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**School reintegration after a burn injury: A qualitative study exploring the psychosocial difficulties experienced by a group of paediatric burn survivors during the school reintegration process.**

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## **ABSTRACT**

Sustaining a burn injury is one of the most traumatic accidents a child or adolescent can experience. In South Africa paediatric burn injury is a significant social problem and incident rates tend to be elevated in informal settlements because of the reliance on fossil fuels (paraffin, wood, and coal) for heating and cooking. The role of mental health professionals in helping young burn survivors and their families through their traumatic ordeal is of paramount importance.

There is currently a shortage of specialised psychosocial assistance for burn patients and their families in South Africa. Given the enormous challenge of paediatric burn injury in South Africa it is alarming that so little research has been undertaken in the field. The present knowledge regarding this issue is largely reliant on international research, which cannot always be generalised to the specific challenges posed by the South African context. The purpose of this study was to provide local insight into the psychosocial adjustment of burn survivors that can inform intervention programmes in this field.

In order to explore the psychosocial adjustment of paediatric burn survivors during the school reintegration process it was decided to interview the burn survivors, their parents and their school teachers. The sample comprised 7 paediatric burn survivors and their respective caregivers and teachers. The study was conducted using a qualitative paradigm. Data was collected by conducting semi-structured interviews with the participants and their caregivers and teachers. Data was analysed by conducting a thematic analysis of the transcribed narratives of the participants, their caregivers and teachers.

The study yielded important information about the social contexts of a small group of burn survivors and their families and the challenges that they face during the school re-integration process and

psychosocial adjustment in general. The majority of the families in this study were experiencing extreme socio-economic difficulties. This was a strong contributing factor in their limitations to fulfil their roles in supporting the burn survivor.

The mental health difficulties of parents as well as participants before *and* after the burn injury showed that the burn injury often meant an additional stress factor to already existing problems. It was found that the burn injury also poses an additional challenge to most of the interviewed teachers, who have to cope with multiple challenges in their classes and therefore have very limited resources (time, empathy, attention) to attend to the specific challenges of the re-integration of burn survivors. The different layers of problems that were experienced by participants, their families and teachers highlighted the reality of the South African context.

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# CHAPTER ONE

## INTRODUCTION

Sustaining a severe burn injury is one of the most traumatic accidents a child or adolescent can experience. A child or adolescent that has to cope with a severe burn injury will have to face the following challenges:

- Terrifying and painful experience of the burn injury itself
- Ongoing painful medical treatment of burn wounds
- Sudden separation from familiar environment to hospital environment where parents are no longer in control and where he/she is sometimes hurt by strangers.
- Relatively long hospitalisation which means absence from school and friends.

According to the first annual report of the National Injury Mortality Surveillance System (NIMSS, 2000) during 1999 burns were the leading cause of death for South Africans under the age of one year, thereby accounting for 20% of the 14 829 fatal injuries registered during this time. Furthermore, burns were the second leading cause of death for children age one to four years. These statistics are thought to reflect approximately 25% of the estimated 60 000 fatal injuries that occur annually in South Africa and should therefore be interpreted conservatively.

Over 80% of fatal burn injuries are said to occur in informal settlements where many South Africans live. Incident rates tend to be elevated in informal settlements because of the reliance on fossil fuels (paraffin, wood, coal) for heating and cooking. With the close proximity of the stove or fire to the ground, the possibility of an adult or a child stumbling into it or upsetting the cooking pots is very great. This risk increases when children play in a cooking area, the implements are unstable, and the surfaces are uneven as is frequently the case. In addition, the use of candles for lighting is a major source of house fires (UNISA Institute for Social and Health Sciences, 2004.)

Liebowitz (2001) stresses the fact that the incidence of children who survive burn injuries in South Africa has not been accurately quantified. According to her this is partly due to the fact that unlike in countries such as the United States of America and the United Kingdom, a National Burns Registry has not been locally established. Instead the present state of epidemiological knowledge regarding paediatric burn injury is largely reliant on statistics from the Red Cross War Memorial Children's Hospital in Cape Town.

Since 1999 the Red Cross Hospital has been the only Western Cape hospital to which moderate to severe burn injured children aged 12 years and younger are referred (Van Niekerk, Rode & Laflamme, 2004). The hospital registers approximately 600-800 moderate to severe burn injuries every year. These injuries are considered moderate to severe if more than 10 % of the body surface area is affected, by at least a superficial partial thickness burn (where the epidermis is partially burnt through and blistered).

These statistics paint a dim picture about the extent of the incidence of burn injury among children in South Africa. The magnitude of the problem is further increased by the traumatic nature of a burn injury. Gilboa (2001) refers to burn injury as "a continuous traumatic stress situation", beginning with the traumatic event of the injury, continuing during hospitalization – which involves severe pain and anxiety – and including emotional difficulties after discharge, upon returning to normal life.

Blakeney (1995) proposes three primary targets for interventions that ease the patient's transition from hospital to home:

1. the patient
2. the patient's family
3. the patient's community.

The "community" that dominates a child's life outside of the family is the school. The school is the domain in which children develop academic skills, social skills, and a sense of self-worth. As burned children struggle to develop a new self-image that incorporates their scars, they need feedback from within their school

community that tells them that they are competent and valuable (Blakeney, 1995). Cahners (1979) also stresses the point that next to the family, the school exerts the greatest influence on a child's normal development and social adjustment. She concludes that for the school aged burned child social re-entry means a return to school and that this step is as critical for social survival as the stabilisation and wound healing had been for physical survival.

Teachers may also feel overwhelmed with the presence of a severely burned child in their classrooms. Blakeney (1995) argues that school personnel often have no information about or experience with burn injury and recovery, and they are susceptible to all the fears, anxieties and failings of human beings. Teachers may have the following concerns when a burned child enters their classes:

- They worry that a burned child will require too much specialised attention and that they will be inadequate in meeting the child's needs.
- They worry that other learners will be insensitive to the burned child or will be frightened by his or her appearance.
- They worry that they do not know what can be expected of the injured child, what special needs he or she may have and what his or her physical limitations are (Blakeney 1995).

#### Note on racial terminology

Swartz, Gibson and Gelman (2002) acknowledge the enormous controversy that exists over the use of racial categories in South African research. They argue that it is essential to recognise that historically constructed racial categories in this country carry important social meanings. In this dissertation I use the term 'African' to refer to indigenous South Africans who generally speak indigenous languages such as Xhosa, Zulu and Sotho. 'Coloured' refers to South Africans of diverse and mixed racial origins, most of whom speak Afrikaans and/or English. 'White' refers to South Africans of European ancestry who were enfranchised under apartheid.

**Aim of the study**

The role of mental health professionals in helping young burn survivors and their families through their traumatic ordeal is of paramount importance. There is currently a shortage of specialised psychosocial assistance for burn patients and their families in South Africa.

Given the enormous challenge regarding the psychosocial rehabilitation of burn patients in South Africa, it is alarming that so little research has been undertaken in the field. The present knowledge regarding this issue is largely reliant on international research, which cannot always be generalised to the specific challenges posed by the South African context. The study, a small scale qualitative exploration, aims to provide knowledge about the psychosocial adjustment of paediatric burn survivors that can inform intervention programmes in this field. Semi-structured interviews were conducted with 7 paediatric burn survivors and their respective caregivers and teachers. The interviews were transcribed and then analysed by applying a process of thematic analysis.

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## CHAPTER TWO

### LITERATURE REVIEW

The literature review will focus on the following aspects of psychosocial adjustment to burn injuries:

- Medical treatment of severe burn injuries
- Psychological and psychiatric disorders associated with burn injury
- Impact of a burn injury on the family

#### **Medical treatment of a burn injury**

It is essential to understand the physical impact of a severe burn injury on the body and the nature of medical procedures associated with burn care, to really understand the extent of trauma experienced by children who sustain severe burn injuries. In cases of extensive burn injury, the patient is confronted with a life-threatening situation in which homeostatic mechanisms and the interaction between the wound and the host from a circulatory and metabolic point of view need to be controlled (Arthurson, 1996). Munster (1993) explains that the medical team's first concern is not the burn wound itself, but the patient's life-sustaining respiration and blood circulation systems. The physician's initial evaluations will focus on determining whether the patient has shock or respiratory insufficiency, either of which may be immediately life threatening. Depending on the depth of skin layers involved, described in terms of first, second, or third degree, and the severity of injury, defined in terms of the percentage of total body surface area (TBSA) involved, it can take weeks to months before wounds are healed. Munster (1993, p.7) defines shock as "a decreased rate of circulation to vital organs; if an inadequate amount of blood is circulating to these organs; they are being deprived of the oxygen they need to function". The severity of shock generally correlates with the TBSA that has been burned. Respiratory insufficiency is defined by Munster (1993, p.8) as "the inability of the lungs to supply oxygen to the body". This condition is more likely

if the patient has smoke inhalation burns. A person's immediate chances for survival after a burn injury are determined by the extent of shock, smoke inhalation, burn size and how much of the total burn is third degree.

Although rapid wound closure occurs in small and superficial wounds, large full-thickness burns do not heal spontaneously and need to be treated with excision and grafting (Williams & Phillips, 1996). The destroyed skin must be replaced by uninjured skin that is harvested from another part of the body. Skin grafting procedures require that burn survivors have to be re-admitted to hospital where they are sometimes immobilised for up to 10 days, often in uncomfortable positions (Knudson-Cooper & Thomas, 1988). Infection or sepsis is the enemy of burn patients and becomes a serious threat in the first weeks after the burn injury. For this reason the burn wound is cleaned by hospital staff once or twice a day and then dressed, usually with a medication designed to kill germs and thick dressings. Cleansing the wound includes debridement which involves removing loose, dead skin and old creams or secretions from the skin. This treatment is very painful and the patient usually receives pain medication beforehand (Munster, 1993). It is understandable that these painful procedures, that the burn survivor is continuously exposed to during the time of hospitalisation and post-discharge (i.e. skin grafting and other surgical procedures) can be experienced as quite traumatic by a young burn patient.

Another common complication of burns is the formation of hypertrophic scars. A hypertrophic scar is red, thickened, hard, and hypersensitive. It affects the patient's appearance negatively and it may produce loss of functioning and deformity as a result of contracture formation. Fortunately, the scars tend to flatten, soften, and become asymptomatic after a period of time, although final maturation of the scar may require as long as 1 to 2 years (Arthurson, 1996; Helm, 1992). Control of hypertrophic scars requires the use of pressure garments and silicone products that cover affected body parts for several months. It is assumed that restricted blood flow to the scars, as a result of external pressure, has a diminishing effect on scar formation.

Apart from hypertrophic scarring, there are also other complications resulting from the decrease of normal functions of the skin of affected body parts. Problems with thermoregulation in case of excessive loss of sweat glands,

neurosensory malfunctions of the skin and the development of cancer in burn scars have been reported (Fleming, Hunt & Purdue, 1990). Hospitalisation for a burn injury is relatively long, averaging about 30 days, and often extends over several months.

### **Psychological and psychiatric disorders associated with burn injury**

Andersson, Sandberg, Rydell and Gerdin (2003) stress the fact that contrary to what one might expect, previous research has found that children seem to adapt fairly well to life following burn injury and that many gain a satisfactory quality of life, even after severe burns. This statement is confirmed by studies that found that most paediatric burn survivors are well adjusted, both psychologically and socially. (Blakeney, Meyer, Moore, Broemeling, Hunt, Herndon & Robson, 1993; Meyer, Blakeney, Holzer, Moore, Murphy, Robson & Herndon, 1995). However, findings in literature also reveal that there are a significant number of burn survivors who have difficulty dealing with their burn injury and its psychological, physical and social consequences. According to Blakeney, Fauerbach, Meyer and Thomas (2002) many burn survivors, as well as their family, friends, and associates have difficulty in coming to terms with the manner in which the injury occurred and with the immediate and delayed consequences of the injury. There are several manifestations of psychosocial distress that are commonly observed in the burns unit in response to these sources of stress. They list the following as the most common:

- Generalised distress (non-specific anxious, depressed or irritable mood)
- Acute traumatic distress (re-experiencing trauma, avoidance and hyper arousal related to the trauma)
- Body-image dissatisfaction (distress over the reactions of self and others related to change in appearance and function)
- Hopelessness depression (hopelessness, anhedonia, withdrawal/lowered motivation related to perceived difficulty in achieving future goals)

- Phobic avoidance (behavioural avoidance often related to aversive stimuli feared or experienced during or following rehabilitation tasks) (p. 788).

For the purpose of this literature review I will focus on depression, post traumatic stress, the meaning of a skin injury and body-image issues as manifestations of psychosocial distress.

### **Depression after a burn injury**

A study by Stoddard, Stroud, Murphy (1992) on depression in paediatric burn survivors revealed that unrecognised depression is common during the lifetimes of most burn survivors. The majority of the 30 children in this study were burned before the age of 7 and did not become depressed until an average of 4.4 years later. The findings of this study also indicate that it is not unusual for depression to develop in response to self-consciousness about disfigurement and feared or actual peer rejection when a child with burns reaches adolescence. Other than expected the study found that there is no statistically significant correlation between burn size, disfigurement and depression. This means that while some children with small burns become seriously depressed and suicidal, others with large burns and severe disfigurement manifest no depression at all (Stoddard et al., 1992).

Research indicates that depression is perhaps best explained by the notion of a predisposing genetic risk, other personality factors (Moore, Blakeney, Broemeling, Portman, Herndon & Robson, 1993), and family and other social support systems that are thought to be more significant determinants of depressive illness in children with burns than the burn trauma or scarring (Blakeney, Portman & Rutan, 1990; Browne, Byrne, Brown, Pennock, Streiner, Roberts, Eyles, Truscott & Dabbs, 1985).

## **Post Traumatic Stress**

Blakeney et al. (2002) report that burn survivors experience a series of traumatic assaults to the body and mind and the fabric of their social network which present extraordinary challenges to psychological resilience. Jiminiz, Bajo, Castillo, Salvador-Robert and Torres (1994) contend that burn injuries are traumatic experiences that are sufficient to meet the diagnostic criteria for Post Traumatic Stress Disorder (PTSD) of the American Psychiatric Association's Diagnostic and Statistical Manual (1994).

According to the Fourth Diagnostic and Statistical Manual (DSM-IV-TR) of the American Psychiatric Association (2000), the diagnosis requires:

...exposure to an extreme traumatic stressor involving direct personal experience of an event that involves actual or threatened death or serious injury, or other threat to one's physical integrity; or witnessing an event that involves death, injury, or a threat to the physical integrity of another person; or learning about unexpected or violent death, serious harm, or threat of death or injury experienced by a family member or other close associate (p.463).

The diagnosis also requires 6 symptoms from 3 different symptom categories (re-experiencing of the traumatic event, numbing of certain responsiveness and avoidance and symptoms of autonomic hyper arousal), within a minimum duration of 1 month.

The diagnostic criteria in the DSM-IV-TR (2000) make special reference to a different presentation of PTSD symptoms in children by adding the following notes:

- In children intense fear, helplessness, or horror may be expressed instead by disorganised or agitated behaviour.
- In young children, repetitive play may occur in which themes or aspects of the trauma are expressed.
- Children may have dreams without recognisable content.

- In young children, trauma-specific re-enactment may occur (p.468).

Being aware of a different presentation of PTSD Symptoms in children can help mental health professionals, members of the burn team and parents/caregivers to ensure that they are alerted to symptoms of PTSD timeously and respond with necessary interventions.

In separate studies undertaken by Powers, Cruse, Daniels and Stevens (1994) and Saxe, Stoddard and Sheridan (1998) between 25 and 38% of burn survivors meet criteria for PTSD of the DSM IV (1994) in the first postburn year, and almost 50% of survivors meet criteria for at least one of the PTSD symptom clusters. Bryant (1996) reports that the incidence of PTSD is greater 12 months after the injury than during hospital admission. During the post-discharge phase, burn victims respond to a variety of stressors, including pain, disfigurement and functional limitations, which can impede the adjustment process. During this phase PTSD is associated with disfigurement and low self-esteem, avoidant coping style and poor social support.

An important developmental concern is the interplay of the processes of trauma resolution and other childhood tasks. Eth and Pynoos (1985) stress the point that after psychic trauma in childhood, schoolwork, play and interpersonal relationships are hampered. The child's growing ability to assume an active role in addressing issues related to changes in current life circumstances may be eroded by traumatic anxiety. When there is continued reworking of traumatic memories, it can also cause enduring effects on the child's cognition and learning abilities. It seems important that these factors be considered by mental health professionals when assessing children's psychosocial adjustment after they have been discharged from hospital and especially during the school reintegration process.

Gilboa, Friedman and Tsur (1994) find the diagnosis of PTSD or PTS (post traumatic stress) in the case of burn injury somewhat inadequate. They contend that both the diagnosis and the related guidelines for treatment during the critical period of hospitalisation must differ from those applied to PTSD. They argue that in PTS, by definition, the trauma has already ended whereas in the

case of the patient with burns the situation is different. Although the traumatic event has ended, the victim still faces periods of severe physical and mental suffering that may qualify for the definition of further or multiple trauma. It thus becomes inadequate to designate the condition as *posttraumatic* stress and Gilboa et al. (1994) propose that it should rather be seen within the context of what has been termed by Straker (1987) as continuous traumatic stress (CTS).

This argument becomes especially relevant in the South African context where some children are exposed to many traumatic events throughout their lives. One of the biggest problems facing South African society today is current levels of domestic and criminal violence. Smith and Holford (1993) state that for many children and adolescents, acute episodes of violence are experienced in the context of multiple traumatic events and adverse factors that have undermined their development from early on. It follows that it is important to not assume that the burn injury happens as an isolated traumatic event, but rather to view it as an event that may cause continuous stress within the context of an environment that may well be continuously traumatic.

### **The meaning of a skin injury**

McQuaid, Barton and Campbell (2000) stress the idea of the body not only being a physical object, but also a psychological construct. They also refer to burns as being one of the ultimate forms of body damage and perhaps more so, as a threat to the sense of being a “whole” individual. A burn injury is always an injury to the covering of the body, that is, the skin. It can result in a change of skin sensation, reduced temperature moderation, reduced physical function and disfigurement (McQuaid et al., 2000).

In an attempt to understand the meaning of the skin in the development of the individual/child, Gilboa (2001) names a few examples of how the skin has certain physical functions that have psychological parallels:

- Since it is the part of us that comes into contact with what is outside of us, it gradually enables us to get to know the world, on the one hand, and set the boundary between us and the other objects in the world, on the other.

- In the pre-symbolic stage of early development, the mother, while nursing and holding, plays a prime role in creating a sense of unity or wholeness through the infant's combined experience of contact between her skin and his. Proper development requires that this physical experience be positive and optimal in degree (pp. 335-336).

This positive, optimal experience in early life creates a 'primary skin' or what Anzieu (1989) calls a "skin ego". This "skin ego" enables a person to interact properly with the environment, to cope with both internal and external stress and to maintain good adjustment. Infants whose mothers do not serve as a "protective shield" as Tustin (1986, in Gilboa, 2001) calls it, develop, in compensation, what Bick (1968) calls a "second skin", which is a sort of rigid armor that should hold the self and eliminate the feeling of holes or tears in the metaphorical covering, preventing leakage or disintegration. In his book "the skin ego" Anzieu (1989) refers specifically to burns when he writes:

Burns produce what is virtually an experimental situation in which certain of the skin's functions are temporarily suspended or impaired and in which it is possible to observe the corresponding repercussions on certain psychical functions. The Skin Ego, deprived of its anaclitic support on the skin, then shows a certain number of weaknesses, which may however in part be remedied by psychological means (p.202).

The word "anaclitic" can be defined as "of or related to relationships that are characterized by the strong dependence of one person on another" ([www.wordreference.com/definition/anaclitic](http://www.wordreference.com/definition/anaclitic)). According to Drever (1964) the term is "employed by psychoanalysts of object choice modeled after the first love object". Anzieu (1989) also uses the term "a skin of words" to describe an empathic way of speaking to burn survivors that is capable of soothing the pain of a victim of serious burns when touching becomes impossible, prohibited or painful. Gilboa (2001) proposes that in the case of a burn, an interdisciplinary team, composed of both physical and mental health professionals, should work integratively, in order to create an alternative "container" of passive support. Such a team should tend to all the patient's needs - physical and emotional -

with sensitivity and empathy, to restore a sense of wholeness and individuation and so promote the healing process.

### **Body image**

The emotional adjustment to burns involves internal changes in the person's self-concept (an internal concept of self). According to Orr, Reznikoff and Smith (1989), body image is a component of the self-concept which is formed from both sensory and social experiences, with cultural and family reactions to one's body; having great importance in determining one's own attitude. After a severe burn, the body is changed and this change must be integrated into a person's body image and self concept (Knudson-Cooper & Thomas, 1988). The key assumption made in research on body-image development in children with burns is that after a burn injury, body image needs revision (Bernstein, 1990; McQuaid et al., 2000; Jessee, Strickland, Leeper & Wales, 1992; Beard, Herndon & Desai, 1989).

Blakeney, Meyer, Moore, Broemeling, Portman, Herndon and Robson (1993) report that some pediatric burn survivors learn to accept the challenges relating to their changed physical appearance and adjust well psychologically, whereas others withdraw and isolate themselves from social interactions. Jessee et al. (1992) explain that some children with disfiguring conditions tend to try to protect the sense of self from complete disintegration by maintaining the mental image of a normal body. This has a devastating effect when at a later stage the child has to confront his/her severe scarring and disfigurement.

Stoddard (1982) found evidence of a type of mourning for the loss of the previous body image, and indeed of the previous self, in children with burns. In the school-aged group, the reaction of the peer group to the child with burns may be particularly influential to the external body image. McQuaid et al. (2000) contend that children with visible deformity may have difficulty making friends and even when they have friends, they may be constantly reminded of their appearance. This may influence the adjustment process after a burn injury negatively.

Bernstein (1990) believes that body image is particularly important to adolescents because during adolescence the actual physicality of the body changes in a way that will never happen again. These physical changes heighten bodily awareness of both the self and others and often adolescents feel insecure about their changing bodies. Since peer approval is of paramount importance during this developmental stage, adolescents cling to their peers for reassurance. Blakeney (1995) argues that an adolescent who may detract from the perceived attractiveness of the group is a threat to each individual in the group and therefore likely to be excluded. This means that an adolescent who suffered a severe burn injury has to deal with many complex body image issues and in addition, may be at high risk for social exclusion during a very difficult time. Orr et al. (1989) found a strong correlation between depression, low-self esteem and poor body-image in a study of 121 survivors of childhood burns. The scores in the results of the study were significantly influenced by perceived social support and the participant's gender. An interesting finding of this study was that girls and young women reported greater depression, lower self-esteem and more negative body images than boys and young men with equivalent burn injuries. This study confirmed an earlier study by Gladstone (1972) who found that girls and women with burn scars have a more negative body image than boys and men with burns. This was found to be particularly true for adolescent girls who have breast scars.

Knudson- Cooper and Thomas (1988) contend that the process through which altered physical appearance due to a burn injury is accepted and integrated into a person's self-concept and body image, is similar to the "grief-process" described by Kübler-Ross (1970). Kübler-Ross (1970) has identified six stages of grief and these stages can be identified in both the burned child and the family. At first, there is a stage of emotional numbness, when nothing seems real, followed by denial that the burn injury could be as bad as it is. Then comes anger and guilt, when one asks, "Why me?"; "Why my child?"; "Why now?"; "What did I do wrong?"; "How could I have let this happen?" During this stage, both the child and the family re-experience the burn accident in their minds, trying to figure out why it happened and what they could have done to prevent it.

Although these stages tend to occur one after another, Knudson-Cooper and Thomas (1988) observe a shifting back and forth between emotions and stages. This occurs because burn patients, especially growing children, often require extensive or reconstructive surgery involving repeated adjustment to a new appearance; the process of adjustment for the child and family can therefore be prolonged over many years.

An awareness of the repeated adjustment to new appearance that burn survivors have to face can help professionals or family members to provide support during grief processes in burn survivors and so facilitate healthy adjustment to bodily changes.

### **Impact of a burn injury on the family**

Knudson-Cooper & Thomas (1988) stress the fact that a childhood burn injury should be viewed as a crisis for the child *and* his family. It is a sudden, traumatic experience that changes the life of the victim and those closest to him/her. It is usually an experience that requires new coping skills and leaves both the child and the family emotionally vulnerable.

Using the Parenting Stress Index (PSI), Blakeney, Moore, Broemeling, Hunt, Herndon and Robson (1993) examined parental stress at various time periods after the child's burn. It was found that parents reported significant depressive symptoms at two years post-injury. There is no doubt that parents who are depressed will be compromised in their parenting abilities and in the support that they can offer their burned child.

Knudson-Cooper and Thomas (1988, p.348) refer to guilt as one of the main sources of emotional stress for parents and other family members. "All parents feel guilty about the burn accident, whether they were actually involved or not. They feel that somehow they have failed in their role as protector of their child". There is also the fear that the child will never forgive the parents and blame them for the accident. They go through a process of imagining what they could have done, or not done, to prevent the accident. Knudson-Cooper and Thomas (1988)

suggest that having to observe their child in pain and being unable to stop it, accompanied by the knowledge that their child will be permanently disfigured and possibly disabled, adds to the guilt. Mason (1993) found that in addition to feelings of guilt, mothers of burned children feel a desire to protect the child from any further harm. According to Mason (1993, p.496) this involves “spoiling the child to repair the damage done to him/her and anxiety at any further potential danger to the child, resulting in the mother becoming protective with the child to the extreme”.

In a separate study of mothers of children with burns, 52% met criteria for a diagnosis of post-traumatic stress disorder and larger burns were strongly correlated with symptoms in the mother (Thomas, Meyer & Blakeney, 2002). Research indicate that family members may continue to experience symptoms of post traumatic stress after a patient has returned home ( Blakeney et.al., 2002). In a study by Mancuso, Bishop, Blakeney, Robert, Gaa (2003) the psychosocial adjustment of 79 siblings of children suffering from burn injuries was investigated. Nonparametric statistics were used to compare psychosocial adjustment of the study group, as measured by the Child Behaviour Checklist with an age matched and gender-matched reference group. The study found that the study group fared worse than the normative group on overall competence, particularly social competence. The results indicate that the burn injury to one child in a family significantly impacts the siblings of that child. Therefore it is important not to “forget” siblings of burned children when planning psychological support services for the family.

Literature regarding the matter of psychosocial adjustment of the burned child seems to regard social support, particularly from the family, as the most consistently recognised contributing factor to the positive psychosocial adjustment of the burned child (Blakeney et al., 1990; Blakeney et al., 2002; Browne, Byrne, Brown, Pennock, Streiner, Roberts, Eyles, Truscott & Dabbs, 1985; Bryant, 1996; Knudson-Cooper & Thomas, 1988).

Forshaw (1987) has identified burn injury events as being more frequent among families with poor socio-economic status, where poverty, poor housing , inferior

diet and overcrowding interact and can lead to sudden tragedy, particularly in the one-parent family. In addition Van Niekerk et al. (2004) found that low socio-economic status of the family, low educational level of the mother and psychosocial stress in the family are all linked to increased risk for childhood burn injuries. This is critical and impacts on the long term recovery period since research has found that positive psychological adjustment was predicted by greater family cohesion, independence and more open expressiveness within the family (Blakeney, Portman & Rutan, 1990). This may be more difficult for a child in a family with poor social problems and lack of family commitment and cohesion. The opposite extreme as Blakeney et al. (1990) reveal, is that poor psychosocial adjustment is predicted by a family environment that is characterised by conflict and diminished cohesion, which can also be predictive of alcoholism, delinquency and other disturbances. The fact that approximately 6 out of 10 children in South Africa live in poverty, when "poor" is defined by the poorest 40% of households (Biersteker & Robinson, 2000), paints a dim picture of not only the possibility of sustaining a burn injury, but also the difficulties that it most probably will cause in the healthy psychosocial adjustment after a burn injury.

For adolescent survivors, families of well adjusted individuals valued and encouraged autonomy within the context of family cohesion ( Blakeney et al.,1990; LeDoux, Meyer, Blakeney & Herndon, 1998).

It is therefore important to examine not only the effects of a paediatric burn on other family members, particularly the parents, but also how these effects impact on the child's psychological and social adjustment.

### **Conclusion**

The literature reviewed suggests the majority of paediatric burn survivors adjust well psychologically, but that they are also a population at risk of developing emotional and behavioural difficulties relating to the burn injury. These difficulties are manifest as depression, post traumatic stress and body-image issues in burn survivors and their families. The important role of the family as a facilitator of psychosocial adjustment after a burn injury has been highlighted. The literature that was reviewed was mainly internationally based and it would

therefore be important to exercise caution in the interpretation of these findings and generalising them to the South African context. This is also important when one considers that the majority of South African children live in poor socio-economic environments and are exposed to many traumatic events throughout their lives. Only two short internationally based articles (Blakeney, 1995 & Cahners, 1979), dealing with the matter of school reintegration of paediatric burn survivors could be found and scant local knowledge about this topic currently exists.

University of Cape Town

## CHAPTER THREE

### METHODOLOGY

#### **A qualitative approach**

The study was conducted using a qualitative paradigm. This approach provides rich information about the ideas and perceptions of participants. In this research the participants were paediatric burn survivors, and their parents and teachers. Knudson -Cooper and Thomas (1988) stress the fact that children who are burned are individuals who are members of families with a particular socio-economic and cultural background. They must function in the context of these social relationships when they return home. For this reason it was important to understand the burn survivors' psychosocial environment before the burn, during hospitalisation, and post-discharge. Furthermore, by gaining such a contextual understanding, valuable recommendations could be made to assist in the planning of future psychological rehabilitation interventions. Miles and Huberman (1984) argue that qualitative approaches offer researchers the best means of "expressing social phenomena as precisely as possible by attending to their range and generality, and to the local and historical contingencies" (p.21). According to Swartz (1989) within a new approach to psychology in South Africa the researcher does not attempt to impose his/her framework onto the data, but instead, "the structure has presented itself from within the data" (p.190). The adoption of this approach requires that the idea of an underlying truth/reality, which a researcher attempts to uncover, is abandoned (Swartz, 1989). In this study meaning was explored through the individual perceptions of the participants.

#### **Sample**

In order to explore the psychosocial adjustment of paediatric burn survivors during the school reintegration process it was decided to interview the burn survivors, their parents and their school teachers. A study by Blakeney et al. (1993) highlights the value of collecting data from multiple sources. In research

undertaken by Andersson et al. (2002) it was found that mothers rated their children as more troubled in terms of differences to norm groups, than either teachers or children themselves. Therefore the inclusion of teachers in this study was seen as particularly important. Hereafter the term “participants” will refer to the paediatric burn survivors who participated in the study, whereas their respective parents and teachers will be referred to as “parents” and “teachers”.

### **Sample criteria**

In order to qualify as a paediatric burn survivor the participant had to have sustained a burn injury before the age of 13 years and the burn injury must have been severe enough for admission to the burns unit at the Red Cross Children’s Hospital. The present admission protocol followed by the burns unit at Red Cross is that children require admission if they have sustained a burn injury that is greater than or equal to 10% of the total body surface area (TBSA) (Van Niekerk et al., 2004).

Since the study aimed to explore issues related to the psychosocial adjustment during the school reintegration process, participants had to have been of school going age and attending school. A study by LeDoux et al. (1998) found that burn survivors experience the first two years following the burn injury as the most difficult in terms of psychosocial adjustment. For this reason it was decided to include participants whose burn injury did not occur more than two years ago.

### **Participants**

The participants comprised of 7 paediatric burn survivors ranging in age from 5 to 14 years. In terms of gender, 2 participants were male and 5 were female. Regarding race, 1 participant was Coloured, 2 were White and 4 were African. Regarding language, 3 participants were Afrikaans speaking and 4 were Xhosa speaking.

A brief introduction of the participants will follow below. In the short presentation of each participant, information such as current age, age at the time

of the burn injury, aetiology of the burn injury and other significant aspects will be conveyed. All participants names have been replaced with pseudonyms to ensure confidentiality.

#### Anneke

Anneke is a 10 year old girl who sustained an 85% TBSA flame burn to her entire body, when she was 9 years old. She lives with her mother and two siblings in a house in a middle class neighbourhood in a Boland town. Anneke, her father and her brother were burned, when a defective gas bottle caught fire and exploded in their holiday home. Her parents are currently separated, but they also experienced marital problems before the accident happened. Anneke, her parents and her brother are currently on anti-depressant medication.

#### Berna

Berna is a 13 year old girl who sustained a 10% TBSA flame burn to her face and upper torso, when she was 12 years old. She lives with her mother and father in a house in Goodwood. She has one brother who is married and whom she sees occasionally over weekends. She and two boys were throwing “spirits” on an open fire when her clothes caught fire. Berna’s mother mentioned symptoms of depression for the past years. She also uses sleep medication on a regular basis.

#### Noluthando

Noluthando is a 15 year old girl who sustained a 40%TBSA flame burn to the side of her face and upper torso, when she was 14 years old. She lives with her mother in a shack in Samora Machel informal settlement. She got burnt when a defective gas bottle exploded in her aunt’s home. The gas caught fire because of a candle that was standing nearby. Her mother recently lost her job and phoned me shortly after the interview, asking if I could find her employment.

#### Anele

Anele is a 9 year old boy who sustained a 30% TBSA flame burn to his face and arms, when he was 8 years old. He lives with his mother, older sister and his baby nephew in a small house with two rooms in Makhaza, Khayelitsha. He got

burnt when a friend threw a burning tyre at him whilst playing. His clothes caught fire and he was helped by some adults who heard his screams.

### Ganief

Ganief is an 8 year old boy who sustained a 10% TBSA flame burn to his right leg, when he was 7 years old. He lives with his mother, two siblings and his mother's cousin and her family in a two bedroomed flat in Hanover Park. Ganief was burned when a man from his neighbourhood threw turpentine on an open fire and Ganief's trousers caught fire. Ganief was involved in a sexual abuse case where he was the perpetrator and the mother of a fellow learner at the school complained to his school teacher about the incident. He also struggles with a learning problem and does not make much progress at school. His stepfather was jailed a few months ago for assaulting and beating the mother and children.

### Bulelwa

Bulelwa is a 5 year old girl who sustained an 80%TBSA flame burn to her entire body when she was 4 years old. She lives with her parents, elder brother and a male family member in a shack in Langa. The accident happened one evening at approximately 19h00, when her mother left her alone in their shack to go to the toilet in the main house on the property. Her father was watching television at one of the neighbours. The mother explains that the gas stove was on at the time, because she was busy boiling water to prepare food for supper. Apparently Bulelwa took a box of matches and set the side of the shack (which was filled with cardboard) alight. By the time the mother got back she just saw smoke coming from the shack and found Bulelwa inside. Her clothes caught fire. They struggled to get inside the shack, because the door was locked and the father had to kick off the door.

### Denise

Denise is a 6 year old girl who sustained an 80% flame burn, when she was 4 years old. She lives with her parents in a small one roomed house in Philippi. She and a friend were playing in her grandmother's house when the accident happened. They switched on the two plate stove and whilst playing, Denise fell against it and her dress caught fire. Her friend got such a fright when he saw

her dress burning that he decided to run out of the house for fear of punishment. Denise's grandmother eventually heard her screams and on investigation saw what happened. She was then taken to the day hospital.

### **Parents**

The sample of parents was mainly comprised of the biological mothers of the participants. One participant was taken care of by his adopted mother. In one case both the mother and father of the participant were interviewed. 3 of the mothers were single parents. One of the participants' parents recently separated and she saw her father sporadically during the week and some weekends. Interviews were conducted with 6 mothers and one parental couple.

The following table provides socio-demographic information about the parents:

Parents of	Age	Language	Race	Education	Employment	Monthly Income	Marital status	Number of dependants
Anele	47	isiXhosa	African	Grade 3	Unemployed	R200	Widow	2
Bulelwa	28M 33F	isiXhosa isiXhosa	African African	Grade 7 Grade7	Unemployed Unemployed	R180	Married	3
Ganief	33	Afrikaans	Coloured	Grade 7	Disability grant	R930	Single	3
Noluthando	40	isiXhosa	African	Grade12	Employed	R1400	Single	1
Berna	48	Afrikaans	White	Grade10	Unemployed	R2500	Married	1
Denise	22	isiXhosa	African	Grade 9	Employed	R2300	relationship	1
Anneke	36	Afrikaans	White	B.A degree	Employed	R7000	Separated	3

### **Teachers**

The class teacher of each participant took part in the study. In one case the class teacher of the previous year of the participant was also interviewed, since her present class teacher felt she could give valuable information about the participant. In total 8 teachers were interviewed.

## **Procedure**

### **Recruiting the sample**

The sample was recruited from the admission records of the Burns unit at the Red Cross Memorial Hospital. The search was conducted manually since these records are not available on a computerized database. As mentioned above the research called for participants that sustained their burn injury not more than two years ago. The records between the beginning of 2003 and August 2004 had been misplaced and this complicated this task as it restricted the number of possible participants available to be contacted. A further complication was that many records lacked information like the age of the child or a contact telephone number. In the end the search yielded 18 participants who met the sample criteria. An attempt at telephonic contact was then made where the nature and purpose of the study was explained to possible participants' parents/caregivers. Of those 18 only 4 participants could be successfully recruited. The reasons for this were either that the parents did not want to take part in the study, or the contact telephone numbers were invalid or outdated. The other 3 participants were recruited by arrangement with a community worker who does follow-up visits of some patients of the Burns unit.

### **Data collection**

Data was collected by conducting semi-structured interviews with each participant and their respective parent/s and teacher. Semi-structured interview schedules for the participants, their parents and their teachers were constructed. Questions in the interview schedules comprised of both close ended and open ended questions. The structured or close ended questions were asked to elicit specific information related to important content areas with regard to psychosocial adjustment. The unstructured or more open ended questions in the interview were useful in exploring individual experiences related to the research question. The following broad areas were covered in the interview schedules:

- Biographical/demographic information about both the parent/s and the participant so as to establish a clear idea of the social and family environment.
- Medical history to determine pre-morbid pathology.
- Detailed questions about the burn injury (when, how, length of hospitalization, surgical procedures and subsequent hospitalizations.
- Questions to elicit participant's attitudes towards their scars/how others react to their scars and how participants respond to these reactions from others.
- Questions to determine current mental state i.e. screening questions for depression and post traumatic stress disorder.
- Questions relating to the school environment i.e. school work, peer group socialization, or any difficulties that are experienced in the school environment.

Copies of each interview schedule are attached.

Interviews with the parents and participants were mainly conducted at each participant's home. In two cases a different location was used due to practical reasons. In the one case a participant and her parents were interviewed at St. Josephs School (where she stays during the week) and in the other case the interview was conducted in a social worker's office at the Hanover Park community health clinic. The latter location was chosen after it was found that the home environment of the participant did not allow for a private and relatively quiet area where the interview could be conducted. The fact that some participants were seen in their home environments and that I could visit and experience their school environments to a certain extent was found to be extremely valuable for the study. It provided rich contextual information about their home and neighbourhood environments that I would have missed when interviewing them in, for example, the hospital.

The duration of the interviews ranged from 15 minutes to 90 minutes depending on the spontaneity of each individual and their willingness to provide information that was sometimes of a sensitive nature. In general the interviews with the teachers and participants were shorter than those with the parents. Interviews were conducted in English, Afrikaans or isiXhosa, depending on what each individual that was interviewed preferred. In the case of isiXhosa being the preferred language of the interview, the assistance of a translator was used. In cases where participants, parents, or teachers did not understand questions, an effort was made to explain or simplify questions so it could be better understood. Interviews were audiotaped using a digital recording machine.

### **Ethics**

Ethical approval for this study was obtained from three different institutions that required ethical approval of research conducted in that specific institution. Firstly, ethical approval was obtained from the Ethics Committees of the Faculty of Medicine and the Psychology Department at the University of Cape Town. This approval together with approval from the Red Cross Hospital Administration allowed access to the admission records at the hospital. Secondly, approval by the Western Cape Education Department allowed access to the participant's schools, to conduct interviews with teachers.

Informed consent was obtained from parents for their own participation, but also for participation of their child and their child's teacher. This was done, because all the participants were under the age of 18 years and thus not considered legally capable of providing informed consent. During the recruitment process parents were asked to also inform their children about the nature of the research, so they could have an understanding of the reason behind the interviews. During the interview participants were again informed about the nature and reason for the interview, to make sure that they had some understanding of why they needed to speak to a total stranger. Permission was asked to audiotape interviews and participants, parents and teachers were assured of confidentiality and anonymity throughout the research process. For

this reason all the participants' names were replaced with pseudonyms in this dissertation.

Two referral appointments to mental health facilities were arranged by myself where it seemed necessary and appropriate services were available. The one was a case of sexual abuse committed by an 8 year old participant that came to my attention and was not followed up by the participant's school or parent. The case was referred to the community social worker. The other was a referral to a school social worker where parents expressed a need to find out about a disability grant for their daughter.

### **Data Analysis**

A process of thematic content analysis was used to analyse the qualitative data in this study (Smith, 1995; Ely, 1991). This process began with the transcribing of the verbatim narrative of the interviews. After all the interviews were transcribed, each interview transcription was read and re-read to get a sense of the detailed information provided during the interviews. During the process of reading through the raw material, marginal notes were made, noting different themes that seemed to emerge from the material. Verbatim quotes that were particularly descriptive of a certain theme were also highlighted during this process. These themes were then grouped into broader categories according to their content.

The analysis was informed by the approach of Terre Blanche and Kelly (1999) who argue that a key principle of interpretive analysis is to stay close to the data and to interpret it from a position of empathic understanding. Furthermore the purpose is not to collect bits and pieces of "real life", but to place real-life events and phenomena into some kind of perspective. In the discussion of findings of this study links are made to the findings of literature in the field.

## **CHAPTER FOUR**

### **RESULTS AND DISCUSSION**

#### **Introduction**

In the discussion of results that follows there will be a focus on four broad themes that were identified as meaningful units during the process of analysis. Firstly, there is the family context of the burn survivors where important observations were made with regard to the parents' socio-economic status and levels of education, their premorbid functioning and the general family environment. Secondly, the impact of the burn injury on the family system, including the strain of hospitalization, specific challenges for parents relating to the burn scars and the impact of the burn injury on siblings will be discussed. Thirdly, the analysis will turn to the individual difficulties presented by the participants, with regard to their premorbid functioning and psychosocial difficulties experienced after the burn injury. Lastly, the school context of the participants, including the reactions of teacher's to the burn scars, communication between parents and the school, and the needs expressed by teachers will be explored.

#### **Discussion**

##### **The family context of the participants.**

##### **Parents' socio-economic status and levels of education**

The following findings with regard to the socio-demographic information of the participants and their parents were found to be common across the group. (Please also refer to the table about the socio-demographic information provided in Chapter 3.) From the information provided in the table it becomes clear that 5 of the 7 parents of the participants were poorly educated. Only one participant's mother obtained a university degree and another participant's mother matriculated. The rest of the participants' parents' education ranged from Grade 3 to Grade 10. It was also found that 6 out of 7 participant's parents were struggling financially in some way. This was evident from information obtained

from parents regarding employment status, income levels, number of dependents in a household and other sources of financial support.

Bulelwa's parents described how financial constraint sometimes prevented them from visiting their daughter in hospital: "We were going there [to the hospital] every day. If we don't have money that day we did not go." Later during the interview, they also mentioned that they sometimes walked all the way from Langa to the hospital (distance of 5 kilometres), when they did not have enough transport money. Anele's mother expressed a need for better financial support from the government, because she believed that this would help her to better deal with the difficulties Anele is experiencing after the burn injury: "I tried my best. I went to the social worker, because I wanted a grant, that disability grant. But I did not get any help from her". She also believed that she would cope better with the problems Anele is experiencing after the burn injury if her financial situation would improve. She mentioned how she was trying her best to improve her financial situation and described how she belonged to a "gooi-gooi" club to save money:

I will try my best as I am doing now. And in our community we have the gooi-gooi where you contribute R50 and at the end of the year you will get the money and buy stuff.

(Anele's mother)

Ganief's mother reported that she did not always have enough money to ensure that her children got food on a daily basis:

Elsje: Die gemeenskap, die klein "community" waar jy bly, is hulle "supportive" of is elkeen maar net vir homself? (The community where you stay, are they supportive or does each person just take care of himself?).

Mother: Elkeen is vir homself. Maar die vrou waar ek uithelp, sy "support" my in baie dinge, as ek n probleem het, en ek moet uitgaan, en ek gaan na haar toe, en ek vra vir haar, dan sê sy dis okay. Sy sal altyd vir my vra: 'Het die kinders iets om te eet vanaand?'. Dan sê ek vir haar, nee, en dan gee sy (Each person just takes care of himself. But the woman where I help out at times supports me with many things, if I have a problem and I have to go

out and I ask her, then she says it's okay. She will always ask me if the children as something to eat and when I say no, she just gives).

Elsje: Gebeur dit dikwels dat die kinders nie iets het om te eet nie? (Does it often happen that the children do not have something to eat?).

Mother: Ja (yes).

(Ganief's mother)

The above mentioned findings are echoed in literature that reports that the incidence of paediatric burn injury is higher in deprived families with low-levels of education (Forshaw, 1987; van Niekerk, 2004). Of further significance is the role that socio-economic status plays in the psychosocial adjustment of children after a burn injury. Browne et al. (1985) found that the most psychosocially competent burn-injured children are children from families of higher socio-economic status. These children have better access to mental health resources, medical care and better schools. They also live in social contexts that might educate children out of stigmatizing attitudes to scarring. This highlights the possibility that the poor socio-economic environment of most of the participants in this study could be seen as a factor hampering the process of psychosocial adjustment after the burn injury. In South Africa, the majority of children live in poverty and as Dawes & Donald (2000) argue, it makes sense for mental health professionals to design interventions that will enhance a sense of coping in the child, despite continuing difficulties.

#### Premorbid and current functioning of parents and general family environment

During the interviews it became evident that 3 of the 7 participants have parents who were struggling with mental health problems even before the accident. Furthermore 2 of the 7 participants' mothers reported longstanding marital conflict that lead to separation. In one of these cases the father was jailed for continuous physical abuse of the mother and children.

Anneke's parents were diagnosed with depression and were on medication for it. Anneke's mother mentioned that she was first diagnosed with post natal

depression shortly after Anneke's birth. After that her doctor advised her to stay on anti-depressant medication, because she constantly experienced depressive episodes.

Berna's mother talked about several symptoms of depression that she was experiencing before the accident happened. She was never given a diagnosis of depression by her doctor, but the symptoms she described during the interview combined with my clinical impression of her mental state at the time of the interview warrant a diagnosis of depression. She mentioned the following during our interview: "Ek kan voel daar kort iets, ek voel baie moeg en afgemat en so aan. Party keer baie, ek voel asof ek deur die dak wil klim..." (I can feel that something is missing, I feel tired and worn down. Sometimes I get very frustrated about this). On further enquiry she mentioned that she also struggles with feelings of anhedonia, concentration problems and sleep disturbance for longer than a year. Ganief's mother mentioned that she was "slow" after she sustained a head injury when she was 10 years old. She has been on a disability grant since the age of 21. Unfortunately she could not tell me what her diagnosis was. She mentioned that she cannot work, because "dis nie aldag dat ek dieselfde is nie, en ek is ook nie te vinnig om te werk nie" (I'm not the same every day and I cannot learn fast).

The descriptions of the participants' parents resonate with findings in a study by Kendall-Grove, Ehde, Patterson and Johnson (1998) that parents of burned children have a substantially higher rate of dysfunction as defined by a history of psychiatric illness, substance abuse or involvement with child welfare services. A question that arises when thinking about mental illness in parents of burned children is not only to what extent the parents' parenting abilities were compromised as a result of a psychiatric diagnosis before the burn injury, but also how the mental illness impacts on their ability to cope with the emotional challenges related to the burn injury in their children. As literature stresses the fact that the psychosocial adjustment of the burned child depends largely on the parent/caregiver's adjustment and use of social resources (Blakeney et al., 2002; Browne et al., 1985), it is essential to identify risk factors in the family system that might undermine healthy psychosocial adjustment. A thorough psychological or psychiatric assessment to identify risk factors such as the

presence of a psychiatric illness in parents fell beyond the scope of this study and more local knowledge on this topic could provide interesting and helpful information to assist in the planning of effective treatment plans for burned children and their families.

### **Impact of the burn injury on the Family System**

#### **Strain of hospitalization**

All the parents in the study reported that they experienced the time of hospitalization as particularly difficult and strenuous. Three of the parents encountered difficulty with transport to and from the hospital due to financial constraints. Bulelwa's parents mentioned that they often walked to the hospital from Langa (distance of 5 kilometres), because they did not have money to pay for transport. Caregivers expressed feeling torn between their injured child and work or their other children. One of the mothers explained the demands of the hospitalization period on her:

Yes, when I worked there was often problems and I had to go to hospital...sometimes she was crying or she wanted food and as a mommy I had to go. But it was difficult, because every time I come from work I go to hospital, weekends I spent at hospital. It was so difficult, she wanted to see somebody in front of her and I had to go to hospital every time.

(Noluthando's mother)

Another mother explained how she experienced the hospital building:

Ek het net gevoel soos een wat in 'n tronk sit, ek weet nie hoe om dit vir jou te sê nie. Jy kan nie uitgaan nie, jy kyk in die vensters vas, jy weet hoe is dit by Rooi Kruis...Ek het een aand tot onder daai kind se bed gelê en slaap, ek jok nie vir jou nie.... Nee dit was nie n lekker tyd nie. Dis iets wat ek nie weer wil herleef nie (I felt like being in jail, I don't know how to explain it to you. You cannot go out, you stare at the windows, you know how it is at Red Cross... One night I even slept underneath that child's bed, I'm not

lying to you. No, it was not a nice time. It is something that I do not want to experience again).

(Berna's mother)

These findings highlight the strain experienced by parents during the child's hospitalization period. Most of the parents reported that they did receive some form of support from family members or friends during the time of hospitalization. In most cases the support was very limited though, and mostly consisted of occasional visits to the burned child so that a parent/caregiver can get "some time out", or taking care of siblings at home. These findings make it clear that each family involved with a burned child has unique needs that need to be established by members of the burn team responsible for psychosocial rehabilitation or therapeutic support. Sometimes it can be transport costs to and from the hospital, sometimes a few people taking turns to "relieve" the parent/caregiver from being ever present at their child's bedside, or sometimes just being attuned to a distressed and tired parent, providing a space for them to talk about their difficulties. Since we know that parents are the most important facilitators in the positive psychosocial adjustment of paediatric burn survivors, it is important that they get enough support during the difficult time of hospitalization so they can also provide better support for their children.

#### Parents reactions to disfigurement

Most of the caregivers reported that they were experiencing difficulty in accepting their children's scars and that during the period of hospitalization and thereafter their main concerns were around the scars:

The scars. That was my biggest fear. You know, as a child I saw people who burnt, you know you get that feeling, wow! And then I thought Denise is such a beautiful child to me, you know. I'm sure every mother their child is the most beautiful to them, but how is she going to handle that with all the scars? You know I'm thinking will she have a boyfriend? You know with all the scars because when she burnt badly the doctors said to me, they will see when she is about 13 what will happen to her breasts. Because it's her

concern also, she says to me: 'Mommy will I have breasts?'. Then I say euh. Yes, I don't want her to ask me these questions because I don't know what to say. I start shivering. Then I say, we'll see, we'll see Denise. Don't think about that. And then like the scars were my worry.

(Denise's mother)

Another mother expressed a feeling of something being torn from her when she looks at her child's scars:

Jy weet dit aan die een kant, dit voel nie soos myne meer nie. Dit voel of dit weggetrek is, verstaan jy wat ek bedoel? Ek weet nou nie wie kan ooit verstaan nie. Voel of een stuk van jou weggeruk is (You know, it does not feel like mine anymore. It feels as if it has been torn away, do you know what I mean? I do not know who will ever understand. It feels as if one piece has been torn from you).

(Berna's mother)

Most of the parents mentioned that they hoped for the scars to "look better" or "heal" in future and were actively trying to make the scars "look better" by applying, for example, "Bio-oil". One of the participant's mothers encouraged her daughter to wear clothes that could hide the scarring on her arms and chest.

These findings give an indication of the anxiety and sense of loss that some parents feel in relation to their child's disfigurement. It resonates with the findings of Knudson-Cooper & Thomas (1988) about the reactions of parents to their child's disfigurement. They argue that family members go through a grief process in order to learn to accept their child's changed appearance after the burn injury.

Another reaction of parents to their children's disfigurement that was noted during the interviews was a sense of "overprotectiveness" that developed in most of the parents. This was also confirmed during the interviews with the burn survivors. Denise's mother reported how she does not want Denise to undress in front of other children:

Not that I am hiding anything but, when, like for instance the swimming thing. I don't want her to take off her clothes when I'm not there. You know, kids are cruel. That is why I don't want her to take part in the swimming.

(Denise's mother)

Anneke's mother mentioned how she sometimes still dresses Anneke (who is now 10 years old and fully capable of dressing herself) for school in the mornings:

Sy is 'n kind wat in die oggende baie 'grumpy' is en ek moet haar basies soos 'n lappop regmaak vir skool. Ek trek haar aan en ek maak haar hare vas, en stuur haar dan na die kar toe (She is a child that can be quite grumpy in the mornings before school and I have to help her as if she was a doll. I dress her, tie her hair and send her to the car).

(Anneke's mother)

One of the girl participants mentioned how she sometimes feels alone when her parents do not want her to play with friends in the afternoon after school. Apparently they changed their "rules" after the burn injury, because they are constantly "worried" that something "bad" might happen to her again. She could not understand why they were being so concerned, because as she explained it: "ek het mos nou 'n selfoon" (I do have a cellphone).

These findings highlight the anxiety experienced by parents with regard to their child's safety and well being after the traumatic experience of a burn injury. The tendency of parents to become overly protective of their burned child finds support in literature (Knudson-Cooper, 1988; Mason, 1993). Unfortunately this might have a negative impact on the psychosocial adjustment process for their child. By being overly protective they are not encouraging their children to deal with and work through the difficulties they experience around their changed bodies. Instead they are encouraging denial and sometimes fostering dependence in their children that is counterproductive when they have to master specific challenges relating to the burn injury and their specific developmental stage. The fact that some parents also encouraged their children to "hide" the scars could enhance the development of a sense of shame about the scars in their child. An

awareness by members of the burn team or other professionals dealing with the support of the family of burn survivors or burn survivors themselves of these tendencies in parents is important as they might hamper the child's healthy adjustment after a serious burn injury.

#### Impact of the burn injury on the siblings of the burned child

Of the 7 participants in the study, 3 had siblings that were between 2 years and 13 years of age. Two participants each had 1 sibling that was much older (between 20 and 30 years old) and 2 participants were single children. One of the mothers of a participant with young siblings reported having difficulties with her other children as a result of the burn injury sustained by the participant. She mentioned that she could not give them the attention that they needed during the period of hospitalization and that they had to cope without her for most of the day. She describes this in the following quote:

Dan moes ek huis toe kom en dan is hier twee kinders by die huis wat ongelooflik "needy" was, want Monique. was toe twintig maande oud gewees. Sy het nie geslaap in die nag nie. Sy het herhaaldelik siek geraak en heelnag by my in die bed geslaap. Ruan moes, ek dink sy kinderdae het net daar geeindig, dit was eintlik ontsettend erg, want hy het my so nodig gehad en ek het net nie gehad om regtig nog te gee nie. So hy was deur 'n redelike afskeep stadium (Then I had to come home to two children that were incredibly needy, because Monique was 20 months and did not sleep at night. Ruan's childhood basically ended there, it was actually quite bad and I was too drained to give any attention to him. So he was somewhat neglected during that time).

(Anneke's mother)

Furthermore one of her children complained that the burned child is being favoured by the mother:

...omdat Ruan baie gesukkel het met dat dit vir hom voel asof Anneke voorgetrek word, sulke simple goed soos sy moes spesiale skoene kry, wat opgebou is, en dan was hy soort van ja, maar Anneke kry nou hierdie

opgeboude skoene en wat kry hy nou? En ek vra vir hom wil jy ook opgeboude skoene hê? Ja, maar hy wil nou iets anders hê. Ja dit was baie moeilik dat daar onkostas, en aandag, en terapie, en goeters aan haar gegee is, wat hy half jaloers op was... (Ruan struggled because he felt as if Anneke was being favoured, simple things like the fact that she had to get built-up shoes. And I asked him if he also wants built-up shoes. He wanted something else. I was difficult that a lot of money was spent on her and that she received attention. He was jealous).

(Anneke's mother)

This finding is in keeping with literature that reminds that the burn injury to one child in a family significantly impacts the siblings of that child (Mancuso et al., 2003). It can easily happen that the siblings of a burned child are “forgotten” throughout the traumatic and often life threatening ordeal for the family. This problem is exacerbated by the fact that siblings of burned children are often not seen in the wards of burn units during the period of hospitalization or follow-up treatment, because of practical reasons. They are therefore often not included in family support groups that are provided at burn units and their adjustment difficulties after the burn injury are thus not addressed. As can be seen in the quote above the psychosocial difficulties experienced by the siblings of a burned child can then add to an already stressful situation at home and in the family system. Not much research has been done about this topic and further research could yield interesting findings about the effect of the burn injury on siblings and the broader extended family. More research on the matter could also help to inform support services for burn survivors and their families, by looking at ways of addressing this issue and including siblings and maybe also other members of the extended family when intervening. This becomes particularly relevant in the South African context where the extended family still plays an important role in the lives of many children.

### **Premorbid functioning of participants.**

Four participants were struggling with emotional, behavioural or scholastic problems before the injury happened. Anneke was diagnosed with “Sensory

Integration Syndrome” when she was two years old and her mother explained that they have learnt to cope with it in the family over the years. She gave a vivid account of what she described as Sensory Integration Syndrome in the following:

Weet jy, dit het begin toe sy so 9 maande oud was, wat sy net verskriklike “tantrums” gegooi het. Sy sal sit en speel en dan die volgende oomblik hak haar kop net uit en dan skree sy vir ’n driekwart uur aanmekaar en sy sal haar eie hare trek, en my hare trek, en my vingers byt, en haar eie vingers byt en dit so trek en slaan, en skop, en skree, ontroosbaar soos ’n wilde dier (You know, it started when she was about 9 months old that she started throwing tantrums. She would sit and play calmly and the next moment start screaming for three hours and pull her hair and bite my fingers and her fingers and hit and kick like a wild animal).

(Anneke’s mother)

Anneke also displayed suicidal ideation in the period before the burn injury, and her mother was about to seek psychological help when the burn injury happened.

Ganief’s teacher and mother explained that he was struggling a lot at school, especially with reading and writing and that he currently receives remedial help from the remedial teacher in his school. His teacher also referred him to the school clinic for a proper psychometric assessment, but complained that the school clinic or school psychologist was not doing anything about the referral. In addition to a possible learning problem he has also been found to steal money even before the burn injury.

Anele’s teacher mentioned that his former teacher complained to her about Anele’s hyperactive and disruptive behaviour and that he experienced concentration difficulties. This was confirmed by his mother, who mentioned that he always struggled to concentrate on homework tasks.

Noluthando’s mother and teacher both referred to her “shyness” and that she is often “afraid” or “too scared” to talk to people. These descriptions could be called feelings of “low self-esteem” in psychological terms. This was the case even before the burn injury. Her teacher also mentioned that she was a “slow” learner

even before the burn injury, but that this did not concern her (the teacher) much, because she was like “most of the learners” in her class.

These findings highlight the presence of premorbid emotional or scholastic problems in some burn survivors. The presence of pre-injury psychiatric illness in burn survivors has been found in a study by Fauerbach, Lawrence, Richter, McGuire, Haythornthwaite, Schmidt and Munster (1997), but no literature could be found to report on the presence of pre-morbid scholastic problems in burn survivors. It is likely that scholastic performance will be affected by the presence of emotional difficulties or a psychiatric diagnosis, since these problems can impact negatively on cognitive skills required in learning processes. In the same way scholastic difficulties can cause significant emotional distress. Munster (1993) and Blakeney et al. (2002) contend that the better adjusted the burn survivor is physically, emotionally and socially before the injury, the more likely he or she is to adapt adequately after the traumatic incident. Furthermore, Blakeney et al. (2002) found that the trauma of serious injury exacerbates preexisting problems in burn survivors. The importance of understanding the child's functioning even before the burn are highlighted in the above mentioned findings.

### **Emotional problems and behavioural difficulties after the burn injury**

Five of the participants demonstrated emotional difficulties that were reported in either the interview with their parents, or teacher or during the research. These difficulties ranged from symptoms of depression (3 participants), symptoms of PTSD (1 participant), oppositional-defiant behaviour (1 participant), aggressive behaviour towards peers (1 participant) and delinquent behaviour (1 participant). In some cases the symptoms could clearly be linked to the burn injury, for example PTSD symptoms related to the burn injury, or feeling depressed because of disfigurement and peer rejection relating to the disfigurement, or behaving aggressively towards peers when being teased about burn scars. In other cases no clear link between the burn injury and the behavioural problems could be found.

In the case of Ganief, it was found that many of the difficulties that he presented with, could not be clearly linked to the burn injury. He was a very troubled boy in many respects. He struggled with a learning problem, demonstrated delinquent behaviour when his teacher discovered that he stole money from his school, was a perpetrator in a sexual abuse incident and demonstrated suicidal behaviour when he tried to jump from a flat window (on the first floor). Fortunately a neighbour alerted his mother in time. In his case the question arose about the impact of his family environment on his behaviour, because there were clear indicators of a dysfunctional family system and poor socio-economic status. It seemed as if the impact of his dysfunctional family environment outweighed the impact of the burn injury by far. As became evident in the results, other participants also presented with “difficult” family environments preceding the burn injury and some participants also had parents with psychological problems.

These findings confirm the existence of emotional and behavioural difficulties and symptomatology in paediatric burn survivors. In some cases it indicated distress experienced by the child as a result of the burn injury and in other cases it is an indication of factors in the child’s environment that cause significant distress and result in behavioural difficulties. These results are confirmed by literature that found the presence of emotional and behavioural difficulties in paediatric burn survivors (Stoddard et al., 1992; Powers et al., 1994; & Saxe et al., 1998) and also stress the role of the family context in the psychosocial adjustment after a burn injury (Browne et al., 1985; Bryant, 1996, Blakeney et al., 2002; & Knudson-Cooper & Thomas, 1988). The presence of depressive symptoms in 3 participants of whom 2 have parents who reported that they experience depressive episodes, could partly be explained by literature, such as findings in a study by Moore et al. (1993) that stress the impact of genetic factors in the development of depression in burn survivors. Unfortunately it was beyond the scope of this study to gain an in depth understanding of the family dynamics of participants and the role it played in current difficulties, but this could be an important area for future research.

### **Learning difficulties and academic performance after the burn injury**

All the participants' parents and teachers reported that the participants were struggling with some academic problem after the burn injury. As mentioned above, in some cases there was clearly a pre-existing learning problem (Noluthando, Anele, Ganief) that continued to be a problem after the burn injury. Ganief's teacher raised her deep frustration with the state of affairs in the school system, when it comes to referral and suitable placement of children with a learning problem for assessments. She expressed this as follows:

Onse kinders bly net hierso, dis 'n dead end and we actually can't do anything... (Our children just stay here, it is a dead end...).

(Ganief's teacher)

Only one participant received home schooling during her absence from school after the burn injury. Of the other 5 participants that were attending school before the burn injury only one was given home work by their class teacher to help them "catch up" while they were absent from school. Reasons that were given by teachers for not arranging homework included the following: feeling sorry for the child, doubting the parents' ability to explain homework tasks to the child, or thinking that a child would not be able to perform activities like writing because of pain and discomfort experienced during hospitalization.

In some cases academic difficulties developed after the burn injury. Bulelwa's teacher reported that she experienced difficulty with tasks that required fine motor skills after the burn injury, especially because she had severe skin contractions in her right hand (as a result of the burn injury). Denise's teacher mentioned a language difficulty, but she attributed this entirely to the fact that it was Denise's (who is Xhosa speaking) first year in an English speaking class. Anneke's teacher and mother mentioned some difficulty with Mathematics and writing after the burn injury and attributed that to the fact that she missed 9 months of schooling after the burn injury. It was expected that the home schooling she did receive during the months that she did not attend school would help her, but her teacher felt that she still had a lot of "catching up" to do. As a consequence of her difficulties with especially Mathematics, Anneke received

remedial help on a weekly basis. Berna's teacher reported that he could not really see a significant change in her academic performance after the burn injury, but that he observed times when there was a significant "dip" in her academic performance. He could not explain these fluctuations in performance that only presented after the burn injury.

These findings suggest that school work missed during a long period of hospitalization was a challenge for some of the participants where in some cases it acted as an additional stressor to an already existing learning difficulty. In other cases it resulted in academic lag. The fact that one of the participant's teachers could not explain fluctuations in academic performance after the burn injury could be an indication that an emotional component is playing a role in her performance. During my interview with this participant, she told me about times that she would feel depressed and lonely (for a day or two) and it could well be that these emotional "dips" impacted negatively on her academic performance.

The way in which the majority of teachers in this study failed to arrange homework for the participants highlights the fact that teachers are often ill informed about the impact of a burn injury on a particular learner and the extent to which a learner will be able to cope with homework tasks. Blakeney (1995) also found that teachers do not know what can be expected of the injured child, what special needs he or she may have and what his or her physical limitations are.

Ganief's teacher highlighted one of the weaknesses in the South African school system at present, namely the process of referral and placement of children with learning problems. Unfortunately this problem leads to a situation where a child, like Ganief, with a learning problem combined with other psychosocial problems "falls through the cracks" and the child is robbed of professional help that could alleviate additional stress caused by an "unattended" learning problem. This becomes especially true in the case of a burn injured child, where an unattended learning problem or academic lag could cause additional stress during an already vulnerable period of adjustment.

## **Impact of disfiguring scars on individual child**

### Reactions of peers to scars

Almost all of the participants reported acceptance by their peers (especially their friends) of their scars and that many children at their respective schools were initially curious about how it happened and asked them about it, but “did become used to it” after a while. At the same time 6 of the 7 participants experienced some form of stigmatization relating to the scars caused by the burn injury. The stigmatization consisted of openly being stared at in public places like shopping malls, or name calling by peers (especially in the school environment). The following descriptions were given by participants or their parents or teachers of distress and humiliation experienced at the hands of peers:

Children at school call me “Nzekezeke”, who is a kwaito guy who wears a balaclava (referring to the head cover he wears). I told the teacher about it and she then beat the children who said it. There are also other children at school that call me “Kentucky”.

(Anele)

When Bulelwa came back in January, some of the kids in the community used to get scared when they see her. They will run and so Bulelwa would get hurt about that because she wants to play with them. But no one called her names, they just run if they see her.

(Bulelwa’s parents)

One of the participants (Noluthando) was clearly distressed when I tried to explore how she was being teased by classmates:

Elsje: Now, about the time that you returned to school. How was that for you to go back to school after such a long time that you have not been to school?

Noluthando: It was difficult. I was scared.

Elsje: What were you scared of?

Noluthando: Of being teased

Elsje: Did it ever happen?

Noluthando: Yes

Elsje: What did they do or say?

Noluthando: (seems distressed, crying softly)

Elsje: It is difficult to talk about this...

At this point of the interview her mother intervened and remarked that she was not aware of the teasing and that she would have reported it to Noluthando's teacher if she knew. As the interview continued it became evident that the teasing was still taking place and that it was not addressed by anyone.

The stigmatization of burned children is widely acknowledged in literature (Liebowitz, 2001; McQuaid et al., 2000; Gilboa et al., 1994; Jessee et al., 1992), and the above mentioned findings confirm what has been found in literature. At a time when burn survivors need social support from their peers, it is understandable that teasing and social rejection can cause great distress. Noluthando's display of distress when I asked her about her peer's reaction highlights the special vulnerability of the adolescent stage of development with regard to peer group approval. This vulnerability is confirmed by literature (Bernstein, 1990 & Blakeney, 1995) which also stresses that adolescents have to deal with complex body image issues, and these may be particularly stressful for an adolescent with burn scars.

#### Reactions of participants to their scars

It was notable that all the participants in the study were pre-occupied with their scars in some way. Many participants tried to deal with their scars by covering them up. Bulelwa's teacher mentioned that she gets upset when someone takes her hat off, because she has not grown hair after the burn injury. Other participants avoid wearing clothes that reveal their scars, even when this sometimes causes uncomfortable situations (for example, wearing a school jacket

during hot summer days, or not wanting to wear a swimsuit). A few participants expressed concern about the impact their scars will have in the future. Denise's mother reported that Denise once asked her if she (Denise) would have breasts one day (also see quote on page 32), since her chest also got burnt during the burn injury. Berna expressed concern about the impact of her scars on romantic relationships in the future and she also mentioned that her disfigurement makes her feel depressed on some days.

These findings draw attention to the level of anxiety that the participants felt with regard to their scars. All the participants seemed to be self-conscious of their scars and their most popular strategy to cope with their scars was camouflage. It highlights the notion that burn survivors are forced to cope with their changed bodies and that this can cause significant distress. It was notable that some participants were particularly concerned about the effect the scars would have on their future. It is important to be aware of this when thinking about the long term psychosocial adjustment of burn survivors. When some of the younger participants in the study reach adolescence they might develop difficulties that they were not faced with before, based on the particular challenges this phase of development brings with it in relation to burn scars. Literature on the issue of the impact of burn scars on psychosocial adjustment stress the fact that body-image issues come to the forefront during adolescence and thus may cause significant distress for the burn scarred adolescent, who has to negotiate being part of a peer group or having a romantic relationship (Bernstein, 1990 & Blakeney, 1995).

## **School Context**

### **Reactions of teachers to scars**

Blakeney (1995) and Cahners (1979) stress the importance of teachers as roleplayers in the school reintegration process. Just as parents go through the various stages of grief, anger and denial, and have difficulty in accepting the new demands on their lives, so school personnel must be helped to work through their feelings. The information that was gathered during my interviews with teachers highlighted that the majority of the teachers sometimes felt

overwhelmed by certain aspects of having a burn disfigured child in their class. Most of them experienced the first encounter with the child's scars as distressing and reported that they did not know how to really "comfort" the child or how to deal with the scars. Bulelwa's teacher reported the following feelings when she first saw Bulelwa after the burn injury:

You do feel bad, it does get to you, because it's not just her, it's other children as well...Why does something so terrible has to happen with such a small child?

Two of the teachers managed the anxiety that they felt by seeing the burn scars by denying the severity of the scars to themselves and others, or by just trying to ignore the fact that they exist. Noluthando's teacher reported that:

I did not want to show her that I was shocked [when seeing the scars]. I did not react. It was just the same [as before] just the same...

It is interesting to note how teachers coped differently with the burn child in their class. Some used his/her presence to address issues related to burn injury, for example prevention of injuries and sending a clear message that teasing of the burned child will not be accepted. Two teachers (of younger participants) "normalized" the burn scars for classmates and encouraged them to touch the scarred skin on the hands of two participants (after asking first):

I addressed it because on two occasions... but it only happened with 2 children that I know about. But the one child said to me, that she didn't want to hold Denise's hand. It could have been a dance or something and when she was told to take her hand then she refused. And she told me: "Denise was gonna squeeze my hand". And I also know that there was another child... And she's got a little naughty streak in her. And she told Denise: "right now I don't want to touch you". She told her that. So I spoke to the whole class that she doesn't have to be picked on, or to be prejudiced about that thing, that there is nothing wrong with Denise. Denise suffered like a bad thing and she got burnt. We had a whole conversation about children getting burnt, how it wasn't their fault, and that accidents happen.

(Denise's teacher)

They haven't said anything to me as yet about them teasing her or bullying her. I don't. It's a rule in the class. We discuss the rules. If a new learner comes in the class, we discuss the rules again. One of them is you don't bully, you don't tease and you don't call names. And they know I'm going to punish them if they do that. And I reinforce the fact that we are all unique and we are all different because God has made us that way. What has happened to us is tragic but we have to live, like in faith and we have to move on. That is my philosophy in the class. And every time a new learner comes I reinforce it again. So when Bulelwa came I said "yes, she's different, yes she's burnt but you shouldn't be afraid to touch her, you touch her". And the only way to do that is if you [the teacher] do it. You [the teacher] touch the child, you kiss the child. And then the other learners see that it's normal.

(Bulelwa's teacher)

This was encouraging to see, since active avoidance of the issue, does not help to alleviate fears and assumptions in classmates about the burned child. The participants whose teachers openly addressed the scarring were teased less often than those whose teachers avoided the issue. This finding is consistent with literature that contends that education about burn treatment and about needs and limitations of the burned child will diminish anxiety related to the unknown. When anxiety decreases, the need for defensive behaviours such as withdrawal and ridicule will also decrease and the burned child's peers will be more accepting and supportive of him/her (Blakeney, 1995).

### Communication between parents and the school

During the interviews a sharp variation in the quality of communication between parents and the school (teacher or school principal) regarding the burn survivor, was noted. Three of the 7 participants' parents were in regular contact with their child's class teacher and these were not necessarily the children with the most physical, emotional or educational problems. For example, there were two extremes in this regard. Bulelwa started her schooling at St. Josephs School for children with special needs (chronic illnesses and learning problems) at the

beginning of this year after being in hospital for 8 months. By the middle of the year when I interviewed her parents, they have had no communication with Bulelwa's class teacher and they have not even met her. They have also not received any report informing them about her progress. At the time of our interview they expressed a need to know if Bulelwa was going to be allowed to stay on at her school or not (she did not have a chronic illness or learning problem). They seemed to feel anxious about this as they knew that Bulelwa was very happy at this school and that moving her to another school could mean stigmatization at the hands of peers (she was badly scarred on her whole body). They hoped that I could help them with their dilemma. On the other extreme there was Anneke's mother who was in regular contact with Anneke's class teacher about different matters relating to Anneke's well being at school. They would give each other regular feedback about Anneke's academic progress and emotional well being to identify areas where Anneke could be better supported.

Some parents were promised that they would be given home-work for their children in order to "catch-up" with missed work, but this was never realized.

These findings suggest that the quality of communication between parents and teachers of the participants varies greatly. There are certainly many reasons that one could find to explain this phenomenon, and unfortunately this aspect was not explored in depth during this study. One aspect that could have played a significant role in this is assertiveness or lack of it on the side of the parents. In Bulelwa's case her parents did not know that it is their right to be informed about their child's progress or placement status at the school. In the case of parents who were promised that homework would be arranged for their children the same applies. It may well be that some parents are pre-occupied with other difficulties that leaves them with little energy to pursue important information about their child's progress at school, but it could also be that these parents were not assertive enough to follow-up these promises. In a sense the mutual help and support that could be given to a child during the school adjustment process is highly compromised when the school and parents do not have an "open" channel in which important information about the child's progress can be communicated. Blakeney (1995) confirms the importance of good communication between parents and the school, and says that parents should be

empowered to actively participate as appropriate advocates for their child. It is therefore important that supportive work with the family of the burned child focus on the importance of actively supporting the child in his /her return to school as soon as possible. That could include arrangement of homework and continued contact with a class teacher or classmates while the child is still in hospital.

### Needs expressed by teachers

Various needs were expressed by teachers when they were asked what they think could help them cope better with the presence of a burned child in their class. Most teachers expressed a need for some form of educational material or input that could equip them to support the integration of the burned child in their classes. They also mentioned that educational input from an organisation like fire fighters about the prevention and immediate dealing with a fire would be helpful to them.

One teacher expressed a need for better communication between the hospital where the burn survivor was treated and the school. He felt that this could help him to be better prepared for what to expect when such a learner enters his class after being in hospital. He also felt that professionals who dealt with the burn survivor at the hospital could help him or give advice about how to best support and cope with the burn survivor on his/her return to school. He expressed this in the following quote:

Dis nogal moeilik om te sê wat sou kon gehelp het, maar 'n mens sou graag van onderwysdepartement se kant af, of van waar sy behandeling gekry het, byvoorbeeld Rooi Kruis se kant af, net gehoor het: 'Luister hierdie dogter kom vanjaar, sy gaan so lyk, dit is wat u moet verwag en dit is hoe u dit kan hanteer. So, ek dink hulle het haar teruggestuur na my toe, sonder om werklik te sê wat ek kan verwag (It is difficult to say what could have helped. One would have appreciated better communication from the side of Red Cross or the education department, informing one about what happened to the learner and what one can expect and how one can handle it. So I think they send her back to me without preparing me enough).

(Berna's teacher)

Some teachers mentioned that they would like some form of training in trauma counselling with children and they stressed the fact that this was not only needed for traumatic events like a burn injury, but also for other traumatic events that the children they teach have to deal with. Examples of such traumatic events were named as sexual abuse, sexual molestation and violence. Two of the teachers expressed a need to receive counselling from a school psychologist or other professional, to help them deal with "emotionally challenging" aspects in their work. Events that their learners are exposed to and that they as teachers know about included, dealing with an HIV-positive learner.

These findings emphasize the fact that children and teachers in the South African context sometimes feel overwhelmed by the multiple traumatic and stressful events that they and the learners that they teach are exposed to. Cahner's (1979) argues that the school cannot be prepared for the burned child's return through educational materials and pictures alone. School personnel should get therapeutic support in the same way as a burned child's family, because just as parents go through the various stages of grief, anger and denial school personnel dealing with the child must be helped to work through their feelings.

Blakeney (1995) addresses the point of continuing communication between the hospital and the school when she argues that continued availability of burn team professionals is necessary for communication with school professionals as problems arise. She points out that teachers are more likely to report difficulties or ask questions if a resource person in the burn team has been identified. Identifying such a resource person can be quite difficult in an environment, like in many hospitals in South Africa, that is under resourced, especially with regard to psychosocial rehabilitation or therapeutic support for the burn survivor and his/her family, while at hospital and post-discharge. As long as burn units in this country do not have the resources or sometimes do not even see the value of a dedicated professional dealing with psychosocial rehabilitation, an important facilitating tool in the school reintegration of young burn survivors will be lost.

## **CHAPTER FIVE**

### **CONCLUSION AND RECOMMENDATIONS**

#### **CONCLUSION:**

The purpose of this study was to provide insight into the psychosocial adjustment of burn survivors that can inform intervention programmes in this field. Literature on the subject highlighted the enormous challenge that pediatric burn injury poses in the South African context and it was found that scant local knowledge regarding this topic currently exists. The literature reviewed was mainly internationally based and this called for caution when interpreting and generalizing findings to the local context. The positive psychosocial adjustment of the majority of young burn survivors that was highlighted by this body of literature should be seen within the context of resources available in first world countries that ensure better rehabilitation resources available to burn survivors and better social security systems to address the vicious cycle of poverty and its impact on people.

The study yielded important information about the social contexts of a small group of burn survivors and their families and the challenges that they face during the school re-integration process and psychosocial adjustment in general.

The majority of the families in this study were experiencing extreme socio-economic difficulties. This was a strong contributing factor in their limitations to fulfill their roles in supporting the burn survivor. The mental health difficulties of parents as well as participants before *and* after the burn injury showed that the burn injury often meant an additional stress factor to already existing problems.

It was found that the burn injury also poses an additional challenge to most of the interviewed teachers who have to cope with multiple challenges in their classes and therefore have very limited resources (time, empathy, attention) to attend to the specific challenges of the re-integration of burn survivors.

While most of the findings of the study reflected what has been said in literature on the topic, there were layers of problems that were experienced by participants,

their families and teachers specific to the South African context, such as the combination of widespread poverty, unemployment, poor access to mental health and educational resources and living in a violent society.

Despite the significant social problem that pediatric burn injury represents in South Africa, little has been done to create or improve psychosocial rehabilitation resources. This can be seen as a significant factor hampering the psychosocial adjustment process as it fails to identify and treat those burn survivors who are presenting with risk factors to develop serious emotional and behavioural problems.

## **RECOMMENDATIONS**

### **Clinical recommendations:**

#### **Education and training to increase awareness around burns**

- Creation of a small resource centre at the burns unit, where burn survivors, their families and other people (like teachers) interested in information regarding burns can have access to information to raise burns awareness. This resource centre could also become “mobile” by accompanying dedicated and trained volunteers (i.e. psychology or social work students) to different community settings (i.e. schools or community day hospitals) where psycho-educational workshops could be held. This might be incorporated in existing community service structures throughout South Africa.
- Training of nurses, teachers, volunteers and students affected by burn injury to raise awareness about how burn survivors can be supported and to identify burn survivors and families that are especially in need of intervention.

### Psychological assessment and therapeutic support service

- Provision of a psychological assessment service at the burns unit to ensure early detection of risk factors and proper intervention, referral and follow-up of burn survivors and their families.
- This assessment service should include a psychometric assessment service that could inform measures taken to support children who missed a lot of school work during the time of hospitalization. Determining weak and strong areas in a learner's academic performance is important when planning effective remedial support. This information could inform both parents and teachers in how they can support the burn survivor when returning to school.
- The continuation of the parent/caregiver support group as it currently exists in the burns unit is important, but it should extend to a similar service for siblings of burn survivors. Exploring the option of providing similar support groups in strategic community settings could be helpful considering the financial impact for families of transport to and from the hospital.
- Provision of psychotherapeutic crisis support during the initial stages of hospitalization for family members of burn survivors.

### Full time psychologist or social worker in the burns unit

To realize the above mentioned recommendations, it would be necessary to create a post for a qualified and dedicated person such as a psychologist or social worker. An important function of such a person would be to co-ordinate the different support services relating to psychosocial rehabilitation. Apart from providing therapeutic support an important aspect of the job would be to provide training as described in the recommendations. This will ensure that more people develop skills that could support burn survivors and raise awareness in the community.

Such a person could also act as a link between the hospital and the respective school, to ensure the availability of an “open” channel to communicate if problems arise during the school re-integration process.

### **Recommendations for further research:**

Further investigation is needed into the family environments of burn survivors and how family dynamics interplay with risk factors of the child, parents/caregivers and the environment and impact on positive psychosocial adjustment after a burn injury. Research that focuses on the siblings of burn survivors and the psychosocial effect that a burn injury might have on them is also needed. Such research could also provide useful information about the impact that the emotional or behavioral difficulties of siblings has on the supportive role of the family during the psychosocial adjustment process of the burn survivor. A broader exploration of learning problems experienced by young burn survivors with specific focus on the link between emotional distress and poor academic performance would assist in rehabilitation programmes. Special focus on adolescents and how they deal with burn disfigurement at such a vulnerable stage of their development is required. Further exploration of how they perceive and negotiate their emerging sexuality when they have been scarred is needed.

Dawes and Donald (2000) argue that the design, delivery and effectiveness of psychosocial interventions with children and adolescents will be enhanced if they are underpinned by theory and research. However, it is often the case that practitioners and researchers work in different worlds. According to Dawes and Donald (2000) practitioners frequently face enormous demands on their time, and the pressing needs of those they serve call for a quick response. On the other hand it often happens that researchers do not make their findings accessible to their applied colleagues (Dawes & Donald, 2000). A lack of dialogue between practitioners and researchers could lead to ineffective and expensive interventions, a situation that a developing country, like South Africa, can ill afford. It is my wish that this dissertation provides an understanding of

paediatric burn survivors' lived contexts, that can assist practitioners in the design of effective interventions in the field of burn rehabilitation.

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**ADDENDUM**  
**Interview Schedules**

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## **Interview Schedule-Parent**

### **1. Demographic Information (child)**

- 1.1 Date of birth
- 1.2 Present age
- 1.3 Age at the time of the burn
- 1.4 Residential area
- 1.5 Home language
- 1.6 Interview language
- 1.7 Family structure
- 1.8 Living arrangements
- 1.9 School attendance
- 1.10 Grade at school

### **2. Demographic Information (parent)**

- 2.1 date of birth
- 2.2 present age
- 2.3 home language
- 2.4 interview language
- 2.5 level of education
- 2.6 employment status
- 2.7 Living arrangements
- 2.8 Monthly income
- 2.9 Relationship to child
- 2.10 Marital status
- 2.11 Number of dependents
- 2.12 Medical history/ past psychiatric history
- 2.13 Substance use history

### **3. Medical history and information about the burn injury**

- 3.1 description of events surrounding burn injury
- 3.2 severity of the burn
- 3.3 skin grafting or other surgery during initial hospitalisation
- 3.4 subsequent hospitalisation for further plastic surgery
- 3.5 other medical history+current medication

### **4. Hospitalisation**

- 4.1 Tell me about the time when your child was in hospital
- 4.2 What were your main concerns at the time?
- 4.3 Did you visit your child/how often?
- 4.4 Did the child have any contact with school friends/or school teachers?

### **5. Returning to School**

- 5.1 Tell me about your child going back to school.
- 5.2 How long after the burn injury did he/she go back?

- 5.3 Was there any contact with the school during the time that your child was absent from school?
- 5.4 Was homework arranged?
- 5.5 How would you describe your child's academic performance before and after the burn injury?
- 5.6 Do you know if your child was teased or bullied on his/her return to school?
- 5.7 How did he/she react to this?
- 5.8 Did you get help from the child's teacher or the principal?
- 5.9 Did your child refuse to go to school?

## 6. **Disfigurement**

- 6.1 Tell me about your child's scars from the burn
- 6.2 Do they worry you?
- 6.3 How do you think your child is coping with the scars?

## 7. **Physical Disability**

- 7.1 Has the burn affected the kind of activities your child can take part in, or restricted the function of his body in any way?

## 8. **Emotional and Behavioural Problems**

- 8.1 Have you, your family or your child receive any counselling to help you to deal with the burn injury?
- 8.2 Have you noticed any changes in your child's behaviour after the burn injury that concerns you?

### 8.3 *Sleeping behaviour (depression, ptsd)*

- 8.3.1 Does your child sleep through the night?
- 8.3.2 Does he/she have nightmares?
- 8.3.3 Does your child have difficulty falling asleep at night?

### 8.4 *Bladder and bowel control*

- 8.4.1 Does your child wet his bed at night or wet himself during the day?
- 8.4.2 Does your child soil his pants?

### 8.5 *Eating Behaviour (depression)*

- 8.5.1 How is your child's appetite?
- 8.5.2 Has he/she put on weight or lost weight over the last few months?

### 8.6 *Social Behaviour*

- 8.6.1 Does your child often play with other children or does he/she prefer to be on their own?
- 8.6.2 Does your child fight or behave aggressively towards other children?
- 8.6.3 How does your child get along with his/her siblings?

### 8.7 *Suicidal behaviour (depression)*

- 8.7.1 Has your child ever threatened to commit suicide, or expressed a wish to die?

8.8 PTSD

- 8.8.1 Does your child have flashback of the burn accident?
- 8.8.2 Does your child engage in repetitive play in which the themes of the burn injury is re-enacted?
- 8.8.3 Does your child have repeated nightmares after the burn injury?
- 8.8.4 Does your child struggle to concentrate on tasks?
- 8.8.5 Does your child experience bodily symptoms of anxiety like, sweating, tummy ache, increased heart rate?
- 8.8.6 Are your child often irritable and does he/she have outbursts of anger?
- 8.8.7 Does your child have an exaggerated startle response?
- 8.8.8 Does your child avoid places or things that remind him/her of the burn accident?

**9. Social Support system**

- 9.1 Who do you talk to when you experience problems?
- 9.2 Is your family or extended family supportive?
- 9.3 Is the community in which you live supportive?
- 9.4 Do you get support from the church or other organisations when you need help?

**10. Future**

- 10.1 What is your biggest concern when you think about your child's future?
- 10.2 What do you think will help you to deal with your child's burn injury in the future?
- 10.3 What would have helped you to cope better with your child's burn injury?

## **Interview Schedule-child**

1. Some **demographic information** as introduction and to create relaxing atmosphere. Also again explaining purpose of interview.
- 2. Burn injury information**
  - 2.1 Can you remember the time that you got burned?
  - 2.2 What happened?
  - 2.3 What did you do?
  - 2.4 Who helped you?
  - 2.5 Screen for PTSD
- 3. Hospitalisation information**
  - 3.1 Tell me about the time that you were in hospital for the burn injury.
  - 3.2 What happened to you while you were in hospital?
  - 3.3 Did your parents/family visit you?
  - 3.4 Did your friends visit you?
  - 3.5 What did you like about the hospital?
  - 3.6 What did you not like about the hospital?
- 4. Returning to school**
  - 4.1 Do you remember going back to school after the burn accident happened?
  - 4.2 How was it like for you to be back at school?
  - 4.3 How did you find your school work after you returned?
  - 4.4 Did other children tease or bully you?
  - 4.5 Who helped you when you were teased or bullied?
  - 4.6 Did you get help from your teacher?
  - 4.7 How is school for you at the moment?
  - 4.8 Do you get on with your teachers?
  - 4.9 Are there any problems at school? How do you deal with these problems?
- 5. Disfigurement**
  - 5.1 Tell me about your scars from the burn.
  - 5.2 Do they sometimes worry you?
  - 5.3 What worries you about them?
  - 5.4 Do some people sometimes say nasty things to you?
  - 5.5 What do they say?
  - 5.6 What do you do when they say these things?
- 6. Physical Disability**
  - 6.1 Can you take part in any sports or hobbies, or does your burn scars prevent you from doing that?
  - 6.2 Do you need someone to help you to do certain things like dressing, eating or washing?
- 7. Social Behaviour**
  - 7.1 Tell me about your friends.
  - 7.2 Do you have friends at school?
  - 7.3 In the neighbourhood where you stay?
  - 7.4 What do you like about your friends?

7.5 What don't you like about your friends?

**8. Social Support**

8.1 Who do you talk to when you have a problem?

**9. Future**

9.1 What is your biggest worry about your future?

9.2 What/who do you think can help you with this?

### **Interview Schedule- Teacher**

- How long have you known.....(child's name)
- When and how did you find out about his/her burn injury?
- Sometimes people are shocked when they see someone with a burn scar.  
What was your reaction when you saw.....(child's name) burn scars for the first time.
- How would you describe.....behaviour in class? Are you aware of any emotional difficulties that.....(child's name) is currently experiencing (depression, anxiety-ptsd,)
- Are you aware of problems in the child's family that could impact on his current behaviour?
- How would you describe his/her interaction with the rest of the class?
- Are you aware of any incidents of teasing or bullying relating to .....(child's name)?
- If so, how do you deal with these incidences?(what helps, what makes it difficult...)
- How would you describe .....(child's name) academic performance?
- Do you know how long ..... (child's name)was absent from school due to the burn injury?
- Do you know how and if .....(child's name) homework was arranged while he was absent form school?
- What would help you as a teacher to deal with the challenges of having a child with a severe burn injury in your class in the future?