved in nurturing nature by active earth-caring'. I appreciate the golden opportunity I have to share these crucial principles with children. I include aspects from these principles in pastoral care and therapy and implement and consolidate them in a practical way at the school's eco-venture club meetings and at the school's recycling centre.

2.5.1.7 Earth caring practices

Moore (1998:3) promotes the idea of 'sacred hopes' that seek 'to inspire the church to minister with the earth in all of its coming and going, its doing and being'. I would like to see all places of worship, and all schools ministering with the earth. To minister with the earth is 'to serve God in such a way that we care for the earth, receive from the earth, and join with the earth in praise of our Maker and in healing our planet' (Moore 1998:3). An ecological spirituality is inclusive so that ministering with the earth can be practised by all people, to all people. I encouraged sharing and learning about different religions and cultures' viewpoints regarding earth-caring when I facilitated Life Orientation classes. Interaction and collaboration between learners during these classes resulted in their realisation that some people and their communities have a vital role in environmental management and development because of their knowledge and traditional practices. I believe that schools have a responsibility to acknowledge and promote the effective
participation of all cultures in the achievement of sustainable environmental management and development. In these classes lively discussions were held about ways that earth-caring could be extended to include people-caring. This notion of care is confirmed by Graham (in Clinebell 1996:107) who recognises 'care of nature as a component of human caring'.

2.5.1.8 Finding ways of indirectly challenging environmental destruction

I acknowledge that children generally are not empowered to directly challenge those responsible for practices leading to environmental destruction and pollution. However, I am obliged to draw attention to the fact that those persons and groups whose voices are silenced due to social and financial marginalisation are also those most endangered by toxic waste. So, for example, race and class appear to be the dominant variables in the location of toxic dumpsites. In a study in the United States, it was demonstrated that 40% of the country's landfill capacity was found to be located in or near communities of people of colour (Moore 1998:121). Thorpe (1996:47) claims that two-thirds of the uranium reserves in the United States are located on the lands of first nation people and that 80% to 90% of the mining and milling has occurred on or adjacent to reservations. He refers to this as 'radioactive colonialism' and states that this has resulted in numerous deaths and illnesses in 'Native American communities, a marginalised people' (47).

One only has to recall the pollution of many of the rivers and coastlines of South Africa and the effects of this pollution on aquatic life, various ecosystems and on those dependant on these waters to realise that again it is the marginalised who suffer the most. As mentioned above, one cannot expect children to be directly involved in preventing abuses such as the above from occurring, but it is my responsibility to create opportunities of awareness for our environment. We can take a stand indirectly by discussing these issues in class and at the eco-venture club or at assemblies, and by communicating our dissatisfaction with such practices by making posters that can be displayed in prominent areas at school and also on our notice boards outside the school. Children can be encouraged to express their dissatisfaction concerning environmental issues by writing articles and making drawings for newspapers.

2.5.1.9 Children teach adults

Pastoral care offered within an educational framework of young people provides opportunities for learning to listen so that adults may reconnect with the nurture of nature as well as their responsibilities as adults for the care of the earth and its people. Adults have much to learn and gain from youth.

Young people especially have the gift of a natural curiosity and wonder that shepherds adults to a more comprehensive appreciation of the earth. It appears as though their delight, novel interest and natural
curiosity in nature is contagious, rubbing off on adults and reminding adults that there should be no taken for granted processes in nature. Questions adults ask themselves could include the following: in what ways can adults create situations and opportunities to learn from children how to rekindle interest and love in nature so that it can become a permanent feature in all our lives? How can adults become child-concerned and also simultaneously nature-concerned? What is it about nature that makes it such a powerful experience of God’s care for all of us?

As a pastoral therapist, I have an opportunity to consider earth-loving issues with children. My entrenchment in eco-spirituality allows many varied and colourful conversations with young people both in therapy and in my involvement in the school’s eco-venture club. I enjoy listening to children’s stories about working in the recycling centre, how they extend the tree and bird themes that are presented at assembly by the different grade classes and their ideas of conservation. These discussions have created wonderful moments of listening to their earth-caring voices. In addition children’s knowledges regarding environmental issues have contributed to rich and novel conversations during therapy sessions.

2.5.10 Eco-education

Various projects and activities regarding ways in which children can practice earth-loving attitudes, values and lifestyles are incorporated in the curriculum. The eco-venture club extends eco-education in activities as well as field trips. This holistic manner of learning seeks to enrich facilitators and learners’ thinking, feeling, attitudes, and their relations with other people, society, nature, and the transcending aspect of their lives (Clinebell 1996:248). As mentioned above, the multi-cultural aspect of the school encourages earth-caring partnerships, drawing on special ecological wisdom of various cultures. Because environmental problems are not selective and occur in all human-established boundaries, this necessitates transnational and multicultural solutions.

2.5.11 Beginnings of children’s spirituality

Earth-loving talk provided opportunities for an exchange of ideas regarding what I considered to be the beginnings of children’s spirituality. When learners feel comfortable and secure in a confidential environment, they are able to cross barriers that adults and religious leaders have imposed on them regarding religious and spiritual beliefs. They are free to talk about religious issues that they would otherwise not talk about. Children know more than I had realised (Heskusius 1995), and conversations left me with challenges and questions I had not thought of before such as whether I thought God liked all butterflies or had favourite coloured ones? Whether if Allah was on earth, he would like doing homework or
would sometimes forget to do it, and whether if God did not have to work all the time what he would do on his off-days.

Conversations and questions from older children were often gender-related. They asked whether it was sufficient for people merely to replace a male God with a female God. Their questions opened up opportunities for debating. For example, how effective would it be to reinterpret the divine in terms of a gender switch? Would introducing the idea of an earth goddess as a new focus of worship be the answer?

2.6 REFLECTIONS

As a pastoral therapist, I chose to be accompanied by the voices of contextual and feminist theology in my journey of commitment towards care and transformation. The way contextual theology connects the faith of a community to the community’s life, mission and social praxis (Cochrane et al 1991) guided my vision of transformation towards a more ethical and just community at school (Graham 1996). The centrality of human experience in feminist theology led me towards regarding therapy as a co-construction where both caregivers and myself and also children and myself co-authored new realities regarding inclusive religious caring practices through our interaction. It was the children’s interest that enabled me to consider eco-spirituality as a practice of pastoral care. I regard this as a ‘sparkling event’ (White 2000:6) in my narrative pastoral practice at school and a highlight in this research project.

I conclude Chapter 2 with a challenge: ‘We cannot love our children fully unless we also learn how to love nature in ways that will leave them a healthy planet’ (Clinebell 1996:79).

In Chapter 3, I explore and co-author with children, their caregivers and facilitators, ways of using narrative pastoral therapy with regard to different kinds of loss.
CHAPTER 3

COUNSELLING CHILDREN DEALING WITH LOSS

3.1 INTRODUCTION

In this chapter I explore and co-author creative ways of doing narrative pastoral care and therapy with children and families in situations where a sibling or caregiver has died. I also pay attention to the effects of a different kind of loss experienced by children living away from one or both of their caregivers. Traditional grief models are deconstructed by co-searching for ways of maintaining an ongoing relationship in spite of separation from caregivers and in the case of death, a continued connection with the one who has died.

Narrative conversations allow people to find a place in their lives for the person who has died or from whom they are separated. This approach resonates with the comment made by Waldegrave (1999:176): ‘to share in these sorts of conversations ... therapists need to pay more attention to beliefs that prioritise ‘connection’ not ‘detachment’. On the other hand traditional psychological approaches assist people to manage their grief prescriptively. Prescriptive steps invite people to resolve their grief by ‘detaching’ from the loved one, letting go of them and their lives.

Personal experience and clinical work contribute to inform the position I have adopted. I heed the warning given by Whitaker (in Hargrave 1994:121) regarding the dangers of countertransference or the reexperiencing of feelings by the therapist in response to clients. On the other hand, I am also aware of the contribution that personal experience can bring to therapy. I identify with the notions of Carter (1991:272-283), who writes about Death in the therapist's own family and comments that sometimes she takes ‘sides emotionally within families’. In a similar vein, Weingarten (1997:xii) disputes the academic discourse that separates the personal from the professional. She (xii) acknowledges the contributions others make to our lives and encourages therapists to make these contributions visible. Jackson (1997:60) confirms that the most creative moments in therapy occur ‘when the personal and professional are unified, revealing that therapist and client are both ordinary people struggling with similar dilemmas’.

3.2 LOSS AND HOPE

Soon after I had started working as a pastoral therapist, I came to realise the extent of the impact of loss through death and/or separation from family and loved ones on many young children's lives. I wondered whether offering an alternative way of dealing with grief such as the metaphor White (1989:29-36) refers to
as 'saying hullo again: the incorporation of the lost relationship in the resolution of grief' could be of value to these young lives. Could this metaphor and its application to loss and grief therapy offer learners opportunities to reposition themselves in relation to the death or separation of a loved one?

I pondered whether the loneliness and despair experienced by such learners would be ameliorated so that relief could pave the way for change. Instead of others’ encouraging children to disconnect, children could be encouraged to re-connect to include a continued relationship with their lost or separated loved one. I considered whether the 'saying hullo again' metaphor could be appropriate to use because so many Black children experience a sense of loss through separation from parents due to residential accommodation problems. Many of these children live with substitute parents, family members and others while their biological parents live elsewhere. It is not unusual for learners to live in child-headed families while parents live in other provinces. Transport and distance make it necessary for many young learners only to see their biological parents once or twice a year. Counsellors at other schools confirmed this problem.

Realising that the number of learners referred for pastoral care and therapy was only the tip of the iceberg, I wondered how I could invite all learners experiencing loss to be aware of the caring services I provide at school. I was afforded an opportunity to extend such an invitation when I presented Life Orientation classes. I invited all learners who had experienced loss of or separation from a loved one to come to talk to me if they wanted to. I especially requested the co-operation of facilitators of younger children in this regard. I am of the opinion that if grief counselling as a practice of pastoral care and/or therapy is available, it will not be necessary for learners to be overwhelmed by loss and despair.

The children’s response to this invitation initiated a practice of self-referral. Children no longer had to wait for referral to therapy until their behaviour and/or feelings of loss had been noticed by facilitators and caregivers. Facilitators also contributed significantly so that a practice of 'immediate counselling' was established. Facilitators are usually first made aware of loss through death or separation either by the learners themselves or by their caregivers. Instead of waiting to see whether grief counselling seems necessary, they now refer all relevant learners for counselling as soon as possible.

Initially, I thought that the practice of self-referral established by the needs of the children themselves would only involve their loss or separation from people. However, the children have taught me that the death of a favourite pet is also a traumatic experience for them.

In addition to providing individual grief counselling, I helped to establish various support and caring teams. Children refer to these as 'The Learners for Learners Caring Club' or the L.L.C. Club. The aim of the L.L.C. Club concerned with loss is to take anybody who has experienced death or separation from a loved one,
including loss through divorce, under their wing. They also meet regularly with me as a group. I continue to meet with new referrals initially, but, after a few meetings with new referrals, and depending on their decision, either continue to meet with them individually or introduce them to a L.L.C. Club.

A caring committee and prayer group of facilitators existed before I started working at the school. These groups normally supported each other, especially during times of loss, but as time passed it was the voices of learners and learners’ talking in class and on the playground that invited facilitators to share their stories regarding loss and other issues with me.

It is against the background sketched above that I explored and co-authored ways of doing narrative pastoral care and therapy with children experiencing loss.

3.3 TOWARDS SETTLED STORIES

Peter, Raama and Sandle were referred individually for counselling because of their traumatic experiences due to loss through death and separation from significant people in their lives. Their facilitators’ concern was that, months after the loss, these young learners still appeared to be ‘emotionally empty’. They seemed to be what Weingarten (2000: 401) refers to as ‘bereft of hope’. They had lost their sparkle, their vitality, their enthusiasm for living; they were lost in a sad and isolated world of their own.

McGoldrick (1991:51) documents a wide range of mental and physical problems associated with unresolved loss, such as depression, addiction, disturbed behaviour, anxiety, phobias or compulsions.

I regard it as a privilege to have accompanied Peter, Raama and Sandle on their journey towards healing.

3.4 PETER’S STORY – THE LOSS OF A BROTHER

3.4.1 A car accident

Peter was in Grade 2 when he was first referred for pastoral therapy. His class facilitator had noticed that since the loss of his brother in a car accident the previous year Peter had become very withdrawn in class, hardly ever spoke and was overcome with emotion at times. White (1989:29) confirms that persons experiencing ‘delayed grief’ or ‘pathological mourning’ look as if they have lost their ‘own selves’ as well as the loved one. Peter’s caregivers supported the idea of his receiving therapy.
3.4.2 Silence speaks out

It is my custom to meet learners at their class and to accompany them to my office when they come to therapy for the first time. I offered Peter my hand in reassurance, but he shook his head and said quietly: 'Not now, my heart is too sad.' When we reached my office, he was silent. I remembered Freeman, Epston and Lobovits (1997:160) comment that 'nonverbal clues may suggest to the therapist a move into other realms of communication...[when a child] is overwhelmed with emotion [or is] struggling for words'. Peter spotted the 'lego' blocks and asked whether he could play with them. Much of our first meeting was spent playing with these plastic blocks. Gradually Peter began to talk in a very subdued voice.

Holding a 'lego' figure, he told me about his caregivers and said that they did not have a family any more, because Ryan, his brother, had died. He felt that when he spoke about Ryan his caregivers cried even more, and so he had stopped talking to them about how much he missed Ryan and just 'cried alone inside my body' instead. He said he longed so much for Ryan, who had always been his 'best buddy'. They had differed in age by only a year and had always done everything together. He said: 'Now I'm all alone and have nobody even to talk to'.

While we were sitting on the carpet among the 'lego' blocks and plastic figures, we started our journey of the 'saying hullo again' metaphor. Peter expressed surprise that he was 'allowed' to talk so freely about Ryan. He remarked: 'It's nice to be able to talk about my brother 'cause now it doesn't feel that he is so far away from me anymore. It feels like heaven where Ryan lives now, is closer to me.'

Playing with 'lego' during our first meeting and at subsequent sessions, I wove questions into our conversation that could offer Peter the experience of a continuation of the mutual love, admiration, fun and special times that he and his brother had shared. These are a few examples of some of the questions: 'What do you think Ryan would tell me about you? What would be the things that he most enjoyed doing together with you? Tell me about some of your favourite fun times you had; do you think that Ryan would like to see you still doing some of those things? What made Ryan happy to have an older brother like you? What kind of movies or television programmes did Ryan enjoy? What game did he like most on 'Sony PlayStation'?

Peter enjoyed this type of conversation and also started asking me questions, such as: 'Why do you think Ryan would say I'm special? Will Ryan always want me to be his brother? Do you think Ryan likes to look down from heaven and to see the things I do and be happy that I am happy? Do you think Ryan would mind if I was happy again?'

38
Peter seemed to need confirmation that to be happy again was all right. He was concerned that Ryan 'might not like to see me smile. Maybe he will think that I've forgotten about him'. It appeared that Peter needed his caregivers' approval that it was 'okay' for him to be happy. He was aware that it was very difficult for them to show their happiness while they still felt so sad. At the end of our sessions, Peter always asked when we could meet again and asked whether it could be soon 'and please can we invite Ryan to join us again from heaven?' As time progressed I asked whether he would like to join other young learners in exploring more ideas and ways of linking with loved ones. He said: 'No, thank you, I think I'd just like to talk to you'.

Over time as we continued to meet, Peter slowly became less withdrawn and the tears of loss and missing his brother did not control his life to the same extent as they had before. Gradually he again became involved in class, his schoolwork improved, he seemed much happier and outgoing and also became more talkative. At that stage, he wondered whether he could invite some special people to join us in therapy.

3.4.3 Honouring grief, talking future

The special people he wanted to invite were his parents. Peter suggested that I talk to them so that they would not have to 'carry on feeling so sad anymore. You can show them how to talk to Ryan in heaven,' he said. And so, at Peter's suggestion, his parents, Peter and myself entered into exploring more of the 'saying hullo again' metaphor.

Titelman (1992:343), writing about Reaction to death in a family says that death is 'the most important nodal event in a family system'. McGoldrick and Walsh (1991:31) refer to untimely losses as 'premature deaths that are "off-time" in terms of chronological or social expectations ... [the] death of a child, tend[s] to be more difficult for families to come to terms with than "timely" deaths'. They (31) remark that the death of a child is possibly the worst loss of all for a family because the natural order is reversed.

The untimely loss became apparent at our first meeting, when Joan, Peter's mother, said more than once: 'You know, one just doesn't expect to lose a child, not some one so young and still with so many years ahead of them. One thinks of old people dying, but not a child'. The course of life is experienced as out of sequence if a child dies before parents. Walsh and McGoldrick (1991:18) use a Chinese saying to illustrate this: 'White hair should never follow black.'

After Ryan's death, Joan and Ross, Peter's father, had received therapy oriented by the normative model of the grief process. However, their experience did not resonate with this particular approach. Joan remarked that, although she was on anti-depressants, 'nothing has helped'. Ross and Joan commented
that they felt they had ‘gone through all the stages of mourning’. However, they said: ‘We just don’t seem able to say ‘goodbye’ permanently and to get on with our lives and that of Peter’s without Ryan being here.’

Their despair at not ‘feeling better’ almost overwhelmed me to the point of joining them in ‘more of the same’ conversations centred on the ‘goodbye’ metaphor (White 1989:29). However, guided by the ‘saying hullo again’ metaphor I was able to introduce questions that I hoped would allow the opportunity for Joan and Ross to reclaim their relationship with Ryan. I enquired whether instead of ‘saying goodbye’ to Ryan it might be more useful to ‘say hullo’ to him. I am sure that I must have looked rather surprised when Joan and Ross seemed completely comfortable with the suggestion. I had not realised that Peter’s feedback of pastoral therapy to them had paved the way for this type of conversation to continue. The kind of questions we discussed during several therapy sessions included the following:

- *What does Ryan see when he looks at you through his loving eyes?*
- *How does he know this about you?*
- *What would he be telling us about you that you could value?*
- *In what way would this change how you feel about yourselves at the moment?*
- *If Ryan were with us now, what would be the things he would most enjoy doing with you? Tell me something about them.*
- *What do you see in yourselves that has been lost since the passing of Ryan?*
- *What do you know about yourselves that you are aware of when you remember the things that Ryan knows about you?*
- *How could you let others know about these discoveries about yourselves that Ryan knows?*
- *How will your next step be influenced by what you now know about yourselves?*

Over time, Joan and Ross discussed how Pain, Self-Blame and Survivor Guilt had tried its best to come between them. They also remarked that Sadness had tried to make them feel isolated in their loss: ‘None of our friends or family have lost a child and they have got no idea what it feels like’. By using externalising\(^1\) conversations, Joan and Ross were given opportunities to objectify and, at times, to personify the problems related to Ryan’s death. In this process, the problems became a separate entity and thus external to Joan and Ross (White 1989:5; White & Epston 1990:38).

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\(^1\) If a problem is externalised and personified, I write it with a capital letter, for example, Pain, Self-Blame and Survivor Guilt. This practice reflects a trend found in narrative literature (Kotzé 2000).
These conversations opened up a way for Joan and Ross to move away from their problem-saturated or dominant stories of Pain, Self-Blame, Survivor-Guilt and Sadness to discover unique outcomes or alternative stories such as Inner Strength, Love, Support, Perseverance and Commitment to each other and Peter. Externalising conversation empowered them to stand up against the problems and gave them space to explore their alternative stories and preferred realities.

McGoldrick and Walsh (1991:38) refer to ‘the loss of parents’ hopes and dreams’ in the case of the loss of a child. This was reflected in comments by Joan and Ross such as ‘we had such dreams of what it would be like to have Ryan around as a teenager’, ‘we wanted Peter and Ryan to enjoy being brothers as they grew up together’, ‘we often thought about what Ryan would become one day’ and ‘we depended on Peter and Ryan continuing our family name into the future’. Externalising conversations created opportunities for Ross and Joan to resolve their experience of Lost Dreams and Desires. Gradually, these conversations assisted them in repositioning themselves in relation to Ryan’s death.

The scope of this research does not allow for fully explaining narrative pastoral practices. However, since I do not view these practices as techniques, but rather as ways of living or doing spirituality, I hope the concepts will become visible to the reader through my commitment to care and transformation. I believe that my ethical practices of accountability, transparency and multiple reflections as well as deconstructing power-knowledge discoveries will become visible to the reader. For relevant literature in this regard (see Basson & Kaiser 2001; Elliot 1998:37-61).

3.4.4 Images of God: inviting spiritual-talk

Not wanting to impose my own spiritual beliefs during therapy, but simultaneously wanting to respect those of Joan, Ross and Peter, I remained cautious on these issues. However, I also risked the possibility that perhaps they experienced this as limiting to therapeutic possibilities. My mind kept returning to the conversation between McLean and Kotzé (2000:171) about whether, from a therapist’s point of view, spirituality was a private domain in a client’s life or whether it was uncertainty that silenced a therapist.

A question I needed to answer was whether respecting their spiritual privacy could actually be a form of professional oppression (Griffith 1995:123). Ross (1994:8) echoes much of this dilemma when she says that ‘we limit our work if we do not address the religious and spiritual components of our [client’s] lives’. She continues to say that disregarding a person’s religious practices can prevent the development of a therapeutic relationship in much the same way as when a therapist is unmindful of the person’s culture.
When inviting God into therapy, I was challenged to move away from what Griffith (1995:125) describes as 'the entrapment of knowing' to conversations of curiosity and wonder. It is only when one distances oneself from 'stories of certainty' and 'already knowingness' that multiple realities can coexist and relationships can develop (1:27). I took strength from Weingarten's (1992:45) suggestion that acknowledgement and repair of the inevitable lapses of intimate interaction that occur between therapist and client can lead to opportunities for a profoundly meaningful collaboration.

God-talk was invited into therapy when Ross remarked on the untimeliness and injustice of the death of Ryan, which had led him and Joan to the most profound questioning of the meaning of life (McGoldrick & Walsh 1991:38) and God. Ross said that they could not believe that God could have done such a thing to them. They felt 'let down' and were 'angry' with God. Externalising Anger as well as Let-Down over the next few meetings gave Ross and Joan opportunities to separate their identity from being angry with and disappointed in God.

As we journeyed together, enabling conversations brought Joan and Ross to a realisation and acceptance that God was neither the author of their anger nor wanted to punish them. They said that a turning point had occurred in their lives when, during therapy, they realised that it was Anger's desires, dreams, motives and way of operating that had separated them from God. The recognition of the immeasurable extent of God's love was a unique outcome that provided a gateway to alternative territories of Joan and Ross' lives (White 1992:127).

We continued to meet together for some months until Joan and Ross decided that they had regained so much of their lives that they no longer needed therapy. Peter still pops in to chat and to talk about Ryan. His schoolwork has improved and according to his class facilitator, he is a normal, well-adjusted and happy lad in Grade 2.

3.5 RAAMA LOSES A MOTHER

3.5.1 A shooting takes away a mother

Violence is common today, rather than rare. 'Everyday violence' is the violence that is intertwined with, and therefore configures, people's everyday lives of public or private work, sustenance, recreation, and intimate relations' (Bar On 1998:45).
Raama, an Indian boy in Grade 3, was referred for pastoral therapy by his maternal grandparents and his facilitator. He is the eldest in a family of four children. His mother had been killed in a shooting incident and Raama and his siblings were taken care of by his maternal grandparents.

Prior to the shooting incident, Raama had been an outgoing, talkative, confident and active little boy in class and at home. However, since the death of his mother, Raama had become completely silent, walked around alone at play-time and in class stared blankly ahead, with no expression on his face. He appeared to be lost in a world of his own. So great was his loss that he spent his school day and time at home silently encapsulated in an expressionless void. Raama had shared a special bond with his mother. Her loss appeared to have been too much for him to endure.

Talking with Raama was difficult. He sat with his head bent, eyes on the ground, silent. I tried to let him know that I understood the intensity of his sadness and loss. I mentioned that my father, whom I had loved, had died some time previously and that I still missed him. I wondered whether my loss could in some way be similar to his. The fact that a grown-up and therapist could experience the loss of a parent and still be missing him appeared to hold some meaning for Raama. For the first time in our conversation, he lifted his tear-filled eyes from the floor, stared at me silently for a long time and then said: 'I thought only children missed and cried about moms and dads who die, not big people like you doing your job.' After confirming that this was indeed the case, he slowly nodded his head as though he had accepted that I too knew what it was like to miss someone who had died. The heaviness in Raama seemed to lift slightly as he looked round the room at the toys and different activities.

He asked to play with the set of plastic farm animals. I enquired whether I could join him and asked what I could build for the farm. 'A safe place for all the animals where nobody can get hurt or killed,' was his reply. And so our first therapy session began as we sat and built a safe place for the farm animals.

Not much was said during that session, but the fact that Raama had allowed me to sit alongside him on the carpet and to build a 'safe place' together with him let me feel that he was comfortable with me to a certain extent. Raama continued to play silently with the animals and ended the session himself by saying: 'Please keep the farm house and animals safe till next time.' His expression changed slightly and there was a flicker of a smile for the first time when I asked him whether he would like to help me keep the animals safe by taking them home until we met again the following week. He slowly chose a family of farm animals, but did not comment on why he had selected them. He said simply: 'I like these.' I found a small box for them and said I looked forward to our next meeting. He held my hand tightly while I walked back with him to his class.
3.5.2 Keeping farm animals safe

Although he had been very withdrawn and reticent at our first meeting, Raama became more talkative at our subsequent sessions. He chose to share something of what he was experiencing through the voices and sounds of the animals he played with. I was reminded of Sharon’s story (Morgan 1999:23). By moving the animals in different positions in relation to each other, Raama explored what the different animals thought and felt in those positions and what actions they could take. Raama’s playing helped me to have a better understanding of how he perceived these relationships. It also allowed me to let Raama know that I acknowledged and valued his understandings and voicing of those understandings (:23). I took care never to rush or hurry Raama in any way during our therapy sessions. He continued to play in this manner for some months before he felt ready to share anything more with me.

‘There was a mommy cow,’ he said one day, as he fondly stroked the plastic animal and held it against his face, rubbing it up and down on his cheek and then his lips. He kissed it gently. He pointed while still holding the cow to his lips and said: ‘There was also a daddy cow and there were four children, a baby horse, a baby sheep, a baby pig and a baby chicken. This family all lived happily together on the farm until one night something terrible, very terrible happened to the mommy cow.’ I asked Raama whether he could tell me what was so ‘terrible’, using the same word as he had to try and let him know that I had listened and taken note of what he had said. He looked away and with no expression in his voice he softly whispered: ‘Someone came in the middle of the night and just killed her for no reason, she wasn’t naughty or anything – she was just killed. She was such a good mommy.’

He then turned to me and looked me in the eyes while a single tear rolled down his cheek. I put out my hand to him, not sure whether he would reciprocate my gesture of comfort or not. Not only did he take my hand, but he stepped towards me and almost fell into my arms, putting his little arms tightly round my neck. He remained holding on to me for some time before letting go. I was overwhelmed with emotion and cried bitterly. Later when I asked him whether he would like to continue telling the story he declined and said that he should be getting back to class. Raama never completed that story. Nor did he play with the farm animals again. I respected his decision. However, it seemed to signal a turning point in his journey of healing. It was as though Raama was to some extent moving towards a settled story where, in his own way, he had found a way of living with the death of his mother (Waldegrave 1999:179).
3.5.3 Grandparents hold a hand

I continued to meet regularly with Raama. After some months he started telling his facilitator that it was time for him to go and visit me and made his own appointments. Gradually Raama became happier, more confident and outgoing. It was at this stage that I met his maternal grandparents, Mr and Mrs Naidoo. They had received therapy after the death of their daughter, but had decided to join Raama when they noticed the difference in his behaviour. They mentioned that although their religion was Hindu they were not opposed to receiving pastoral therapy from someone outside their faith, as long as I respected their beliefs. When I enquired how I could best assist them as a pastoral therapist from a different religious background, they said: ‘We just want you to listen to us.’ I asked for their help to guide us as we travelled together so that our pastoral therapy journey would be mutually acceptable.

They did not mind that I started from a Christian perspective and said that they were sure they could only benefit from what we would share and learn from each other. We agreed to comment freely when issues arose that did not resonate with our respective religious beliefs. It was important to prevent a fragmentation of values and normative practices (Gerkin 1991:14) from occurring on both sides.

3.5.4 A pilgrimage from pain to hope

I confirm the stance adopted by Hudson (1999:34), who says that listening is an ‘essential component of the pilgrim attitude’. He (34) adds that it is almost impossible to show genuine concern, especially for those in pain, unless therapists first take time to listen. Anderson (1997:152) extends this by saying listening and hearing are vital reciprocal activities. Listening does not imply that therapists remain silent but that they are able to communicate their understanding of what is being shared. Weingarten (1995:16,17) speaks of ‘radical listening’. Pastoral therapists can contribute to the development of authentic voices by initiating an active and genuine stance of listening.

Ackermann’s words (1996:34) provided the inspiration needed by Mr and Mrs Naidoo. Ackermann (:34) says that belief in the role of human agency in the restoration of God’s creation lies at the heart of justice, love, freedom, equality and an abundance of righteousness.

Mr and Mrs Naidoo agreed that the above approaches foster good relations between people, irrespective of race or creed. The perpetrator of their daughter’s death had been acquitted of the murder charge on a technicality and they felt that justice, equality and righteousness had not been practised. However, they were determined that what had occurred would not prevent them from living their lives together with their
grandchildren in a manner that would 'mend creation'. I believe that narrative pastoral therapy provided the vehicle for Mr and Mrs Naidoo to tell the stories of injustice that they had experienced due to the apparently senseless and brutal death of their daughter. I confirm Reinhartz's (1992:136) stance that injustices can be righted when 'people tell their stories'. The production of an oral text may 'right the injustice' of a particular person's (or group's) voice being unheard. Elshtain (in Reinhartz 1992:136) makes the striking comments that one 'who bears witness voices the discontents of society's silenced, ignored, abused, or invisible members. The witness proffers reasons for that suffering in order that the silenced may find a voice, cry out for justice, demand to be seen'.

In this way Mr and Mrs Naidoo and Raama were able to join me in developing our capacity for love and loving (Isherwood & McEwan 1993:70). They agreed that when love is connected with becoming or concern for the becoming of others, that is for each other and also for their grandchildren, then love expresses a commitment to justice in the world (:70).

Together we felt that we had wove a tapestry of non-violent transformation and that I had moved away from asking the question whether something was Christian to whether something was healthy (Isherwood & McEwan 1993:83,86). Through the transformative interaction of dialogue, we were changed and could bring more to the continuous process of communication and co-operation (Knitter 1995:30). Mr and Mrs Naidoo commented that the accepting and non-critical attitude towards Hinduism that I had offered in pastoral therapy had assisted in the healing and restoration as a family so that they were able once more to take part in their normal social activities (Sevenhuysen 1998:131). Prior to therapy, their lives had been so torn apart that even everyday living was a problem. Mr Naidoo stated that previously, provision for their religious needs and desires had not been met in therapy. Nor had they found a place where they felt safe and secure (Gerkin 1991:118). He reiterated that the respect and acknowledgement of Hinduism shown them in pastoral therapy had opened a door and means to hope (see Weingarten 2000).

According to Campbell (1985:11,12), the goal of pastoral care is helping people to know love as something that is both given and received. I understand the reciprocal nature of care to be a communion of interdependence containing equal elements of reciprocal responsibility and reciprocal need (Firtel 1986:76). I experienced this to be the case in pastoral therapy with Mr and Mrs Naidoo.

3.5.5 ‘Talking to Mom Book’ – the extension of memories

Traditional forms of therapy concentrate on the different stages or phases of loss through death, such as denial, anger and acceptance (Kubler-Ross 1969). However, narrative pastoral therapy gave Raama the
opportunity to keep his mother's memory alive and close by, something he could reach out to, hold and talk to whenever he wanted.

During one of our conversations, Raama brought out a small photo album that he held closely to his chest. When I enquired whether he would like to show it to me, he proudly pointed to every photo of his mother explaining everything in the photograph in great detail.

Because of the special way in which Raama shared this photograph album with me, I wondered whether he might enjoy extending this to another activity such as a memory book that he could make during therapy. Before presenting Raama with the idea, I first asked his grandparents whether they were comfortable with the idea and checked that it would not be contrary to their religious beliefs. The suggestion carried their approval and they offered to become involved with the project at home as well. However, they felt that, as it had been my idea, I should approach Raama first, before they became involved with it at home.

I put the idea of a memory book to Raama at our next meeting. He seemed very eager and with a big smile declared that he thought it would be 'a very good idea'. 'I will call it my Talking to Mom Book,' he said. I watched with intense happiness as he designed the cover of his memory book, a warm feeling filling my heart at the obvious joy he experienced while painting. He decided to paint large pink flowers, saying that they were especially for mom, 'cause she likes pink flowers'.

Time was put aside during our following meetings so that Raama could work on his book of memories. Included in this book were various photographs of his mother. Raama chose the way he wanted to assemble the photographs. Between the photographs he included his own drawings and paintings of the family pets, the house and garden, cars and so forth. He also cut out and pasted in magazine pictures of his mother's favourite food, perfume, clothes, holiday places – in fact, anything he said that reminded him of her. This project continued over some months, and, in spite of his grandparents’ offer to help him at home, Raama refused their assistance. He wanted to complete it on his own during therapy.

I wonder whether the value of this project will ever be fully realised. It gave Raama and me an opportunity to explore and co-create narrative pastoral practice in a way I had previously not considered. Raama’s memory book provided an extension for maintaining an ongoing relationship with his mother, entertaining a notion of connection that had an 'impact on many aspects of communication, functioning and relationships' (Waldgrave 1999:179). In addition, something special and remarkable happened as a result of Raama's 'Talking to Mom Book'.
3.5.6 Learners for Learners Caring Club

When I asked Raama whether I had his permission to tell other young people about his project, he agreed wholeheartedly. Before taking it home, he showed it to his grade class and other classes, so that, according to him ‘they can see that we don’t only talk when we come and visit you, we do things too’. It is thanks to Raama that a number of other young learners also became interested in making memory books. Raama was one of the first children to become involved in the ‘Learners for Learners Caring Club’. Shortly after joining, he enthusiastically became one of the leaders for that age group. Raama seemed to flourish with this responsibility and took his new position seriously.

3.5.7 Time to say good bye

When Raama had completed the memory book to his satisfaction and was ready to show it to everyone at home, he proudly announced: ‘I don’t think I need to come and talk with you anymore.’

The sad look on Raama’s face at the start of therapy and the withdrawn behaviour that had attempted to control his life in so many ways had been transformed over a period of eight months. Raama returned to his former self, a happy, smiling lad who was talkative, confident, eager to learn and actively involved in class. His grandparents confirmed that the same applied at home.

I was reminded of Gerkin’s (1997:238) comments on maintaining communities of memory. I wondered whether Raama’s memory book and the acknowledgement that he received at school from facilitators and peers alike had tied him to a community, a community of caring, offering him the comfort, meaning and security that ‘sacred places’ can provide.

3.6 SANDILE GOES BAREFOOT

3.6.1 Away from home – a better education

Sandile, a Grade 5 Sotho-speaking learner, was referred for counselling by her class facilitator. It was felt that she was just not settling down and adjusting to her new school as expected. She was unable to do her schoolwork and homework, never spoke and was often in tears. With the assistance of an interpreter, I discovered at the end of our first therapy meeting that Sandile had previously lived in a rural village in Venda with her caregivers, siblings and extended family. She had been sent to school in Pretoria to receive what her caregivers believed would be ‘a good education in the city’. Sandile lived in a child-headed
household with a group of other young children. The eldest was seventeen years old (see Basson & Kaiser 2001:15). Having been brought up and educated in her mother tongue, Sandile could barely speak or understand a word of English.

3.6.2 At the doll’s house

During our first conversation, Sandile stared blankly at me, nodding and shaking her head intermittently, not saying a word. I used many hand signs and gesticulated profusely – eventually Sandile chose to play with the doll’s house. I sat next to her and following her suggestion, played ‘Barbies’ as well. We did not allow the lack of a common language to stand in the way of communicating with one another. What struck me most during that conversation was that, in spite of the tangible sense of loss she experienced through separation from loved ones, Sandile still maintained a sense of humour. Towards the end of the session, she found it amusing to watch my demonstrative attempts in trying to communicate with her in some way. What we lacked in language skills was compensated for by Sandile’s soft giggles at my actions. Sandile held my hand tightly while I walked back to class with her after our first therapy meeting. At her classroom door she turned, gave me a hug and waved goodbye.

At our first meeting and in many others to come, Sandile and I shared a great deal, simply by sitting side by side in front of the doll’s house playing together. It was at the doll’s house that pastoral therapy and our first English lessons began. Feeling secure there, she shared with me the extent of her loss through separation from her loved ones, even though in the beginning she was unable to use words that I could understand. The expression on her face and the sounds she made while playing with the dolls were an indication of her intense sadness and loneliness. Playing house enabled me to enter her world of separation from her loved ones. From her play it was obvious that even when Sandile went ‘home’ after school she felt lonely and isolated, lost in a world of despair and at times without hope.

Sandile taught me that pastoral care and therapy do not depend on a particular language – something I had not realised before. While playing with the toys: farm animals, dolls, kitchen utensils and dress-up clothes, Sandile introduced me to her way of life back home. Playing in this way, with me close at her side, she created her own metaphor for ‘saying hullo again’. Using this metaphor, she demonstrated how distraught she felt when taken from a rural community and way of life with close family ties to an alienating and disconnected existence in city life. Her identification with and obvious delight in playing with the doll’s house extended what she considered necessary for re-connecting with her family in Venda. Because of the language difficulty, I did not ask her questions related to the ‘saying hullo again’ metaphor. I believe that supporting her and being there with her while she played assisted her own interpretation of maintaining a
relationship with her loved ones. After a number of occasions of meeting with me in this manner, she felt confident enough to start speaking English to me. Her first words were: ‘I like it here with you. I am with my family and talk to them here’.

3.6.3 ‘My foots get angry’

Among many other adjustments to urban school life, Sandile found it very irritating in the beginning to keep on her school shoes for the duration of the entire school day. I was forever intervening on her behalf so that she would not get into trouble for longing to be barefoot in class. When she was able to speak a little English, she would say to me, ‘You don’t understand – my foots they get so, so angry in shoes. My foots, they get too hot.’ Bridging cultural differences is an aspect of pastoral care with Sandile that required me to ask her facilitator to allow Sandile to go barefoot in class. It meant so much to Sandile to be able to wriggle her feet round freely on the floor in class and to feel the grass on the playground. I feel sure that if Sandile had had the necessary vocabulary she would have described the reaction of her feet in her shoes as one of ‘claustrophobia’.

Sandile’s incredible patience and understanding, her determination and perseverance in learning to speak and write English and her ability to adjust to her new home life and school enabled her to honour and respect what was expected and required of her by her caregivers. Sandile needed to know that she had not disappointed or let them down in any way, because, as she was eventually able to tell me, ‘it’s a privilege to get a decent education’. Because Sandile seemed to be concerned that her parents should know about her progress at school apart from her school reports, I offered to write to them and let them know that they could indeed be proud of their daughter.

Learners in Grade 5 are still required to bring items from home to school and I offered to help Sandile with these requests (empty containers, wool, material, paper, etc). Sandile was keen to participate in a fashion show held at school for the ‘Mother and Daughter Tea’, but was upset because her mother would not be there. Together, other facilitators and I attended the function with her and ensured that it was a memorable occasion for her. I made sure that her photographs from the tea were posted to her parents with an accompanying letter and drawings from Sandile.
3.6.4 Doing hope with Sandile

Hope is something too important — its effects on body and soul too significant — to be left to individuals. Hope must be the responsibility of the community. Where this is so, and when this is so, there will be a sense of wonder, which has been called the abyss where radical amazement occurs. There is an abyss. Often. We can look across or we can look in. We can find ourselves in it or know others who are. When we enter the abyss, when we see it, then radical amazement is ours. Ours. Together. With hope.

(Weingarten 2000:402)

I believe that in crisis situations such as that experienced by Sandile, it is not their responsibility to do hope for themselves (402). Instead it is the responsibility of others who love and care for them to do hope with them. As a pastoral therapist, I believe that I have a role to play in doing hope with people at school. In the same way that schools should act as communities of care, concern and acknowledgement (Basson & Kaiser 2001:16), they should also act as communities of doing hope with others. Networking with facilitators so that together we do hope with others, especially children, has created a crucible of care and hope being practised at school.

It was my duty when journeying together with Sandile to continuously do hope for and with her. It is particularly children in crises who look for and need a sense of hope and promise (Lester 1987:46). I regarded it as my responsibility to liaise with facilitators to ensure that we constantly did hope with her in a variety of ways.

Weingarten (2000:401) gives a further reason for doing hope with people. She comments that ‘higher hope’ people feel more positive and experience more positive thinking than those with ‘lower hope’. Studies have indicated that children with ‘high hope’ are able to associate themselves with positive events in their environments, while distancing themselves from negative issues in their lives. In children, higher hope results in increased feelings of competency and reduced feelings of depression (401).

3.7 REFLECTIONS

It is the uniqueness of the way in which stories evolve in counselling sessions that invites me to regard narrative pastoral practices as challenging and exciting. These stories have had an impact on my own life and therapy, changing me by leaving an indelible stamp of the courage and hope I witness from my conversations with children. I agree with Reinharz (1992:194), who says that, ‘although changing the researcher [therapist] is not a common intention in feminist research, [therapy] it is a common consequence’. She adds that many feminist researchers relate that they are deeply changed by what they learn about themselves (:194).
Counselling at the primary school where I work helped me to connect with the everyday suffering and healing of children. For me, this commitment resonates with contextual and feminist theologies which advocate giving a voice to the voiceless. My beliefs honour bell hooks (2000:67), an African American feminist, who says: 'To experience solidarity we must have a community of interests, shared beliefs and goals around which to unite...Solidarity requires sustained, ongoing commitment.'

Chapter 4 challenges the effects of a chronic illness in the life of a young person with diabetes. Addressing diabetes, epilepsy and HIV/AIDS in an informative manner forms part of this chapter.
CHAPTER 4

CHALLENGING THE EFFECTS OF CHRONIC ILLNESS IN CHILDREN

4.1 INTRODUCTION

In my work as a pastoral therapist I was faced with the impact that chronic illness has on learners and their families. Chronic illness challenges the human spirit. Seriously ill children are faced with issues well beyond their years. For families it is heartbreaking to have a child compromised by severe illness or disability just when children should be at their most carefree. As a pastoral therapist I provided an opportunity for some learners to explore and co-author ways of challenging the effects of their chronic illnesses. Together we created contexts in which helpful conversations took place (Weingarten 2001:111-125). I was inspired by the courage and perseverance these learners and their families brought to bear on a potentially devastating life circumstance.

The Education White Paper – Special Needs Education (2001) outlines a policy of commitment to the provision of educational opportunities. This envisaged policy is particularly directed at those learners who experience or have experienced barriers to learning and development because of the inability of the education and training system to accommodate the diversity of learning needs, and for those learners who continue to be excluded from it. I agree with this policy described above because inclusive and caring practices at school are essential if the needs of all learners are to be considered. Ballard (1994:19) warns: ‘The call for the right to inclusion in schools and communities should not be misunderstood as a move to hide disability or to pretend that everyone is the same. Inclusion is not a policy of assimilation but of valuing diversity.’ The wishes of parents and children with disabilities (:18,19) are often ignored in professional assessments of ‘needs’, especially in education. Ballard (:19) cites Ferguson, who comments that ‘[f]orced separation can never be equal, and equal separation can never be forced’.

4.2 THE VOICE OF ILLNESS

Learners with diabetes, epilepsy and HIV/AIDS experience these illnesses as especially difficult and challenging to manage. As they start school, chronically ill learners have to assume a more active and responsible role in the control of their illness (Wood 1995:443). To interact and negotiate directly with school personnel without the assistance and support of their parents can be daunting for these learners. I became involved in the increasing autonomy or personal boundaries of these children and also with
facilitators and peers who needed understanding regarding the illness and ways of assisting children with illness.

I have an ethical commitment to participate in transforming the school culture towards more ethical ways of being. In this regard the pastoral practice of mutual care constituted my pastoral participation. The area of chronic childhood illness challenged me to work towards a culture of mutual care. Children with diabetes, epilepsy and HIV/AIDS experienced exclusion, marginalisation and teasing. Chronic childhood illnesses are not unique to a particular school, but are present at all schools. It is hoped that sharing these illness narratives will benefit the narrators as well as the listener(s) and that this will contribute to a more tolerant, inclusive and just society (Waldegrave, 1990:5-25).

In the rest of this chapter, I introduce Sue's journey with diabetes and then look at HIV/AIDS and epilepsy in schools.

4.3 DIABETES

Sue's journey with diabetes does not follow a progressive illness narrative – what Weingarten (2001:121) refers to as the 'darling' of illness narratives, but rather a chaotic one (:117). This chaotic narrative reflects the disruptive influence of diabetes on Sue's life. Sue aptly describes a chaos narrative when she says: 'It's as if my whole body is out of control and no matter how hard I try, there is nothing I can do. It feels like I'm speeding down the wrong way in a one way street and all the cars are hooting at me, but there is nothing I can do, I have no breaks.'

Diabetes mellitus or Type I diabetes is also referred to as 'insulin dependent diabetes' (Brackenridge [s a]:10). When diabetes occurs in children, it is most frequently Type I (where the body produces little or no insulin). Because of this, sugar cannot enter cells to be used for energy. When insulin is absent, blood sugar remains high. Insulin injections are essential in the life of a Type I diabetic. In Type II diabetes, the body makes insulin but cannot use the insulin it produces. Type II is also called 'non-insulin-dependent diabetes' because people with this type of diabetes do not have to use insulin to live (Brackenridge [s a]:12). The learners with diabetes at the school where I work all have Type I diabetes.

4.3.1 Travelling with Sue

Sue was an eleven year-old learner with Type I diabetes when we first met. The effects of teasing and unkind remarks by learners at Sue's previous school had had an impact on her life and affected her health.
This resulted in difficulty controlling her diabetes and she was either frequently ill at home or was in hospital. Emotional stress of any kind, especially conflict situations in relationships, can rapidly elevate blood sugar levels with serious consequences (Williamson 1997:244). Sue and her family experienced resistance from Sue’s facilitators, who would not understand the implications of diabetes. Unable to change the culture of the school, Sue’s parents felt forced to transfer Sue to a different school.

I am the pastoral therapist at Sue’s new school and met Sue and her parents on the first day she joined our school. When Sue enrolled, the school secretary learned about the difficulties Sue had experienced at her previous school and offered my services. Sue and her family were very happy to learn that in addition to the individual therapy offered at school, I had created a support group for learners with diabetes who met with me regularly. Sue was welcome to join us.

Sue and I held hands as she guided me through her journey with diabetes. She was well-travelled, having been down many roads before. She did not require a map, for she knew the routes only too well. Sue described diabetes as a series ‘of road signs’. She said: ‘Some are regulatory and they’re awful, others are warning and are not that bad, but the best are information road signs. The signs follow no real order and I can’t say what comes next.’ It is within this context that I invite the reader to join Sue’s journey ‘of road signs’.

4.3.2 Regulatory sign: unpredictability of diabetes

Because of the unpredictability of the effects of diabetes I realised that children with diabetes require more than individual therapy and support group meetings. They need the security of knowing that they can receive immediate physical attention as well. I therefore liaised with facilitators and secretaries for learners to come directly to me when necessary, instead of reporting to the office and being referred to the sickroom where they might remain unattended to and alone for some time. Because there is no staff member permanently employed in the sickroom to attend to ill learners, the secretaries were more than happy for me to assist learners with diabetes. I have a glucometer and ketone testing kit in my office and have been given written permission by parents to assist children in emergencies. Realising how quickly problems relating to diabetes occur, I contact parents whenever a learner with diabetes reports that he/she is feeling ill. I remain with the learner until the learner is fetched from school. Parents appreciate the care given to their children. In this way a special relationship develops not only between learners and myself, but also between myself and their parents.
4.3.3 Information sign: Diabetes informs a therapist

I made a concerted effort to learn about diabetes from learners and their parents. In addition, I read appropriate literature and spoke with doctors and nurses who specialise in the treatment of childhood diabetes. This helped me to understand the different terms learners used when talking about diabetes. I also learned about the complications of the illness. During our first meeting, Sue said: 'Thank goodness, somebody knows at last what I am talking about.' Ketone and blood glucose levels, insulin dosages and hypo/hyperglycaemia or 'highs' and 'lows' are terms frequently referred to in my office. My being able to join in and understand what learners are referring to has encouraged rapport in counselling (White, Kolman, Wexler, Polin, & Winter 1984:749-755). I believe that what Levine (1997:71) refers to as the 'therapeutic space' was affected by my understanding of diabetes. Sue and her family commented that my knowledge about diabetes contributed to Sue's adjustment to her new school. Sue felt that at last that someone outside her family had made an effort to join in her experience of diabetes.

4.3.4 Information sign: learners teach facilitators

Children in the support group for diabetes took turns to bring various magazines on diabetes to our meetings, for example, articles by Pullen (2001); Mazur (1999); Thompson (1998). Children were given an opportunity to discuss articles and aspects from these magazines and to give their points of view. Inviting facilitators to join us at group meetings offered learners a rare chance of being the experts and for a change to teach adults about their illness (White 2000:3-24). Including facilitators in this way led to a new understanding by the facilitators and respect for the problems and issues regarding diabetes. One facilitator remarked: 'I didn't realise all these issues about diabetes and its difficulties before listening to you.' Trusting and believing, listening, responding and honouring children's stories became important elements in co-authoring new conversations between learners and facilitators as suggested by Anderson (1997:140-165).

4.3.5 Warning sign: label jars, not children

I was moved at our first meeting by how important it was for Sue to be treated like an 'ordinary kid' by learners and facilitators alike. For a long time afterwards, her words reverberated in my head -- she expressed a desire to be regarded 'as an ordinary child who just happens to have diabetes and not as a diabetic child'. Similar experiences were mentioned by other children with diabetes. Their wish was one of the reasons why the support group was not referred to as the diabetic support group, but was instead referred to as a support group for learners with diabetes.
Sue said: ‘I work hard to stop diabetes giving me a label of being different. Just because I do something differently doesn’t mean that I can’t do it’. Her comments resonate with those of Szczesniak (1997:40,41). Ballard (1994:18) expounds on the concept of labelling, saying that what often occurs is that in the ‘sickness or medical’ model, people ‘are labelled as damaged’ or inadequate and are consequently viewed almost exclusively in terms of their ‘problems or deficits’. Commenting on the language of disability, Ballard (1994:13) says that, because labelling creates difference, it has the ability to encourage discrimination, adding that ‘jars ... should be labelled and not people’.

Because chronically ill children often have no say over their own bodies, their psychosocial competency and development of autonomy may be hampered or delayed (Wood 1995:441). Children often think of themselves and identify themselves to others, as ‘a diabetic’, for example, instead of focusing on their talents or skills. According to learners with diabetes, an important aspect of individual and pastoral group therapy was spending time co-creating different ways of removing ‘diabetic labels’ from their lives. Learners with diabetes welcome anything that cuts diabetes down to size and that allows them to feel that they are who they are despite it (Weingarten 2001:112). Sue remarked that God was the one person ‘who loves me just as I am’.

4.3.6 Information sign: God-talk

Sue said that she and her family ‘knew God’ and that they gained strength from their relationship with God. Ann, Sue’s mother, confirmed her daughter’s active role at Sunday School and at Junior cell-group. I asked Sue and Ann whether their conversations with God had changed in any way since Sue’s diagnosis of diabetes. They both nodded and Sue said: ‘We always knew God, but now we know Him in a different way. He gives me the strength I need to get through every day – even the difficult days when diabetes tries its best to get the better of me’. Asking questions about God-self relationships is a way of learning and speaking the language of the person consulting me and is an important ‘aspect of our effort to cast therapy within the world of meaning in which the [clients] and families live’ (Goolishian in Griffith & Griffith 1993:6).

Informed by narrative practice (White & Epston 1990), I asked Sue questions such as these: ‘What does God see, looking at you?’ ‘What do you think God says when you get through a difficult day?’ ‘In what ways can we use God’s strength to help us inform others about diabetes?’ ‘Who first told you the things you know about God?’ ‘What would you like to tell the person who first told you about God?’ ‘The relationship you have with God – what does it say about who you are as a person and what does it say about the values you choose and stand for?’ Sue seemed intrigued by these questions and came up with interesting and challenging ideas. So, for example, she asked me whether I had ever been cross with or had blamed
God for something? Did I think it was wrong to get cross with God sometimes? Did I know ways of preventing this from happening? Why did God allow children to have diabetes and in what ways could we ask God to stand with her against diabetes? Together we co-searched for ways to invite 'healing spiritual talk' (Andrews & Kotzé 2000:322-339) into therapy by exploring new spiritual meanings and understandings from these questions.

Sue frequently asked me to close our sessions with prayer. I saw this as a contribution that I could bring to the therapy session (see Heitink 1999). I realise that prayer during therapy does not necessarily make the therapy pastoral. When prayer is used, it should be in terms of contextual interpretation 'reached through dialogical conversation...that both partners in conversation subscribe to' (Myburg 2000:80). In reflecting on the value of dialogical conversations long after they have passed, Brueggemann (1993:62), comments that '[t]he voiced text continues in our zone of imagination' (62) as new constructs emerge. Roth (1995:142) comments that in conversations relating to God, pastoral therapists are challenged ‘to honour the indeterminacy of the relationship by open-heartedly receiving that relationship into the room, by believing that it holds numerous possibilities for movement, and by conversing in a way that brings forward its many possibilities’.

It was my responsibility to facilitate the maintenance, further development and deconstruction of Sue's spiritual story. My dialogue with Sue turned to her tradition and facilitated the growth and creative development of her particular life stories (see Gerkin 1997:113). By choosing to position myself with Sue, I respected the uniqueness of her experience of diabetes. I agree with Boyd (1996:2), who says that a 'spirituality of listening' or 'agape-listening' suggests that caring means conversations that help both therapist and client. Agape-listening 'initiates us into a deepening experience of spirituality' that calls us to openness to the client's reality as well as to 'learning something for ourselves from that same experience' (Boyd 1996:97). Realising the important role that religion played in Sue's life, I adopt the stance of Ross (1994:8), who argues that disregarding the religious and spiritual components of clients' lives can prevent the development of a therapeutic alliance.

In re-symbolising Christ as the disabled God, Eiesland (1994) explores a liberation theology of disability. She urges churches to examine theological attitudes and practices regarding disability that limit rather than empower, that segregate instead of including. Eiesland (1994) also discusses alternative theological practices and attitudes that promote inclusion, recognition and acceptance by able-bodied society and churches. Gutierréz (1988:147) aptly captures the notions of Eiesland (1994) when he says: 'As a sacramental community, the Church should signify in its own internal structure the salvation whose fulfillment it announces. Its organisation ought to serve this task...the Church itself in its concrete existence.
ought to be a place of liberation.' I consider it to be my responsibility when I speak with Sue and other learners with chronic illnesses to co-search for alternative structures and symbols of religious life that question oppressive beliefs and values regarding chronic illness and disability. Similarly, deconstructing religious beliefs and practices that maintain structures of stigmatisation and marginalisation are equally important in conversations regarding chronic illness and disability.

4.3.7 Warning sign: chaos' narratives

When Sue and her mother, Ann, shared some of their stories with me during our first meeting, I enquired whether sharing their experience of illness narratives with me would be helpful to them (see Weingarten 2001:111-125). Ann commented: 'Gosh, nobody ever wants to listen to our stories of diabetes.'

Weingarten (2001:114) emphasises the telling of illness narratives as important steps for empowering a person with an illness. Weingarten (:121) applies Gergen's (1994:196-197) description of types of stories, classified by their plot, to illness. The interrelationships between plots, character roles and themes or values determine whether narrative coherence is established or not.

Ann commented that the learners and facilitators at Sue's old school had not given diabetes a place; they did not want to listen to Sue's illness narratives (see Wright, Watson & Bell 1996:171). Sue, her family, friends, the school community and medical personnel all played a part in her illness narratives. People want to hear a restitution or progressive narrative where Sue's story features modern medicine as the star and where recovery can be almost guaranteed (see Weingarten 2001:117). Sue tried to speak to friends at her previous school about what it was like for her to live with diabetes. Their response was similar to that described by Boyd (1996:97): 'We have enough troubles of our own, we don't want to hear about yours as well.'

Because diabetes is a chronic illness and there is no cure, it is difficult to create a progressive narrative. At her previous school, Sue's story of diabetes had been a chaos narrative (Weingarten 2001:117). No matter how she tried, her inability to control her glucose levels increased and Sue's experience of diabetes was that of 'a run-away car'. Not only did Sue feel helpless in controlling her diabetes, she was also denied an opportunity to tell her story as she experienced it. Her experience was similar to that told by Grobbelaar & Ann (2001:85). Pressured into remaining silent at school, Sue carried the burden of her illness alone. Again her experience was similar to that of others (White & Epston 1990:16). Sue believed that diabetes did not allow her any form of support from her friends, who refrained from 'speaking the unspeakable' (Wright et al 1996:188).
She reacted by withdrawing from friendships, becoming an unhappy loner. The rejection and marginalisation she experienced led to stress. This resulted in ‘chaotic’ glucose and ketone levels, dangerously complicating the effects of diabetes that were already difficult to control. Sue was forced to spend a lot of time at home or in hospital. ‘Illness is huge. Illness, or more accurately, our relationship to it, threatens the way we know ourselves and how others know us also’ (Weingarten 2001:112). I listened to how diabetes had invited uncertainty into Sue’s relationships both at school and outside her home. At school, learners and facilitators were unsure of what to do and how to understand diabetes; they did not know how to ‘know’ her (p.112). For Sue, the diagnosis of diabetes threatened her identity as a young teenager and as a daughter. Her parents felt helpless when people introduced them not as Sue’s parents, but ‘the parents of the diabetic girl’.

A regressive narrative usurped what little energy the family had to manage the diabetes. In a society where the discourse of individual performance is valued, people want to hear a progressive discourse, but will bear with a stability narrative. Sue spoke to me of the need to be considered as ‘a normal kid’ because stigmatisation and marginalisation had left her feeling ‘labelled and different’. A dominant story of rejection, marginalisation and a chaos illness narrative directed many of Sue’s conversations when she started therapy (White 1989:5; White & Epston 1990:30).

I experienced a connection to the overwhelming effects of chronic illness described by Sue and Ann and remembered how at times the problem-saturated description of Multiple Sclerosis had been the dominant story of my life. Having been married for twenty-three years to someone with Multiple Sclerosis, I had taken a long journey with chronic illness, a journey in many ways similar to that of Sue and Ann. I identified with so much of their experience of chronic illness. They allowed me to share with them my personal story, a story that informs my therapy practice and the life I live (see Weingarten 1997:xi).

4.3.8 Warning sign: Diabetes the chairperson

By deconstructing problem stories through externalising conversations1, a narrative therapist provides opportunities for the development of new and different stories by which the client wants to live (Epston 1994; Freedman & Combs 1996). My commitment to practise pastoral care as I really listened to Sue, trying to understand the stories of her life and working with her complementary stories resonates with what Morgan (2000:2) says about narrative therapy: ‘Narrative therapy seeks to be a respectful, non-blaming approach to counselling and community work, which centres people as the experts in their lives. It views

1 If a problem is externalised and personified, I write it with a capital letter, for example, Diabetes, Testing Regularly, Correct Eating and Exercise. This practice reflects a trend found in narrative literature (Kotzé 2000).
problems as separate from people and assumes that people have many skills, competencies, beliefs, values, commitments and abilities that will assist them to reduce the influence of problems in their lives.’ Narrative therapy led me to regard Sue’s life as a story ‘and to work with [her] to experience [her] life stories in ways that are meaningful and fulfilling’ (Freedman & Combs 1996:1).

Sue and I used externalising conversations to talk about the influence of Diabetes in her life. Sue spoke about what Diabetes had attempted to ‘steal’ from her. She said: ‘It has tried to steal everything from me – my pancreas, my health, my energy, my sport activities, my choices and my independence. I can’t even decide what and when to eat – Diabetes does that for me.’ Sue remarked that she did not have a choice to lead a normal life because of the constant reminder of illness that tried to control and dominate her world. She said that syringes, needles, lancets, glucometer, insulin, insulin pen and reactant test strips such as ketodiatistix monopolised her entire being. They went wherever she went. ‘I can never go anywhere without my bag of medicine things. It almost feels like I’m stuck to this bag – like it’s part of me. My life and body don’t really belong to me. They belong to Diabetes and this bag. It feels like Diabetes owns all of me. It just leaves no room for me.’

At that stage it seemed that Sue’s illness story mirrored what Frank (1998:197) refers to as ‘deep illness’ – illness is ‘deep’ when it is regarded as permanent, affecting almost all choices and decisions in life and changing one’s identity. Adopting an attitude of deconstructive listening, I tried to make space for aspects of Sue’s life where she had been in the driver’s seat regarding Diabetes (see Freedman & Combs 1996:46). Threads of pastoral care and narrative pastoral therapy were incorporated in a slowly developing progressive narrative journey. Over time Sue related more to her life narratives as actively constructed stories where she played some role and shaped the course of her life without Diabetes trying to overtake her. However, choosing to privilege these voices over the more problematic voices of Diabetes did not discount the previous attempts that Diabetes had made to make Sue feel invisible.

4.3.9 Information sign: co-creating visibility

Although Sue’s experience of invisibility at athletic meetings was no longer part of her life, it still bothered her and she expressed the desire to talk about it during our therapy. She remarked: ‘People just didn’t see me, they didn’t hear me.’ This had occurred during sport meetings at her previous school where, according to Sue, ‘normal children’ competed and had fun. Sue, on the other hand, struggled just to get out of bed and to drag herself to school, often having to check glucose and ketone levels and inject herself during the course of the morning. Ann heard comments from caregivers about ‘how energetic and well-trained and practised their children were’. Sue was simply not seen, only athletes who achieved were acknowledged.
and rewarded. Sue received no recognition for even taking part. Greenspan (1998:45) relates that in similar circumstances she and her daughter felt like ghosts, their presence was ignored. She (44-45) comments that ‘this closing off on the part of the able-bodied keeps both child and mother on the periphery of consciousness, the outside edge of everything we call “normal life”’. 

Sue spoke about the visibility and affirmation she experienced at her new school. Regarding athletic events, she commented: ‘I know I can’t win, but it makes a big difference when I get noticed and thanked for taking part. It makes me want to try even harder next time.’ Sue’s association with inclusion and acceptance gradually cleared the road ahead for more experiences of a stability narrative. However, a road sign warning – the hospital ‘gaze’ – attempted to disrupt the journey.

4.3.10 Warning sign: the hospital ‘gaze’

Learners in the support group for diabetes expressed their feelings regarding doctors and the medical fraternity in general. I was surprised by how well-informed they were. One of the group members said: ‘You must understand that when you have diabetes you spend a lot of time in hospitals and at doctors and there is nothing you can tell me about them.’ Children with diabetes experience themselves as ‘veterans of the medical system, each with their own bag of medical horror stories’ (Greenspan :52). Type I diabetes makes children highly medicalised and this is one of the primary causes of marginalisation for them and their families.

Greenspan (:52) says that generally, mothers are responsible for taking their children to doctors. Mothers are the ones who have to brave the challenges and limitations of the medical order in relation to a child who is dependent on the system. This was confirmed when I spoke with mothers of learners with diabetes. They commented that doctors frequently ignored their own and their child’s knowledge and insight concerning diabetes. Children were seldom consulted about their fears or preferences and this resulted in mothers feeling inadequate and unable to protect their children. Together we co-authored ways that doctors could regard mothers and children as partners in the treatment of diabetes. Because a ‘cure’ for diabetes is not possible, they agreed that co-operative management was essential. The scope of this research project did no allow for submission of these suggestions to doctors. However, these issues will receive attention in the future.

Mothers and children commented that doctors and medical staff in teaching hospitals seemed to be permanently watching and maintaining control when children were admitted to hospital. Referring to hospital patients and professors, Fillingham (1993:66), writing on Foucault says: ‘The professor of medicine
becomes a very powerful figure...he walks from one [patient] to another, turning his all-powerful eye on each one.' A kind of active vision, what Foucault (1973:107) calls 'the observing gaze' or 'The Panoptican' (1977:195), is exalted to great importance in medicine. The idea is that patients are isolated in a small room, where they may all be constantly kept under surveillance by the doctor from a central control area, 'an unbroken succession of observations' (Foucault 1980:157). Foucault (1973:109) also says that '[i]n such a domain everything must be possible' from the doctor's point of view. In the experience of the families I consulted with, in academic hospitals, professors, medical personnel and medicine assumed powerful and knowledgeable positions. The attitude of superiority and 'all knowingness' held by medical personnel towards patients and their families resulted in children and families being silenced and marginalised. Referring to the hierarchy of knowledge in hospitals, Foucault (1973:60) says that 'it is understandable that the clinic should have had only one direction – from top to bottom, from constituted knowledge to ignorance'.

Parents wondered whether their knowledge and understanding of childhood diabetes would be valued and accepted by doctors and staff at private hospitals. However, due to financial constraints they had no option, but to accept treatment at academic hospitals and to regard it as part of their contribution to the knowledge of others (Foucault 1973:83). Foucault (1973:83) raises a pertinent question: 'by what right can one transform into an object of clinical observation a patient whose poverty has compelled him to seek assistance at the hospital?'

4.3.11 Information sign: Diabetes takes a backseat

Individual pastoral therapy and care as well as interest and understanding from members of the support team helped to unlock Sue's voice and illuminated the road towards a progressive illness narrative. Through externalising conversations (White 1989; White 1995a; Freedman & Combs 1996; White & Epston 1990; Morgan 2000), we challenged the stronghold of the dominant story so that Sue slowly recognised and related to a progressive narrative regarding Diabetes. She gradually loosened the controlling position Diabetes had on her life and gained her place in the driver's seat. I involved facilitators by inviting them to our group support meetings. This played an important role in the support and understanding Sue received at school. Likewise, there was a big change in the attitudes of learners and facilitators after I arranged for Sue to give a talk and demonstration in class about Diabetes. Classmates and facilitators were almost spellbound as they listened to Sue speak about Diabetes and watched while she tested her blood glucose levels and injected herself with insulin. Facilitators and learners initiated a willingness to listen and learn about diabetes from what Sue shared with them that day. This resulted in a better understanding of
Diabetes. Adjustments were made in class to accommodate Diabetes so that Sue felt more accepted and included at school. For example, learners began to respect Sue as the 'expert' on Diabetes and refrained from telling her what to eat and not eat, they no longer thought that she wanted to 'bunk' class when she needed to inject insulin or needed to lie down in the sick-room. Some learners ensured that at parties there was something that Sue could eat and they consulted her regarding hospitals and doctors accepting her knowledge on these matters 'as the best'.

It was at this stage that Sue began to refer to therapy as a 'Grand Prix' because she believed that it provided her with the opportunity to change positions on the track. Whereas previously she had felt that her car skidded and went out of control much of the time, she now felt that she was mostly in the winning lane. In the chaos position on the track she felt invisible, silenced and marginalised. Sue's 'Grand Prix' gave her a chance to co-author ways of inviting a stability narrative into her life where visibility, a voice and acceptance at school made her 'the normal kid' she desperately wanted to be. In addition to experiencing acceptance and inclusion at school, it was also important to Sue that a preferred story of her life carried God's approval.

Narratives around spirituality can offer choices for alternative stories (Andrews & Kotzé 2000:329). From what Sue had previously shared with me regarding her relationship with God, I was challenged to proceed tentatively while listening for the other 'not yet said' spiritual stories. I wondered whether the conversations about 'God's approval' could lead to 'meaning creating' talk where Sue could be invited to explore new spiritual meanings and understandings of her recent experience of inclusion and acceptance at school. I agree with the notions of Griffith (1995), set out in Opening therapy to conversations with a personal God, that in therapy with clients suffering medical illness one should attempt to open up space for the most significant conversations to be heard and understood in the sessions. The client's significant conversations may also form part of their 'inner dialogue' (Andersen 1993). 'These conversations are often organised around important intrapersonal discourses that cannot be publicly expressed with safety, that is secret understandings that cannot be spoken' (Griffith & Griffith 1993:6). I asked Sue questions about this inner dialogue. Therapy provided an opportunity for Sue to speak about personal spiritual issues that she did not wish to discuss publicly in class. These conversations led to new self-narratives that had a healing effect (1993:6). In our conversations, space for personal agency was created by asking questions such as: 'If God were to look at your situation at school now, what would He see and say?'

One day, during a group meeting for learners with diabetes, I asked how we could extend other learners' understanding of Diabetes. We thought about this and came up with the suggestion of a play written by the 'experts' on Diabetes (see 4.6.1). The play assisted Sue to secure a stability narrative in her life that later
paved the way for a progressive narrative regarding the negative effects of Diabetes. I understand that because Diabetes is a chronic illness and cannot be cured, a progressive narrative was aimed at minimising the negative effects of Diabetes in Sue’s life.

4.3.12 The checkered flag

The play resulted in new and different perceptions of Diabetes for facilitators and learners in an entertaining and playful manner. Further understanding, acceptance and friendship given to Sue after the play consolidated a progressive narrative in her life so that the negative effects of Diabetes have been minimised. Sue has only been hospitalised once in the two years since she started at her new school and has spent a minimum of time ill at home. According to Sue, her biggest dream has been realised: ‘I have become just another kid in class and am treated like everyone else.’

I experienced a warm and content feeling when, as Sue put it: ‘I think I have reached the end of my journey of road signs with you. Now, I see plenty of the “information signs ahead”’. Accompanying Sue on her journey enriched my life in so many ways. Her courage and determination will always remain with me.

A journey of a different kind that I travel silently with children and their caregivers is HIV/AIDS.

4.4 THE SILENCE OF HIV/AIDS

4.4.1 Introduction


4.4.2 Co-searching ways of breaking the silence

In spite of the Gauteng Education Department’s having issued all State schools with an HIV/AIDS policy, very little has been done to implement it. The stigma and secrecy attached to the illness and a lack of funds and resources for the programme also causes difficulties. Unfortunately, this results in the silencing of the very voices that need to be heard. Caregivers are not forthcoming with information regarding children
infected with HIV/AIDS, because they fear that the children will be ostracised and marginalised or even refused admission to school (Black 1993:355-369).

Engaging in issues associated with learners with HIV/AIDS and their families as well as caregivers with HIV/AIDS whose children are unaffected is something not routinely or regularly considered at schools by counsellors or therapists. I experienced a need to start addressing some of these issues in an appropriate and sensitive way without jeopardising the identity of the clients.

Parents of learners with HIV/AIDS insisted on confidentiality and did not give me permission to include any aspects of this therapy in my research project. Because of the fear of marginalisation and rejection, group or team support was not permitted. Nor was I allowed to document anything during therapy or to have a record of visits. Initially I found this difficult, but now I regard it as a challenge. I have realised that there are other ways of exploring and co-authoring creative ways of doing narrative pastoral practice that can be just as exciting, rewarding and beneficial for both parties. Unable to honour the voices of learners with HIV/AIDS at school by co-searching ways of inclusion and acceptance of learners with HIV/AIDS with facilitators and other children encouraged me to consider an alternative way. 'Effective therapy must be continually re-created in the context of participant interaction' (Efran & Clarfield 1992:211).

Having read an article where HIV/AIDS is 'interviewed' (Sliep 1996:5-11), I wondered whether a play written by children with HIV/AIDS who are in counselling with me, could inform other children about this illness. I also pondered whether a play could de-stigmatised HIV/AIDS in a way that could assist people to openly acknowledge their illness without fear of marginalisation and exclusion.

I put this idea individually to children with HIV/AIDS consulting me, as well as to their caregivers. They thought the play was a good suggestion, but they had reservations. Although the caregivers agreed that their children could write a play on HIV/AIDS, it had to be written at home under their supervision. Furthermore, the fear of stigmatisation and being ostracised at school prevented the children with HIV/AIDS who were in counselling with me from acting in the play. I was also requested to produce the play as well as portray the role of HIV/AIDS. Because this play was written at home, it does not always reflect the ideas of the children as the caregivers also gave enthusiastic input in the writing. Respecting the confidentiality of these learners prevented collective co-authorship regarding their various contributions to the play. However, I liaised individually with the respective children and their caregivers to ensure that the final script met with their approval.
4.5 CO-CREATING NARRATIVES

4.5.1 Background

Due to the involvement and enthusiasm with which learners with diabetes and HIV/AIDS participated in writing their own play, I asked the support group for learners with epilepsy whether they would like to do likewise. I was given a unanimous 'yes'. Unfortunately, the scope of this research project does not permit the inclusion of therapy with these learners as part of my narrative pastoral practice with children with chronic illnesses. However, I regard including their play as a way of acknowledging and honouring their voices.

Not only learners with diabetes and epilepsy were involved in writing the plays. They invited whoever in their particular class was interested to be co-scriptwriters and participants. All preparation for these plays was done by the participants and myself at breaks and after school in my office. Scriptwriting, painting, cutting and pasting became the 'buzzwords' at school.

Because the plays were only presented in class during the Life Orientation lessons that I offered, they continued over a period of a few weeks until all the Grade 6 and 7 classes had watched. It is co-incidental that this year the learners with diabetes, epilepsy and HIV/AIDS are all in these grades. Learners who were not involved in the plays formed the audiences.

As a result of the success and obvious fun and enjoyment (Freeman, Epston & Lobovits 1997) of producing and presenting these plays using the knowledges of the 'experts' on chronic illness, the Head of Art and Culture at school wants to extend these plays next year so that they can be presented formally in the hall to all pupils and caregivers. I realise that the learners in Grade 7 will no longer be at primary school next year, but I will acknowledge their contribution to the plays.

4.6 INTRODUCING DIABETES, EPILEPSY AND HIV/AIDS

4.6.1 Spotlight on Diabetes

Personalising Diabetes (see 4.3.8) by using externalised language encouraged learners to be informed by Diabetes and provided an opportunity for questions and comments from learners in the audience.

Sue: Hullo. My name is Diabetes.
Rashid: Hi there. My name is also Diabetes.
Sue: I am a chronic illness. This means that there’s no cure for me and I am with people for their whole life. I can be anybody’s illness. I work in all ages, in children and also grown-ups. I like girls and boys, men and women. In fact I work all over the world in all kinds of people.

Rashid: Yes, that’s right and I like Indian people in South Africa especially. We have one of the highest rates of Diabetes in the world and it’s all to do with our genes.

Sam: Your jeans, you mean your denims?

Rashid: No, man, not those kinds of jeans. The genes I’m talking about are small things in our bodies.

Sam: Tell us how you work Diabetes?

Sue: Well, you see it’s my job to make sure you don’t get enough insulin and sometimes I try so hard that your body isn’t able to make any insulin.

Sam: What’s insulin?

Rashid: Insulin is something made by a gland in our bodies called the pancreas. Insulin allows the body to use sugar and other starches by controlling the way sugar is used in the body. Another word for sugar is glucose.

Janet [holding up a big poster of the internal parts of the body, points to the pancreas: This is the pancreas.

Craig: Oh, I see, but if you don’t have any insulin how can you get it?

Sue: Let me explain. Sometimes when the pancreas still makes insulin you only have to be on a special diet or use tablets. It is only when there is too little insulin or none at all that you have to get injections.

Mpho: Injections, oh, gosh, isn’t that painful, needles and all of that? It sounds very scary to me.

Sue: No, not really. You get used to it after a while.

Craig: But who gives you these injections?

Rashid: In the beginning the doctor or nurse show you what to do. Usually your parents are also taught how to inject you, but it’s a good thing for you to do this yourself.

Mpho: Why is that so?

Rashid: Well, ... I’m a sneaky thing and sometimes for no real reason I change the glucose levels in your blood and that’s not a good thing. Sometimes I make them higher and sometimes I make them lower and then you see it’s necessary for you to be able to test yourself and inject insulin if you need it. Doing this can prevent you from getting really ill.

Sue: You prick your finger with a thing called a lancet and then you test your blood in a machine called a glucometer. This shows what your glucose levels are and then you know how much insulin to inject. This you do with a special thing that looks almost like a pen. It’s quite easy really. Sometimes you also have to test for ketones.

Sally: Key who? Keystones? What are keystones?

Rashid: No, not keystones, ketones. These are acids made when the body breaks down fat for energy. This happens when there isn’t enough insulin to use the glucose and it also happens when you’re ill.

Sally: Okay, so now I understand about glucose levels and ketones.

Sue: Would you like us to show you how to test for glucose and ketone levels?

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2 Rashid knew about the high incidence of diabetes in the Indian population of South Africa because of an article in a magazine that we discussed at one of our group support meetings (Pullen 2001:5-9).
Sally: Sure, if it's all right with you.

"Sue and Rashid slowly show the audience the entire procedure, explaining as they proceed. They also have a sample of urine in a bottle that they test for ketone levels."

Don: Wow, you really are brave and you make it look so easy. Thank you for showing us what to do. Now we know that it's nothing to be afraid of and that young people, even children, can do this by themselves.

Sue: You're welcome. I guess that Testing Regularly and Injecting could be thought of as friends of Diabetes, something standing on the side of Diabetes. Testing regularly and Injecting when necessary and not only when you don't feel well would be good friends to always have with you.

Rashid: You see, the more you know about Diabetes the more in control of it you feel and the less you have to be scared of it.

Don: Yes, that makes sense. "The support actors nod their heads and agree with each other. Who else are your friends, Diabetes? Who would be on your side?"

Rashid: Umm, now let me see – who else would be my friends? "Scratching his head and looking deep in thought." Testing Regularly and Injecting when necessary like I've said and then Correct Eating and also Exercising or Playing Sport is important and would be good friends of mine.

"Thembi and Amy hold up posters illustrating healthy food and different kinds of exercise and sport"

Sue: Enough Sleep, Good Hygiene and Drinking Water would also be my friends.

"Thembi, Don and Amy hold up posters of people sleeping, bathing and showering, brushing their teeth and hair, keeping finger and toe nails short and clean, washing hands before meals and drinking water."

Sue: I think Judgement is a friend too – deciding whether I may eat a sweet or have a piece of cake at a birthday party.

Rashid: Yes, Sue, I think you're right about that. I also think that Judgement is a good friend of Diabetes. You know, people for some reason or other think that Diabetes may never, ever eat anything sweet and that's not true. If my levels are okay then I can sometimes eat these things in small quantities as a special treat. People always think it's their business to tell me what to eat or what not to eat and that's not right. I mean, I don't tell them what to eat, do I?

Sue: People even go so far as to grab sweets or cake right out of my hands at a party here at school and that really makes me mad. I mean, since when are they the experts about Diabetes? After all who knows more about Diabetes than Diabetes itself?

Roy: Yes, you are quite right Diabetes. You are the expert and know more about it than any of us here.

Rashid: The other people who would be on the side of Diabetes are Parents. They're the ones who're always there to look after us and help when there's a crisis.

Sue: Yes, Rashid you're quite right. Last night when I went to bed I had Ketones and it was my mother who got up during the night to check the levels with me and who injected me in my sleep when my glucose suddenly hit a high.

"Tshepe and Josephine enter dressed as Mom and Dad and go and give Sue and Rashid a hug and kiss."

Rashid: Of course Regular Medical Check Ups would also be on the side of Diabetes.

Sue: Yes, and also remember that not all hospitals know what to do when we children suddenly go into a hypo or hyper coma. I remember going to one hospital and nearly dying there because the staff weren't trained to treat diabetic children properly.

"Oratile and Sonia enter dressed as doctors and nurses and walk around."

69
Rashid: Whew, yes, that can be frightening. That also happened to me and then my mom and dad carried me back to the car and went to another hospital where they were trained to treat diabetic children.

Amy: What can we do, Diabetes, to help you have more friends?

Rashid: Thank you, that's very kind of you to ask. Responsibility would be a good friend to have too. You know I have to work hard to keep Responsibility close to me because when I have Responsibility sitting right next to me then someone tries to take it away from me by telling me what to do and what not to do.

Sue: Another and perhaps the most important friend of Diabetes would be that you all just treat us as Normal Kids, who enjoy doing all the things you do, who want to enjoy life and have fun just as much as you do. We have the same dreams and desires as the rest of you. Just accept us the way we are.

George: We're really sorry for doing the things we've done. I guess when you don't really know anything about an illness then it's easy to criticise and do the wrong things.

Rashid: It's all right, we know. We just hope that now we've told you about ourselves you will find it easier to understand Diabetes.

All: Yes, thank you. I'm sure we will.

George: Please may I ask you one more question? I've heard that you can get Diabetes from hugging or kissing someone with diabetes. Is that true?

Sue [laughs loudly] No, that's not true at all. Diabetes isn't like measles or mumps, it's not catchy. It can't be spread from person to person.

Rashid: I think that stories like these would be things standing against Diabetes and not for Diabetes. What do you think, Sue?

Sue: Yes, Rashid, I agree with you, rumours and stories would definitely not be friends of Diabetes.

Rashid: Standing together and working together and remembering that we're just normal kids who happen to have Diabetes would be the best friends Diabetes could have.

[They all take hands and bow together.]

4.6.2 Epilepsy takes centre stage

The learners involved in this section of the play decided to present their play differently. They decided to tell the others in the class all about epilepsy by using a dialogue. Two friends have a similar story to share.

Tom: Whew, Sipho I thought they were never going to give us a chance to introduce ourselves.

Sipho: You're right, but I must say that I really found it interesting hearing all about Diabetes.

Tom: Yes, and just like Diabetes told us I was also reminded that epilepsy is found in all cultures and races and that all people – young and old – can get epilepsy. What did you think of the play, Sipho?

Sipho: Yes, Tom, I never realised all those things and listening to what Diabetes had to say has helped me to talk about epilepsy.

Tom: Me too.

Tom: Tell me Sipho, when did you first discover you had epilepsy?
Sipho: Well, it was quite a few years ago, now that I think about it. It all happened after I bumped my head badly when I fell out of a tree. At first the doctors just thought I had concussion or something, but after a while, when I kept getting blackouts they realised that something else must be the problem.

Tom: So, carry on with your story.

Sipho: Well, I went into hospital for some tests. You know brain scans and things like that.

Tom: Yes, I remember them well. I also had scans after I had encephalitis. I got these blackouts and the doctors didn’t know why until they did all those tests and then they told me I had epilepsy. At first I was scared and didn’t know what this was going to do to me. How did you feel?

Sipho: Yes, Tom, I know exactly how you must’ve felt because that is just how I felt. Alone and scared. The doctors don’t really explain things to you in a way that you can understand. I didn’t want to ask mom because she had so much to do at the time. She was really so busy keeping everything and everybody looked after then, because my dad left us. You know, Sipho, I’m so glad that I can talk to you about epilepsy because I thought that I was the only one with this at school.

Tom: Yes, me too. That’s also the way I used to feel before going for therapy and joining the support group at school. Now I have the opportunity to talk to Nevi and the others in the group. I feel a lot better now.

Sipho: You mean that there is a kind of group of others at school also with epilepsy and that you all meet together?

Tom: Yes, we meet every two weeks and if we have a problem with anything, then we can just go to her anytime and talk to her. Hey Sipho, and by the way I’m really sorry to hear about your dad. That must really have been tough on all of you. You must remember that you can also come to talk to me if you need to.

Sipho: Thanks Tom, I’ll remember that, and I think I’d like to join you the next time you go and talk to Nevi. Can I come with you?

Tom: Yes, of course. I’ll come and meet you at your class and we can go together.

Sipho: Do other people also call what you have epileptic attacks? You know, I don’t like this word. To me it sounds as though there is a battle or big fight going on and I just don’t like the word.

Tom: Yes, you’re right. I also didn’t like the word and in our meetings we decided to think of another word that we were happy with.

Sipho: That sounds interesting. What is it?

Tom: We thought of the word episode or absence, an epileptic episode sounded much better to us. What do you think?

Sipho: Yes, I agree with you. Epileptic episode or absence sounds much better to me too.

Tom: Did people also treat you differently after they heard about your epilepsy? Sometimes I get the feeling they think that I am crazy or something.

Sipho: Gee, I’m sorry to hear that. No, actually no one was funny to me. Perhaps that’s because Nevi explained it all to the class and that made a big difference.

Tom: Wow, you’re really lucky.

Sipho: Maybe you should also get Nevi to explain epilepsy to the class. It really makes a big difference when everyone understands, you know. Then people don’t talk behind your back.

Tom: Yes, Sipho, I think that will be a good idea.
Sipho: You know, Tom, it is easier once people understand that having epilepsy doesn’t mean that you’re nuts or anything and that it is caused by a change in the electrical rhythm in the brain - that’s all.

Tom: What kind of epilepsy do you have Sipho? Grand mal or petit mal?

Sipho: I’ve got petit mal – the kind where you don’t lose consciousness but just sort of blank out for a short while. Usually no one even notices anything and I’m the only one who is aware of it.

Tom: Yes, mine is the same now. I used to get the big episodes where I would actually lose consciousness and fall to the ground, but since the doctors have got my medication correct, it’s much better.

Sipho: Yes, medication, that is the most important thing to remember to take every day and not just when we feel like taking it. Are you also on Epilam?

Tom: Yes, Sipho, Epilam. That’s the name of my tablets too.

Sipho: Is there anything you are not allowed to do, like not play sport? I’m allowed to play sport but I have to avoid contact sport like soccer and rugby where you can get bumped on the head, but that’s okay because there are lots of other sports to choose from. I’ve also got to drink enough water when it’s hot. Oh yes, and when I get sick I’ve got to make sure that I don’t get a high temperature.

Tom: Yes, what you’ve said is basically the same for me too.

Sipho: And what Diabetes told us about Correct Eating Habits, Enough Sleep and Regular Medical Check-ups would also be true for epilepsy.

Tom: Yes, that’s true and I think we should add that we are also just Normal Kids like every one else.

Sipho: We like doing what other children do. Just because we have epilepsy doesn’t make us different.

Tom: Wow, Sipho, I really want to thank you for this talk we’ve had. It has helped me so much to think differently about epilepsy. Being able to talk to you has made me realise that having epilepsy is nothing to be ashamed of.

Sipho: You’re welcome Tom. I’ve also enjoyed talking to you. I’ll be looking out for you on the playground. Take care now. Bye-bye.

Tom: Cheers, Sipho.

4.6.3 Interviewing HIV/AIDS

As mentioned previously, I was requested by the parents of learners with HIV/AIDS to portray the role of HIV/AIDS in the play. This section of the play takes the form of an interview.

HIV/AIDS: Hullo, my name is HIV/AIDS and I’m here today to tell you all about myself and for you to ask questions. I know that you have heard a lot about me on television, in newspapers and magazines, from your parents and here at school during Life Orientation classes.

Lindy: Yes, I would like to ask you a question.

HIV/AIDS: Sure thing, please go ahead.

Lindy: Tell us, whose illness are you? What are you? Who do you belong to?

HIV/AIDS: I’m everybody and anybody’s illness. I am a tiny germ called a virus. I do not belong to any special language, colour or culture group. I infect men and women, girls and boys. I’m sure that you don’t know what HIV/AIDS stands for, that this is not my full name.
Lucky: Sorry to tell you, but I do know. It stands for Human Immune-Deficiency Virus and AIDS stands for Acquired Immune Deficiency Syndrome – so there.

HIV/AIDS [looking scared and intimidated]: Oh, no, I’d better be careful. I really don’t like it when people know too much about me. Knowledge and understanding are not good for my reputation. I thrive and grow well in communities where ignorance about me is big.

Lerato [Sounding very excited]: Really, I’ll remember that. What else would stand against you?

HIV/AIDS: People, families and communities uniting and standing together, looking after one another. I hate unity. Part of my plan of destruction is to go around disorganising and destroying relationships. Oops, I’d better be careful now and not talk so loudly. [Whispering] If families, and communities care for each other, stand together and fight against me, then I won’t be able to come between them and cause trouble.

Dale: These are things that we need to remember. Is someone writing all this down?

Lerato: I’ve been making notes all the time. We need to know more about you. How are you spread?

HIV/AIDS: Mostly by people having unprotected sex with different partners and by drug addicts who share the same needles. I can also be transferred from pregnant mothers who are HIV positive to their unborn babies.

Dale: Whew, it’s as easy as that, then?

HIV/AIDS [Looking very smug and full of herself]: Yes, look here, man, you really don’t want to mess around with the likes of me. You really don’t want to take chances with me.

[Lindy looks around at the others and nods]

HIV/AIDS: I bet you didn’t know that I am so dangerous and that I can infect you the very first time you meet me.

Lucky [Looking very surprised]: What do you mean, the very first time? I didn’t think that was possible.

HIV/AIDS: Ah, yes, you see, that’s where you all make your mistake. Everyone underestimates my strength. You only need to have unprotected sex once with some one who is infected and then it’s too late. You must remember that I never miss an opportunity. I’m always ready for action and to add another victim to my list.

Paul: Can you also be spread by infected blood? What about blood transfusions?

HIV/AIDS: Yes, I can be spread by infected blood, but the chances of getting it through a blood transfusion are minimal because blood is properly checked and tested at blood transfusion centres and blood banks. However, infected blood from needles of drug addicts when needles are shared gives me easy access to continue my list of victims.

Paul: Gosh, this is definitely very serious. You really are an awesome illness. Actually, awesome is too mild a word to describe you. You are actually a horrendous, revolting monster.

HIV/AIDS [Looking very happy with herself and rubbing her hands together]: Yes, that’s me. Always alert and ready to strike.

Penny: Do you have any cure?

HIV/AIDS: Not yet. Thousands of scientists all over the world are working day and night to try and find a cure for me, but at present I'm still able to trick them from finding one. The best they can offer is a medication called A.Z.T. but this is only effective if used within a few hours after I enter your body and it has to be used for sometime afterwards as well. There is still no absolute proof that this medication, called anti-retroviral medication, is one hundred percent effective.
Penny: Is this the medication that the Government is having so much to say about using it for unborn babies whose mothers are HIV positive?

HIV/AIDS: Yes, and you know, the longer they can't make up their minds what to do, the more time they give me to continue working and causing havoc in so many lives.

Soujei: Do you have a favourite place in the world where you like to work?

HIV/AIDS: Ah, yes, Africa is my favourite continent. You see the poor and hungry people there are what helps me to thrive. Also the fact that women in Africa, especially in Sub-Saharan Africa, where the highest numbers of HIV/AIDS occur, are extremely disempowered.

Soujei: Do you favour any age group?

HIV/AIDS: Oh, no, I'm much too clever for that. I infect old and young people, people who are well before I enter their lives and also people who are ill at the time. Once I'm in someone's body, there is nothing they can do to get rid of me. In fact, I've trained myself so that I can infect babies before they are even born.

Penny: Wow, you mean you can do this while the babies are still in their mother's stomachs?

HIV/AIDS: Yes, sure. Nothing is too much trouble for me. I'm very clever. You see, ages before people first knew about me, I had plenty of time on my hands. I was around planning and scheming for a long time making sure that what I did and was about to do was guaranteed to be successful. I just went on quietly doing my job and no one even noticed me for a long, long time.

Ben: You sure are a strong kind of illness, aren't you?

HIV/AIDS: Yes, well, I suppose that would be partly why I'm so successful. I always make sure that I do a thorough job.

Ben: What else makes you successful?

HIV/AIDS: Well, let me think. Oh, yes, my size and the fact that to almost every one except laboratory people I am invisible. Yes, come to think of it, my invisibility has definitely been a huge advantage.

Grace: Why is that?

HIV/AIDS: You know, unlike so many other illnesses that one can see, such as measles, chicken pox and mumps, you usually can't see the proof of me until it's too late.

Grace: Is it true that you can only be seen by using a special kind of microscope?

HIV/AIDS: Yes, that's absolutely correct. I am so small that it is impossible to see me under an ordinary light microscope. You have to use an electron microscope to see me.

Kristen: What else helps you in your work?

HIV/AIDS: The fact that people believe that it cannot happen to them, that only other people can get infected. Oh, yes and then I really enjoy helping people to believe in all sorts of untrue stories about me. However, my speciality is the huge effect I have on people and their families by making them keep quiet and remaining secret about me once they are positive with me.

Kristen: It seems that there are still some things that can be done to make you powerless.

HIV/AIDS: Yes, and what would they be?

Paul: To inform people that they should only have safe sex by using a condom, to only have sex with a single, life long-partner.

Lindy: Yes, and don't do drugs or share needles.

Ben: Use A.Z.T. after possible infection and stand together with those who are HIV positive.
Lucky: Find ways to lift the silence and secrecy of victims.

Grace: Open the doors of communication. Find ways to care for 'Aids Orphans'. All these things would decrease your strength.

HIV/AIDS [Looking extremely frightened and physically decreasing in size]: Enough, enough, I don't want to hear any more. You're making me lose my energy and power. Keep quiet.

Lerato: No, we won't keep quiet. We want you to listen to us for a change. We believe that prayer and God have a huge role to play in breaking the control and silence that you use.

HIV/AIDS: Shush, Shush, I am already feeling weaker just at the mention of prayer and God.

Paul: Good, this is what we want to hear from you for a change. We are sick and tired of hearing how bossy you are all the time. You think we're just going to sit down and accept all of this but you're wrong. We're not going to hand over our lives to you.

HIV/AIDS: Well, you see it doesn't matter what faith you are. Just the mention of prayer and people standing together against me is a daunting thought. You know that my aim is to separate people and not have them uniting. [Cringing and bending down, getting smaller and smaller.] Oh, no, I can't afford to have religion and prayer weaken me in any way, no, no, no.

[The actors from the previous plays come forward and do a rap.]

HIV/AIDS, Epilepsy and Diabetes
Don't be wrong, together we can meet these.
  We can do what you do;
  We can talk like you talk;
  We can run and we can play;
  We enjoy fun every day.
We're no different, we're not here to scare;
  All we want is for you to care,
  Because what we have is not our fault.
Don't push us away and lock us in a vault.
  Old, young, black or white,
  Can't you see we're all right.
You can't get us from knives or forks, toilet seats or even a cup;
  Just remember that together we can all look up.
  Don't be afraid to give us a hug,
  Because what we have is not a bug.
  So let's be friends and take my hand —
  Together we will walk through our beautiful land.

4.7 REFLECTION

As a pastoral therapist I have an ethical commitment to participate in transforming the school culture towards a mutual and ethical caring community. The experiences of marginalisation, exclusion and teasing of children with diabetes and epilepsy challenged me to work towards a culture of mutual care at school. A practice of mutual care was initiated when the children with diabetes and epilepsy who received
counselling, shared their knowledges with me and afterwards also with the facilitators and their fellow learners. Sharing their knowledges by means of the play contributed not only to practices of mutual care with regards to these particular illnesses, but mutual care was extended in general to other areas at school. The confidentiality surrounding the children with HIV/AIDS prevented me from establishing my vision of a community of care for them at school. However, their comments regarding how much counselling meant to them indicated that they experienced a small haven of care at school where I was able to share my love, understanding and acceptance. I will endeavour to continue exploring ways to lift the veil of silence in people with HIV/AIDS.

In Chapter Five, the pastoral therapy and co-search are reflected upon, extending my journey of commitment, care and transformation.
CHAPTER 5

GOODBYE, BUT NOT FareWELL

5.1 FareWELL – NOT TO THE RESEARCH

A dissertation has to be completed. However, research is never completed. My research is part of my commitment as a pastoral therapist guided by the ethics and values of a contextual approach to practical theology and pastoral care (see Bosch 1991:423; Cochrane, De Gruchy & Petersen 1991) – I do what I do not merely for the purpose of completing a dissertation. The reflecting process also never ends. It is ongoing because the researcher, participants and readers remain in a reflecting stance towards the research process. As Gergen and Gergen (1991:93) say:

The present writing is but one iteration of its completion. Yet, more might well be done... A future exposition...is sorely needed so that readers can join writers and friends to become authors within the reflexive circle. In principle the spiral knows no boundaries. With socially reflexive research one need never say ‘goodbye’.

My research curiosity focused on the following question: How can narrative pastoral practice at a primary school enhance transformation towards an inclusive and caring community? I formulated the following aims in this regard:

• to develop inclusive and caring practices between a culturally and religiously diverse community of learners as well as between them and the facilitators, and

• to explore and co-author creative ways of doing narrative pastoral practice.

In view of these aims, I would like to reflect on the multiple reflections that occurred during and after the therapy-as-research process.

5.2 MULTIPLE REFLECTIONS ON MULTIPLE REFLECTIONS

Because I am a feminist researcher, I wanted to go back to the lived experience of research via multiple reflections (see Reinharz 1992:258). Drawing on feminist theology, I agree with the stance of McBride (1996:184) that reflection and action cannot be separated and that reflection is an on-going process that
develops the possibility for alternative actions which, when reflected upon, result in the initiation of ‘new questions and new fields of possibility’ (McBride 1996:185). I therefore regard this chapter as only another reflection of the many I did during this study, albeit a reflection on the reflections – perhaps the full stop for the purposes of the dissertation, but a mere semi-colon on my ongoing engagement with the research-as-therapy and therapy-as-research.

Reinharz (1992:194) believes that learning should occur on three levels in any research project: the researcher learns about herself (see 1.2 and 5.9); about the subject matter under study, or what I would like to call research curiosity (see 1.6.1); and about how to conduct research, or how to co-search with children (see 1.5 and 5.3). With this in mind, I will now enter into some reflections on the research project, weaving together these three levels of learning.

5.3 PASTORAL PRAXIS AS POLITICAL CARE TOWARDS ETHICAL TRANSFORMATION

Pastoral praxis as political care challenges me to take a political stance on various important issues. I did this by what I call a ‘school-desk theology’. Below, I explain this way of working and thinking.

5.3.1 School desk theology

McTaggart (1997:6) emphasises action research as a commitment to concrete practice to inform future action. I believe that the threads of action research that contributed to practices of pastoral care in this project have been woven into further tapestries of care for the future. My commitment to ethical practices in counselling children changed me and my practice, as well as other people involved in the children’s lives. For example, children with diabetes and epilepsy used their knowledges and experiences of their respective illnesses to inform me, and by writing and producing a play, their classmates and facilitators. Sharing their knowledges in this way led towards slow transformation of the school towards a community of acknowledgement and support (White 1995b:64).

The use of a contextual approach to practical theology allowed for different interpretations of the truth and also opened up opportunities for diverse expressions of spirituality. A contextual approach supports socially relevant change. Consequently this study became a forum for addressing cultural and religious inclusivity, earth-caring as well as the effects of loss and chronic illness on children.
Feminist pastoral care and counselling has a pastoral, but also a prophetic aspect (Bons-Storm 1996:27). The oppression of children called me to challenge invisible dominant discourses that hold learners, facilitators and parents captive. Prophetic pastoral practice seeks to expose and overcome oppressive injustices. Brueggemann (in Gerkin 1991:71) states:

The task of prophetic ministry is to nurture, nourish and evoke a consciousness and perception alternative to the consciousness and perception of the dominant culture around us.

Graham (1998:138) explains how a ‘kitchen table theology’ extends well beyond the academic sphere. Seeking justice and care, some feminists claim the right to have their kitchen tables recognised as a site of legitimate theological work. Therefore, in the light of this, a ‘school desk theology’ may be equally valid when caring for and counselling the most vulnerable members of our society, children. ‘School desk theology’ required me to ‘care with’ and sustain children with HIV/AIDS and their caregivers while at the same time challenging marginalisation and stigmatisation in order to transform the school community to a just, inclusive and caring environment. Ackermann (1993:21) espouses a praxis that is ‘just, loving, freeing and which leads to peace and wholeness’. This challenges practical theology and pastoral therapists to participate in transforming values and attitudes towards a just and ethical society (Kotzé & Kotzé 2001). I attempted to face this complex challenge. This attempt is exemplified in the politics of care I used in addressing HIV/AIDS. I continuously co-authored ethical and accountable ways of caring and speaking with young people, as well as collaborating with facilitators and caregivers.

Sevenhuijzen (1998:19) states that an ethics of care cannot but be political, if it wants to break with the patterns of domination that have surrounded caring activities and moral feelings for too long and to establish new modes of being “truly moral”. The challenge for me was therefore constantly to find new ways of caring with learners and not just caring for them – finding ways to care in which faith can be experienced as something practical and lived in communicative acts. One way of reflecting on how narrative pastoral therapy with children is research (co-search) is to hold myself accountable to the learners.

5.3.2 Consciousness raising

As a woman pastoral therapist I was aware that the feminist maxim that the personal is political also rang true for me. However, it was through this study that I came to realise the extent of political pastoral care at a primary school. Through my connection with HIV/AIDS children and their families, I became aware of the need for consciousness-raising and challenging of religious and cultural discourses surrounding HIV/AIDS,
discourses which stigmatise and silence the voices of children struggling with the illness. The fear of stigmatisation and marginalisation experienced both by the parents of children with HIV/AIDS and the children themselves seem unjust and oppressive. Because of the secrecy surrounding HIV/AIDS in children, they do not experience direct marginalisation or stigmatisation at school. However, they are marginalised by being 'unplugged' from care and support of their friends, fellow students and facilitators. Apart from me, nobody at school is allowed to know about their HIV/AIDS. These children are silenced from speaking about their or their parents' illness. This poses a challenge when I venture into the territory of the politics of care. Such issues in the politics of care also pose a major challenge for practical theology and pastoral care.

The HIV/AIDS-play was a first step towards changing the attitudes of other children at school. It attempted to raise the consciousness of children about HIV/AIDS, to look at the illness through different eyes and to create attitudes that will enable communities of care and concern to arise. Such consciousness-raising must be done cautiously, as '[e]ducation that pushes the balance to extreme caution is likely to be dangerous if effective, and likely not to be effective because it runs counter to normal human response' (Landau-Stanton & Clements 1993:24). I believe that the play on HIV/AIDS found this balance. However, this is but the beginning of a process of searching for new ways to address the politics of HIV/AIDS in pastoral praxis.

Cultural and religious inclusivity is another issue relating to the politics of pastoral care that I had to find creative ways to address.

5.3.3 Politics of cultural and religious inclusivity

Speaking with children and caregivers of different religions, listening and respecting their viewpoints as well as learning from them about their religion is a further example of an 'experience of concrete practice' (McTaggart 1997:6). From a pastoral viewpoint, these experiences served to work towards inclusive religious and caring practices among the diverse cultural and religious learner and caregiver community and also between learners and their facilitators (see 5.6.1).

Diverse religious traditions or 'spiritualities' challenge a pastoral therapist to create opportunities to introduce tolerance and understanding for differences and to create a space for the extension of all religious rights and beliefs at school, an essential process in schools in South Africa and elsewhere. Transformation away from entrenching and preferencing one religion at school and towards a pluralistic acceptance of all religions (Kritzinger 1998:241) should 'allow Christians to be fully committed to Jesus and
fully open to other ways' (Knitter quoted by Kritzinger 1998:241). As a pastoral therapist engaging in inter-religious dialogue, co-operation and interaction with children, facilitators and parents, I identify with the notions of Hick (1980:52), who says:

We have to realize that the universe of faiths centres upon God, and not upon Christianity or upon any other religion. He is the sun, the originative source of light and life, whom all the religions reflect in their own different ways.

'Anyone who knows only one culture,' says Augsburger, 'knows no culture.' In coming to know a second or third culture, a person 'discovers how much that was taken to be reality is actually an interpretation of realities that are seen in part and known in part' (Augsburger 1986:18). I believe that the same applies to religion. I therefore agree with Kritzinger (1998:247), that we cannot meet the challenges posed by other religious communities by merely studying their beliefs and practices from books. Continuous dialogue with children, facilitators and caregivers of all religions is the vital praxis out of which a valid and 'credible Theology of Religions develops' (:247). When children of different religious backgrounds sit next to each other in school, it creates a context for this dialogue to begin at an early formative age, but only if fundamentalist confessional restrictiveness or exclusivity can be challenged successfully. Allowing this to happen among children appealed to me as a possibility of a school desk theology.

MoGurk (1998:131) explains the concept of interculturation as the experience of moving into other cultures and faiths and then coming back to one's own culture and faith 'with renewed insight and creativity, in order to share common higher-order universal values as a basis for mutual enrichment'. I regard interculturization as a recognisable process of moulding unity in diversity in an ongoing historical experience. When MoGurk (:130) says that making historical-cultural processes explicit agendas in schools, education becomes a 'practical theology of social transformation', he is using the term 'practical theology' in the contextual sense of a theological praxis.

With caregivers and children I co-authored ways that can contribute to practices of religious inclusivity at school to ensure that children of different religious traditions are acknowledged in a meaningful and respectful manner. Unfortunately, I have not been able to implement all the suggestions aimed at religious inclusivity that were put forward during the conversations that I had with children and their caregivers. However, I have initiated a custom that children from different religions take turns in leading the devotion ritual at assembly each week, deciding on a relevant prayer, reading and song that links with the theme for the week. Children of different religions have started to represent their religious festive days by displays or posters in the hall. The Valediction service at the end of this year will not preference a particular religion, but will instead recognise and acknowledge the religious diversity of the children and their parents. Several
suggestions still need to be implemented: hymn singing can be extended to include not only Christian hymns but also songs of other religions; children can be encouraged to write and to produce plays to demonstrate cultural and religious diversity and caregivers can be invited to watch or participate; and the Christian opening and concluding prayers and Bible readings at meetings for parents can be alternated with prayers and scriptural readings relevant to other religions. Pastoral therapists and facilitators need to negotiate spiritual issues and sensitivity to accommodate children of all religious denominations. Care should be taken to honour the non-religious children, such as children who are atheists or agnostics as a minority group, and to guard against marginalising them from a religious point of view.

A challenge in the tertiary education of facilitators and religious leaders, including pastoral therapists, would be to orient curricula to enhance attitudes and values of inclusivity, respect and curiosity. This would imply moving away from exclusive and oppressive theologies which talk down to other religions and try to colonise all who believe differently – in short, moving away from fundamentalism.

5.4 CO-SEARCH WITH CHILDREN

5.4.1 Introduction

I learned that in writing up this document, honouring children’s voices, was not an easy aspect of the co-search. Speaking with children in therapy is one thing, but trying to do justice to their voices afterwards on paper, is a different matter. However, this has to be considered in doing co-searching with children. At times, like Morgan (1999:vii), I struggled to find ways of representing the complexity of what occurs in therapy sessions with children while simultaneously trying not to omit relevant conversations. Sometimes I quoted children’s voices verbatim in an attempt to give a richer description of their experiences during the therapy-as-research process. I regarded reflecting on my ways of narrative pastoral care and counselling as a way of learning how to co-search with children.

5.4.2 Reflecting on narrative pastoral practices with children

I view my involvement with the learners, caregivers and facilitators and other areas in the school as being in-community (Cochrane et al 1991:2). Joining the children on their playground at break, trying to secure employment for a single mother, helping victims of domestic violence and their children to find a safe place to stay, sitting with ill children in the sick-room, visiting children and facilitators in hospital, attending
funerals of parents and liaising with social workers became ‘moments of insertion’ for me (Cochrane et al 1991:17):

The moment of insertion locates our pastoral responses in the lived experience of individuals and communities. What people are feeling, what they are undergoing, how they perceive this, how they respond – these are the experiences that constitute the primary data of the context.

I recall many ‘moments of insertion’ (Cochrane et al 1991:17) during the past two and a half years that I have been at this school. They occurred not only when the children, caregivers and facilitators needed pastoral care in moments of pain or sorrow, ‘but also when the community of faith is struggling to be faithful to its prophetic task’ (1991:17). In both the school and the family (home) context such moments are quite critical. The results of violence and suffering are everyday events that children bring to school and they take on a new dimension when related to oppression (:17), especially the oppression of women (mothers) and children. What Cochrane et al (:17,18) describe relates to my everyday experiences at school:

The daily encounter with hunger, malnutrition, ... the breakdown of personal relationships ... suppressed rage and anger which boils out in rapes and other attacks, the desperate actions of the unemployed or their resignation in the face of life – all these things are not the abnormal, but the normal for many pastors in South Africa.

Moments during which I was directly confronted with these realities were the basic points of departure for a ‘holistic practical theology which refuses to reduce its concerns to the atomized individual or family’ (:18).

As a pastoral therapist and as a person, I am committed to strive towards ‘doing right’ instead of ‘being right’ (Rossouw 1993:903). My practice was guided not only by my own belief system, but also by the ethics of narrative pastoral therapy, which privileges practices of accountability, transparency, and power sharing. Amongst other aspects of counselling I regard these as important ethical, political pastoral practices.

5.4.3 Accountability and transparency

Like Elliot (1998:37-61), I realised the value of accountability, transparency and trust as part of my ethical practice. Accountability is not a process of acquisition of information, but an ongoing commitment to learning and changing (see Swan 1998:37). One way of being accountable is to be completely transparent with the participants in therapy (see Niehaus & Jane 2001:73). Allowing children, caregivers and facilitators to have access to my conversation notes meant they were free to change or add anything that I had
omitted or recorded incorrectly to those notes. Encouraging the participants' reflections during and after the therapy-as-research process contributed to my accountability. Before I ended each conversation with children and caregivers we negotiated what I could discuss with the facilitators. I never reported anything back to the facilitators (from conversations with the children or caregivers) that was not negotiated beforehand. This practice of negotiation strengthened the trust relationship between children and myself. Practices of accountability and transparency deconstructed the power/knowledge relation that could have existed between the children and myself. I also invited power sharing practices to accompany our co-search journey.

5.4.4 Power sharing practices

At schools there are very strong hierarchical systems prescribing 'what is spoken and who may speak' (Foucault 1980:61). At most primary schools children have no choice or say regarding, for example their attendance, uniform, subjects, facilitators, method of instruction, examinations or discipline. They find themselves at the bottom of powerful hierarchies within learner and school subcultures: I was constantly confronted by adults' power over children. Hence I needed to find ways of co-searching, collaborating and participating with children to encourage sharing power in counselling. I agree with White (1995a:168), who says:

I have an ethical commitment to bring forth the extent to which the process of therapy is a two-way process, and to try to find ways of identifying, acknowledging, and articulating the extent to which the therapeutic interactions are actually shaping of the work itself, and also shaping of myself.

A transparent stance made it possible for me to enter into a relationship of collaboration and participation, because it liberated me from playing the role of 'expert' with all the answers. I could honestly tell children that I did not have certain knowledges, choosing instead to rely on their expertise and knowledge to clarify situations from their experience. By declining invitations to be placed in the expert position, I avoided discourses that maintained adult supremacy. Honouring children's voices by taking a position against ageism (White 1995b:53) was another form of power sharing. This way of working enriched my life and uncovered treasures I would otherwise not have come to know. Challenging adults' power over young people required me to consider the implications of real partnership.

Real partnership implied not only asking the question, 'what does it mean to be an adult?' (Black in Denborough 1996:43), but also stepping outside of that meaning. I tried to give of myself – to exchange and be transparent regarding my stories, fears and desires and to challenge what it meant to be a counsellor – taking a stand against power-abuse in the counselling situation. However, I agree with Black
(in Denborough 1996:43) that doing this on my own was ‘pretty isolating’ and that therapists/researchers need to come together with children to challenge the broader traditions of power-abuse at school. My accompanying children to collaborate with facilitators in finding ways to incorporate power sharing, to struggle together against the inherent hierarchies, the constant competition and the power structures of schooling, encouraged learners and facilitators to join hands as partners on the journey of education.

Honouring the local knowledges or solution knowledges (White 2000:21,22) of children was another way that I invited equity into the therapy-as-research process.

5.4.5 Honouring local knowledges

Remaining connected to the local knowledges of children is an important aspect of power and knowledge sharing. I relinquished concerns about my self and instead considered the nature of the other. This attitude contributed to my relating to children’s local knowledges. Heshusius (1995:121) refers to this as ‘a participatory mode of consciousness’; and captures the gist of this when she says that the self-other, adult-child distance disappears when we realise that children know far more than we give them credit for (:120). White (2000:22) refers to this as the ‘know how’ that children have at their finger tips, but that is often disregarded by adults.

The self-other, adult-child distinction was blurred when I acknowledged the contribution and value of children’s solution knowledges. I realised the value of narrowing this gap and of richly describing children’s solution knowledges throughout the therapy-as-research process (Heshusius 1995:120; White 2000:21). So, for example I spoke with Peter (see 3.4.3) and it was his idea that his parents receive therapy; Sue co-authored with facilitators and classmates in ways she regarded best so that they would respect her knowledge and experience of diabetes (4.3.4). The words, ‘[k]ids know more than you think’ (Heshusius 1995:120) took on new meaning and significance for me when the support teams for diabetes and epilepsy produced and directed their respective plays (see 4.5). Sandile’s (see 3.6.3) reluctance to wear school shoes arose because she had never worn shoes before and wearing them was really an uncomfortable experience for her. I had to ‘translate’ this knowledge to the facilitators instead of explaining to Sandile that wearing shoes was part of the school uniform (see 3.6.3). Raama chose to complete his memory book during therapy before taking it home (see 3.5.5). By respecting this and not trying to include his grandparents’ assistance, was one way of indicating that I valued his decision and that he knew what was best. I agree with Davies (1993:9), who says that children are constantly deprived of agency and that children’s status
... is never fully guaranteed. It is always partial and conditional. They can be positioned as beings without agency and autonomy at any moment, usually when they are read by adults as not knowing how they should behave.

I constantly counteracted and exposed discourses subjugating children’s knowledges (Jennings & Graham 1996:165-181). Using Heshusius’ (1995) idea of ‘participatory consciousness’, I challenged myself to listen to children’s voices while conducting research as well as doing therapy in ways that focused on their agency so that their multi-voiced identities were acknowledged and honoured (Monk et al 1997:231; White 2000:21). Winslade and Monk (1999:30) refer to the relationship between therapist and client as a negotiating co-authorship that focuses on shared contributions to a process of creation. So, for example, it was my task to find ways, when talking with children who have a chronic illness, that were deconstructive of stories of incapability and labelling and to position myself and them in places that offered them agency and voice (Davies 1996). Reflection on action research was another important aspect for reflecting on the therapy-as-research process.

5.5 ACTION RESEARCH AND REFLECTIONS

Berge and Ve (2000:129) argue that action research is important because action research implies ‘learning from actions’. However, because change through action research takes time, the researcher needs to allow sufficient time for inquiry and reflection. I was in the fortunate position as a researcher/pastoral therapist because my permanent employment at school afforded me the opportunity to learn from actions and to conduct this therapy-as-research project without time limits.

A second important reason for action research is the participants’ aim to achieve equality in relationships (Berge & Ve 2000:131). Narrowing the gap between facilitators and researchers and raising the status of the facilitators’ work was an important aspect of my action research. Attending staff meetings and in-service training sessions, becoming involved in various activities at school such as the eco-venture club and assisting with Life Orientation classes, being willing to do playground duty and working the same hours as the facilitators made me ‘one of the staff.’ My experience was that actions which resulted in collective experiences paved the way for better understanding. Facilitators commented as follows: ‘We see you doing the same duties as us.’ ‘You’re a pastoral therapist, but you don’t regard yourself as better than us.’ ‘Thank you for acknowledging how hard we work.’ Co-authoring regularly with facilitators as a researcher and pastoral therapist (see Chapter 3) as well as including learners in conversations with facilitators with regard to the effects of chronic illness (see Chapter 4) and co-constructing alternative ways of discipline (see 5.3.2.5) contributed towards exploring and co-creating creative ways of doing narrative pastoral practice
while simultaneously establishing a more caring (Bosch 1991; Heitink 1999), and inclusive school community.

A further reason for using action research in my research project was that it ‘works at a local level’ (Berge & Ve 2000:131). Engaging with facilitators, learners and caregivers was an essential element in representing the local level of this research project. I became especially aware of the relevance of local level during the rehearsals and production of the plays on diabetes, epilepsy and HIV/AIDS. Although the classes involved in the plays appeared to be fairly uniform regarding age, race and gender, the learners responded differently and were divided in their attitudes of support and understanding toward the effects of chronic illness before the plays. However, afterwards, they stood united in their acceptance, support and positive attitude toward chronic illness. The significance of action research working at a local level took on new meaning for me in this project when children as the experts told facilitators authoritatively how to understand learners with chronic illness (see Chapter 4).

Berge and Ve (2000:131) talk about action research teams. While, in this research project, I reflected with the participants, colleagues, theoretical discourses, my supervisor and the principal, I did not have a team to assist me in the research and to bring about changes in different practice as is expected of emancipatory action research (Zuber-Skeritt 1996).

According to Berge and Ve (2000:132), self-reflection is vital for action research. Multiple reflexive conversations occurred during the process of therapy-as-research. Reflections took place between the children amongst themselves in a group context, the children and myself as therapist-researcher, caregivers and myself, caregivers and children, children and facilitators and facilitators and myself. These reflections challenged my thinking and doing throughout the study. The process of continuous reflexivity continuously repositioned the journey towards a more caring and just school environment by exploring and co-authoring creative ways of doing narrative pastoral practice. Together we were ‘better prepared to make normalising processes visible’ and to co-create different ways of inclusion (Berge & Ve 2000:132), whether these were relevant to learners, caregivers, facilitators or religious caring practices.

Action research focuses on practice, reflecting and changing practice (McTaggart 1996:251). McTaggart (1997:39) adds that ‘[p]articipatory action research is not simply problem solving.’ Both problem posing as well as problem solving are involved in participatory action research. It is prompted by a search to enhance the world by changing it and discerning how to improve it from the effects of the changes made. I believe that in this research project both problem posing as well as problem solving received attention. A question I asked throughout this study was how I as a therapist and researcher could assist in bringing about change
at school in ways that would encourage a more just, inclusive and tolerant school community with regard to developing inclusive religious and cultural practices, the effects of chronic illness in children and the impact of loss on young lives. Participatory action research is not research done on other people. It is research by particular people on their own work, to help them improve what they do, including how they work with and care for others (McTaggart 1997:29). ‘Everyone in action research, whether a researcher, facilitator or learner, is involved in relational actions, both as inquirer and inquired’ (Berge & Ve 2000:35). We are in the world, we discern, ask questions, theorise about, and this world becomes known through our communication with it. Action research provided me with opportunities for exchanging experiences with learners, facilitators and caregivers in ways that allowed each of us to benefit from a modified and nuanced awareness of the complexities of chronic illness, loss through death and separation as well as religious inclusivity. Winslade and Monk (1999:30) refer to the relationship between therapist and client as a negotiating co-authorship that focuses on shared contributions to a process of creation.

5.6 TALKING TO YOU IS LIKE HUNDREDS AND THOUSANDS

'Talking to you is like a rainbow,' a support group member commented when reflecting on the therapy/research journey. Using the metaphor of a rainbow reminded me of the metaphor of research as Hundreds and Thousands (see 1.5.2) — one comment, perhaps not very significant considered in isolation, but introducing a definite pattern when strung together. Rashid explained how his experiences during the research journey could be compared to the different colours of the rainbow. Because the children participating in the therapy/research identified with Rashid’s metaphor they wanted this to be included in the research report.

Rashid: Red reminds me of how angry I was when I first started therapy. I couldn’t understand what I had done to get diabetes, but now I feel warm and happy like the sun, like yellow (see 4.6.1).

Sue: Blue is a cold colour and makes me think of how sad and lonely I was when I was teased about my diabetes before coming to this school. Red stands for love and happiness and this is how I feel now – happy and accepted at school (see 4.3).

Raama: My mother is proud of me when she looks down and sees my memory book of her with the pink roses. My book lets me talk to her whenever I want to. I like pink because it reminds me of my mom (see 3.5).

Sandile: You helped me to go barefoot when I missed my house and family. Getting my feet brown made me happy because I thought of the ground – ready for planting at home (see 3.6).
Peter: Blue is like the sky where Ryan lives and now I know that he doesn’t mind to see me smiling and being happy (see 3.4.2).

Sipho: I think black would say how I felt when I heard I had epilepsy. Then after I went to talk to you and joined the support group and we wrote the play, epilepsy wasn’t such an issue for me anymore. Epilepsy is now like white, nearly transparent – I don’t see it any more (see 4.6.2).

Individual reflections with parents of children with HIV/AIDS included:

You are the only one I can trust to talk to Rose about her illness. Since Rose started therapy with you she has become so much more positive about life.

Thank you for what you do for Sashen. You have made such a difference in his life.

Because of coming for therapy Mondi no longer believes that it is his fault he has HIV/AIDS.

By talking to you Thapiso realises that God is not punishing him by giving him HIV/AIDS. I know that you will carry on helping us so that one day we will be able to talk openly about HIV/AIDS.

Children with HIV/AIDS commented individually as follows:

I really enjoyed helping to write the play even if I couldn’t take part in it or if nobody else knows that I wrote part of the play.

The only time that I can be honest about my illness and not have to keep quiet about it is when I come and talk to you. With you I can just let my feelings all pour out. I feel so much better afterwards.

You always listen properly when I talk to you. You ask the kind of questions that make me feel better. I will carry on coming to you until I’m allowed to talk openly about my sickness. I mean if it’s not my fault that I’m sick why do I have to make a secret out of it?

5.7 SPRINKLINGS OF HUNDREDS AND THOUSANDS

Facilitators, parents, siblings and friends of learners sprinkled the hundreds and thousands from the therapy. Sprinkling occurred when comments or reflections were expressed regarding the negotiated changes they had witnessed (Weingarten 2000) in learners either during therapy or when learners felt that therapy was no longer necessary (see Chapter 3).

Shortly after commencing work as pastoral therapist at school, I was confronted by some interesting comments from facilitators and parents. Comments ranged widely. A facilitator said: ‘Sandile has seen you once and she is still withdrawn in class and doesn’t do her homework properly.’ A parent commented: ‘I
thought Rob was in therapy with you, so when can we expect to see some changes in his aggression at home?’ The impression was created that immediately after children started therapy, there would be a marked ‘difference’, mostly in the behaviour of the child. It was almost as though something magical was expected to occur after my meeting with children for the first time (see White 1997:127; Shim 1995:66). Assisting adults in the child’s life to understand that this would not usually be the case proved to be challenging, but at the same time also worthwhile. This negotiation process now stands me in good stead, especially with regard to facilitators with whom I have established co-operation, involvement and understanding on behalf of the learners.

By contrast, acknowledgement was received regarding the difference that therapy made in the lives of learners. Positive comments made by facilitators, friends at school and parents were encouraging. These comments left me with renewed inspiration and motivation for practising narrative pastoral therapy. Some of the comments shared with me included: ‘We have never been listened to like this before. You didn’t give us advice nor tell us we were handling diabetes incorrectly. You just listened’ (comment by Ann, Sue’s mother) and a comment from Peter’s mother: ‘Thanks to Peter and you, we have a new connection with Ryan’. Throughout this study I regarded my role as that of a pastoral therapist who listened curiously to the stories of children, parents and facilitators. Listening in a deconstructive way to people as they explained their life stories to me constantly reminded me that we are all multi-storied (McLean 1997:14).

Children extended the pastoral care they received to their friends at school and also their families so that children became not only receivers but also givers of care. Receiving and giving care in this way contributed to a practice of mutual care. Children who had received pastoral care showed concern, love and care for others at school and also at home. Facilitators, children and parents made comments such as ‘Raama has become such a caring child and always shows concern when others in class are sad.’ Sandile said she thought she ‘must make a support group for children who also miss their parents because they stay far from them’, and Sipho’s mother remarked: ‘Sipho would like to help out over weekends at the home for handicapped children near our house.’ These comments stressed the importance White’s (1995b:64) comment concerning the structuring of schools as communities of acknowledgement or ‘sanctuaries of care’ (see Anderson & Johnson 1994).

5.8 COMMITMENT, CARE AND TRANSFORMATION

I believe that practical theology can make a contribution to the transformation of society (see Heitink 1999:175). All the participants in this research-as-therapy process positioned themselves according to their own spirituality. I was aware of the effects that spiritual ‘truths’ played in the thoughts, emotions and
behaviour of all the participants. I witnessed a living, a ‘doing’, of practical theology through the various contributions of the plays that invited fellow classmates to understand the implications of chronic illness. During the therapy-as-research process, children began ‘doing’, that is, not only receiving pastoral care, but giving pastoral care to others at school. These actions of mutual care and also between facilitators and learners contributed to enhancing transformation towards an inclusive and caring school community. I was reminded of ‘a fusion of horizons’ (Gerkin 1984:47), that includes an understanding process between people, and where alternative stories (narratives) with new meanings are created. Conversations with the caregivers from diverse religious and cultural backgrounds, the children experiencing loss in different ways, the collaboration between facilitators and myself in this regard as well as children with chronic illnesses sharing their experiences with learners and facilitators led to the fusing of horizons. In trying to understand one another’s stories (narratives), new stories (narratives) were created amongst us where respect for others’ personal knowledges was acknowledged.

During this process there was a fusion of peoples’ stories (narratives) about their lived experience, their understanding of the stories (narratives) of others as well as stories (narratives) regarding their relationship with God. There was a contribution to theology in general, and practical theology in particular when learners and facilitators moved towards a school community of inclusive and caring practices. I agree with the stance held by Ackermann (1993:22) regarding the use of language in therapy. Ackermann (:22) believes that language that is inclusive and non-discriminatory can be described in practical theological terms as healing and therapeutic, ‘apart from the fact that such language reflects an holistic view of humanity implicit in the values of the reign of God’. The reign of God is described by Ackermann (:21) as demanding justice, love, freedom and shalom, and in so doing, ‘calls for the priority of praxis, praxis which is just, loving, freeing and which leads to peace and wholeness’.

5.9 HUNDREDS AND THOUSANDS ON MY TONGUE

I confirm Reinhart’s (1992:194) notion that many feminist researchers are profoundly changed by the participatory process. The research project invited me to understand as well as to practice the concept that narrative pastoral practices can be extended to people of all cultures and religions. I learned that these practices do not restrict a therapist to consulting with people of one particular religious affiliation, but can instead be of benefit to all people, irrespective of their religion or, even if people are non-religious. This study opened up new possibilities for me to become other than the person I was (Wylie 1994) by learning, understanding, appreciating and sharing in the different religious life-worlds of children and caregivers and then returning to my own faith with renewed vision and inspiration. I agree with Suchocki (1987:149,150),
who says that from a feminist perspective justice should be the ‘fundamental criterion of value and the focus of dialogue and action among religions’.

The research process encouraged me to realise once more how privileged I am to work with children and to reconsider what adults can learn from children. Listening curiously to the stories I heard reaffirmed the importance of never underestimating their local knowledges, that these are not subordinate to my ‘expert’ knowledge and that I have to respect their preferred ways of attending to their concerns and difficulties.

The expert knowledges of children with chronic illness changed my understanding and knowledge of their illnesses and made me realise the impact that chronic illness has on young lives and families. I also became aware that families find a therapist’s invitation to participate in meaningful conversations about the impact of illness in their lives one of the most useful ways to invite families to move beyond and overcome problems. The research process encouraged me to identify with the notion of Wright, Watson and Bell (1996:161), who say: ‘The capacity of clinicians to be “witnesses” to the stories of suffering of patients and families is central to providing care; it is frequently the genesis of healing, if not curing’.

I was aware of the powerful secrecy that HIV/AIDS imposes on people for fear of being stigmatised and marginalised. However, nothing could have prepared me for the intensity of the grip that kept both the caregivers of children with HIV/AIDS and children with HIV/AIDS captives of silence regarding their illness. At times, I felt that I too had become a victim of silence because of the confidentiality and secrecy regarding the counselling of these children and their families. I felt trapped and disempowered by not being permitted to negotiate further practices of care and support with the facilitators and others at school. Before the research project I was sure that my practices of pastoral care and therapy regarding HIV/AIDS would in some way contribute to an inclusive, supportive and just community of care at school where HIV/AIDS would no longer have the power to keep people silent about their illness, but I had to introduce a different way in which children with HIV/AIDS could voice their knowledges and experiences regarding their illness while still remaining anonymous. I had to accept that they were more than happy about the anonymous individual contributions that they had made to the writing of the play.

I learned that my own spirituality became a part of the reflecting process, contributing to connectedness and preventing spiritual talk in the therapy-as-research process from becoming sterile (Andrews & Kotzé 2000:334). I wondered how the spiritual stories people brought to therapy touched and influenced me and why I was so deeply moved by their stories. I became aware how spirituality often created spaces for new self-narratives and how these had a healing effect on people (Griffith & Griffith 1993:6). It came as a surprise to me that a third research aim developed while co-creating aspects of inclusive and religious
practices with the learners, caregivers and facilitators – eco-spirituality as a practice of pastoral care, where caring for the earth is consistent with caring for people. Various ways of caring for the earth and people led to the beginnings of a ‘children’s spirituality’.

I find it difficult to do justice to the value and meaning I attach to the writing up of this document. Not only has my life been transformed and enriched by the experiences of the therapy-as-research journey, but a re-living and a re-appreciation of this journey has occurred during the writing of this research as co-search.

5.10 CARING FOR CHILDREN, CARING FOR THE FUTURE

I write my recommendations for future research and pastoral caring practices with children, caregivers and staff members from the position of a pastoral therapist who is employed full-time at the school.

I am aware that my practices of pastoral care regarding HIV/AIDS will have to be considered differently in the future. Throughout the therapy-as-research process I experienced the confidentiality resulting in complete secrecy of the children with HIV/AIDS as an inhibiting factor. The secrecy prevented me from collaborating with people at school and elsewhere, such as the church and various organisations, in providing other forms of care. At times the implications of being the only one responsible for doing care weighed very heavily on my shoulders and I almost felt burdened in my isolation. One can only imagine what secrecy does to children and how they must feel. I realise that to continue exploring ways of lifting the silence of HIV/AIDS will require involving other people, organisations and the church because I cannot continue to do this alone.

The other question that remains is how this confidentiality complicates matters for the facilitators – they do not have sufficient information to understand and interpret specific behaviours or absenteeism of learners. Sharing relevant knowledge and understanding could, however, have contributed to better ‘care with’ the learner. Facilitators may also at times be at risk when attending to a learner who has injured him/herself. Contact with bodily fluids may be a risk and facilitators may not be aware or have received information in this regard.

In the future I would like to collaborate with other schools in our area at school so that together we could seek financial assistance from private companies to purchase anti-retroviral medication. In this way schools could unite in their extended care for pupils and take a proactive stand against one of the consequences of rape.
On other aspects of children’s lives, my vision for future collaborative inquiry between facilitators and learners would include negotiating new ways of being with learners. One way could be extending children’s local knowledges by encouraging facilitators to promote learners’ feeling free to ask what Davies (1993:41) refers to as ‘non-askable questions’. I am interested in co-authoring ways with learners that encourage sharing puzzlement and wonder with facilitators and myself. By valuing and sharing childhood puzzlement, therapists and facilitators can position themselves in conversation with children so that opportunities for collaborative inquiry are encouraged (Nelson 2000:31). I will continue to explore ethical and collaborative ways of accommodating different perspectives that adults and children might bring to a problem as well as possible alternatives.

Realising and appreciating the value of the various support teams as well as the Learners for Learners Caring Clubs, I would like to see these continue, but only while they benefit learners and serve a purpose. I do not think that it would be in the interest of narrative pastoral practices merely to continue support teams without continuous critical reflection from both learners and myself. Children need to be consulted with when initiating new clubs or support teams so that their interests and needs are provided for. My experience in speaking with many mothers who are victims of domestic violence has been their enormous need for some kind of group support. I envision a support group at school for these women too.

I will continue to introduce and implement ways for inclusive religious practices that are co-authored by caregivers, children and myself (see 5.5). In the future I would like to assist facilitators in making provision for all children with regard to differentiated religious education classes before the new inclusive religious education curriculum is implemented at school.

Negotiating ways of speaking with learners without first having to obtain permission from parents would be a welcome relief. The voices of children are frequently silenced by their parents when I have to send an official letter home requesting permission for children to receive counselling. I believe that children should be given the freedom to decide when to seek counselling or for facilitators to refer children for counselling after ensuring that this meets with the child’s approval.

On the journey towards developing narrative pastoral practices that promote transformation towards an inclusive and caring community, I was left with the following question: How can schools make the National Education Department more aware of the need for full-time employment of narrative pastoral therapists paid by the department? The fact that I have to consult with over three hundred and fifty children at any given time, as well as speak with facilitators, caregivers, other family members and also engage regularly with social workers is an indication of how urgent it is that the Department recognise and fund full-time
pastoral therapists at schools. Apart from addressing these issues in writing to the Department I have another suggestion. Like De Jager (2001:106), I would like to invite relevant representatives from the Department and also the Ministry of Education to our school. I would like to share with these representatives the various ways in which narrative pastoral therapists, learners, caregivers and facilitators can play a fundamental role in transformation to a just, inclusive and caring school community.

My central vision of future caring practices at school would include shared responsibility between church and school of 'doing what we can do to create better conditions for the flourishing of all children, particularly those in greatest need' (Couture 2000:47). I echo the words of Couture (2000:50), who says that because children are the most vulnerable group in society they should be 'the ethical lens through which we need to look more closely at our relations with children'. A further recommendation for a shared responsibility between church and school would be that together society could help in sustaining and caring for the therapist to prevent secondary traumatic stress and 'burn-out' (Figley 1995).

I close this research project with a feeling that this has been the greatest learning and enriching experience in my life and also with some very meaningful and moving words from Barry. Johnson (in Anderson & Johnson 1994:11) relates how one Sunday each year she talks to children about the stained glass window at church. She reminds them that Jesus said:

‘to such belongs the kingdom of heaven.’ And I often ask them why Jesus said everyone must become like a child. On one occasion, nine-year-old Barry responded very quickly to that question. ‘I know, I know!’ he said. ‘Because if everyone was a child, then no one would hurt children anymore.’ I don’t remember what I said after that, but it really didn’t matter. Barry had spoken a truth.
BIBLIOGRAPHY


