

8

THE BURNED CHILD: SCARRED FOR LIFE?
A STUDY OF THE LONG-TERM PSYCHOSOCIAL
ADJUSTMENT OF PAEDIATRIC BURN
SURVIVORS

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Lesley Liebowitz

September 2001

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ABSTRACT

Paediatric burn injury is a significant social problem in South Africa. Despite the magnitude of the problem and its potentially devastating physical, psychological and social consequences, the plight of burn-injured children in the local context is an unrecognized one, and has thus escaped empirical scrutiny to date. The purpose of this study is therefore to investigate the long-term psychosocial sequelae of children who survive thermal injuries with a view to determining their obstacles to optimal psychological functioning and social reintegration. It is intended that the findings of this research be utilized in the development of a contextually appropriate rehabilitation programme for these children. The sample comprised 40 paediatric burn survivors (referred to as the participants) between the ages of 8 and 21 years and their respective caregivers, all of whom were recruited from the admission records to the Red Cross War Memorial Children's Hospital and the Tygerberg Hospital. Data was collected from three sources: the medical records of each of the participants, and by conducting semi-structured individual interviews with each of the 40 participants and their caregivers. The content of the interviews aimed at eliciting a rich and contextually situated description of the burn injury, its subsequent treatment, the nature of the behavioural and emotional distress experienced by the participants and their scholastic adjustment. The effect of paediatric burn injury on the family and the caregivers' use of social support resources were also explored. A substantial component of the interview focused on the impact of disfigurement on the social relationships of the burned child. The participants' use of coping strategies and social support in mediating against the negative effect of strained social interactions was also considered. The interviews concluded with an investigation of the future prospects of the participants as voiced by themselves and their caregivers. The data was analysed by conducting a thematic analysis of the narratives of the participants and their caregivers. In terms of the findings, the participants and their caregivers chronicled many challenges with post-burn adjustment, both psychologically and socially. The emotional and behavioural difficulties experienced by many of the participants included depressive, suicidal and anxious behaviour; changes in sleeping patterns; lack of bladder and bowel control; and general delinquent conduct such as lying, stealing and promiscuity. Furthermore, many participants evidenced poor scholastic adjustment and significant academic lag. Social ridicule in the form of name-calling and bullying, evoked by the

participants' disfiguring burn scars, was found to be a pervasive problem, particularly at school. The challenges experienced by the participants in social interactions were compounded by their lack of adaptive strategies for coping with the consequences of their injury. The responses of the caregivers in this research provided testament to the notion that paediatric burn injury is an assault on the family as a unit, and has ramifications that extend beyond the burned child. The limited social resources available to these caregivers complicated the daunting task of caring for a burn-disfigured child in the long-term. The findings of the present research therefore clearly indicate that children who sustain burns as well as their caregivers are a population greatly in need of intervention to provide adequate preparation for the psychosocial consequences of a burn injury. As such, several contextually appropriate recommendations are suggested. These include the implementation of a school reintegration programme, the introduction of burn camps, the creation of a full-time post for a social worker or psychologist in the Burns Unit, establishing support groups for both burn-injured children and their caregivers, and the need for education regarding the prevention, causes and treatment of paediatric burn injury.

TABLE OF CONTENTS

CHAPTER ONE	1
INTRODUCTION	1
THE NATURE OF THE PROBLEM: PAEDIATRIC BURNS IN THE SOUTH AFRICAN CONTEXT.....	1
THE LONG-TERM PSYCHOSOCIAL ADJUSTMENT OF PAEDIATRIC BURN INJURY	3
Conceptualizing psychosocial adjustment in terms of psychological and psychiatric disorders	4
<i>Sleep disorders</i>	4
<i>Depressive, anxiety and post-traumatic stress disorders</i>	5
<i>The problem with conceptualizing psychosocial adjustment in terms of psychological and psychiatric disorders</i>	7
Conceptualizing psychosocial adjustment in terms of self-esteem and body image.....	7
<i>The problem with conceptualizing psychosocial adjustment in terms of global variables</i>	9
Conceptualizing psychosocial adjustment in terms of social competence and general adaptive behaviour	10
Predicting positive psychosocial adjustment in the paediatric burn survivor	15
<i>Size and severity of the burn injury</i>	15
<i>Locus of the burn injury</i>	15
<i>Age at the time of the burn injury, gender and level of intelligence of the child</i>	16
<i>Length of time since the burn injury</i>	16
<i>Social support as the most important predictor of psychosocial adjustment</i>	17
<i>Psychosocial effects of paediatric burn injury on the family</i>	18
<i>Characteristics of the family environment and maternal activities as the most significant predictors of psychosocial adjustment</i>	20
The stigmatizing effect of disfigurement	22
CONCLUSION	25
THE PRESENT RESEARCH	26

FORMAT OF THE THESIS.....	28
CHAPTER TWO	29
METHOD	29
SAMPLE.....	29
Sample criteria.....	29
The participants.....	31
The caregivers.....	31
Recruiting the sample.....	32
PROCEDURE.....	34
Ethical considerations	36
<i>Institutional review board approval</i>	36
<i>Informed consent to participation in the research</i>	37
<i>Confidentiality</i>	38
<i>Responsibilities to the participants</i>	38
MEASURES	39
DATA ANALYSIS	43
Analysis of quantitative data	43
Analysis of qualitative data.....	43
CHAPTER THREE.....	45
RESULTS AND DISCUSSION.....	45
INTRODUCTION.....	45
THE BURN INJURY	45
Aetiology of the burn injury	45
Locus of the burn injury	47
Scarring, skin grafts, tissue expanders and amputations	47
THE HOSPITALIZATION PERIOD	52
The importance of visiting	54
Caregivers' guilt	55
RETURNING HOME WITH THE BURNED CHILD	55
POST-DISCHARGE TREATMENT.....	57
Compliance with clinic appointments.....	57
Compliance with wearing pressure garments and splints	58

Subsequent plastic surgery	58
Referrals	61
The reality of ongoing corrective surgery	61
The need for education regarding the nature and consequences of burn injury.....	64
PAEDIATRIC BURN INJURY AND THE FAMILY	65
Caregivers' levels of education and socio-economic status.....	65
Family environment	66
Caregivers' use of social resources.....	66
The effect of the burn injury on the siblings of the burned child	68
EMOTIONAL AND BEHAVIOURAL INDICATORS OF DISTRESS	69
Depressive behaviour	69
Suicidal behaviour	70
Changes in eating behaviour	71
Control of bladder and bowel functions	71
Disturbed sleeping behaviour	72
Situation specific anxiety.....	73
Caregivers' concerns about general antisocial conduct/delinquency	74
Professional psychological counselling	76
Referrals	77
SOMATIC COMPLAINTS	77
SCHOLASTIC PERFORMANCE	77
Hyperactivity.....	78
Preventing academic lag	79
Referrals	80
THE IMPACT OF DISFIGUREMENT	80
Social ridicule: teasing, name-calling and bullying	80
<i>School as the site of social ridicule</i>	<i>81</i>
<i>Introducing a formal school entry/reintegration programme</i>	<i>82</i>
Participants' immediate reactions to teasing	86
Participants' general strategies for coping with disfigurement	88
<i>Camouflage.....</i>	<i>88</i>
<i>Non-avoidant cognitive coping strategies: positive self-talk and social comparison.....</i>	<i>89</i>

<i>Avoidant coping strategies: Social withdrawal and shrinking from contact</i>	91
Caregivers' reactions to disfigurement.....	92
<i>Caregivers' immediate reactions to teasing</i>	92
Caregivers' general strategies for coping with the participants' disfigurement	93
<i>Encouragement and reassurance</i>	93
<i>Restricting social interaction and encouraging camouflage</i>	93
Forming romantic relationships.....	94
PARTICIPANTS' USE OF SOCIAL SUPPORT	96
Religious support	96
Recreational activities and sports	97
Peer support	97
Family support.....	98
<i>The pitfalls of seeking support</i>	98
FACING THE FUTURE	99
Employment and career aspirations	99
Advice for other caregivers of burn-injured children.....	100
Advice for other paediatric burn survivors	101
Caregivers' concerns for the future of the participant	102
<i>Sophistication, passivity and complacency</i>	104
Wishful thinking	105
CHAPTER FOUR	107
CONCLUSION AND RECOMMENDATIONS.....	107
CONCLUSION	107
RECOMMENDATIONS.....	109
Recommendations for policy and practice	109
<i>Support for the burn-injured and disfigured child</i>	109
<i>Burn-disfigured versus disfigured</i>	112
<i>Caregiver support groups</i>	113
<i>The need for education and burns awareness</i>	114
<i>Debunking disfigurement</i>	115
<i>School entry/reintegration programme</i>	115

<i>Burn camps</i>	116
<i>The creation of a full-time post for a psychologist/social worker in the Burns Unit</i>	118
Recommendations for further research	119
CHALLENGES	120
Recruiting the participants	121
Striking a balance between empathy and detached inquiry.....	121
LIMITATIONS OF THE STUDY	122
REFERENCES	123
APPENDIX A: THE PARTICIPANTS.....	133
APPENDIX B: ETHICAL DOCUMENTATION	146
APPENDIX C: THE INTERVIEW SCHEDULE	151

LIST OF TABLES

Table 1.	Locus of the burn injury.....	47
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LIST OF FIGURES

Figure 1.	Greg: Hypertrophic scarring	48
Figure 2.	Ncanisa: Keloid scarring	48
Figure 3.	Neville: The aesthetic effect of a skin graft.....	49
Figure 4.	Sipho: A tissue expander	50
Figure 5.	Busisiwe: Multiple digit amputations.....	51
Figure 6.	Shannon: Multiple limb amputations	51
Figure 7.	Busisiwe: The cosmetic effect of skin appendage amputation and alopecia.....	52
Figure 8.	Shannon: Limb amputation and digit contractures	59
Figure 9.	Nomawetu: Axilla contractures	60

CHAPTER ONE

INTRODUCTION

THE NATURE OF THE PROBLEM: PAEDIATRIC BURNS IN THE SOUTH AFRICAN CONTEXT

Paediatric burns are a significant social problem in South Africa. 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 one fifth 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 (NIMSS, 2000). These statistics are thought to reflect approximately 25% of the estimated 60 000 fatal injuries that occur annually in South Africa (NIMSS, 2000) and should therefore be interpreted conservatively.

The incidence of children who survive burn injuries in South Africa has not been accurately quantified. 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 (henceforth referred to as the Hospital) in Cape Town. Since the Hospital is a regional paediatric facility that serves a well-defined population, data collected from the Hospital is useful for understanding the extent of this population's burn problem. According to Hospital records, in the period from 1990 to 1999 a total of 7355 children were treated for burn injuries at the Trauma Unit of the Hospital. Furthermore, the number of children requiring hospitalization for their burn injuries appears to be on the rise: while 578 children were admitted to the Burns Unit at the Hospital in 1999, 684 children required admission in 2000. Taken together with those burn-injured children who are treated at the Hospital's outpatient facility, the number of thermal injuries treated at the Hospital annually is estimated at 2000 (H. Rode, personal communication, January 2001).

The magnitude of the problem as evidenced by these statistics is compounded by the serious nature of a thermal trauma. The range of injury caused by burns, whether

physical, psychological or social, is extensive. The physical injury characteristically comprises the damage and loss of skin, the healing of which leaves a legacy of cosmetic deformity. In some cases the loss of digits, limbs or facial features result in significant physical disability. In terms of psychological injury, the burned child suffers not only from the profound effect of the original trauma, but also from protracted and painful hospital procedures, and ultimately, has to endure the long-term consequences of disfigurement and disability. This in turn has important implications for the child's successful social reintegration into the community.

Given both the enormous numbers and the potentially devastating consequences of paediatric burn injury in South Africa, it is therefore somewhat alarming to discover the paucity of local research on the psychosocial adjustment that follows this type of injury. Indeed, to date only one South African study has empirically examined the long-term psychosocial adjustment of paediatric burn survivors (De Wet, Cywes, Davies & van der Riet, 1979). The dearth of empirical investigation into this phenomenon reflects the notion that burn injury in South Africa is a largely unrecognized problem. The failure to take cognisance of this problem is explicable by at least two factors. The first is that local researchers interested in matters of public health have only recently adopted an epidemiological model for understanding these concerns¹. The second factor is the socio-demographic nature of the population that is affected by burn injuries. Although information regarding the profile of the paediatric burn survivor is scanty and has received the empirical attention of only one South African study, the findings suggest that children under the age of five years are most vulnerable to burn injuries (De Kock, 1979). The author also reported that the incidence of thermal injury is higher in deprived families who live in improper housing in a crowded environment, or move frequently. From this information one can infer that the population who sustain burn injuries in childhood can easily escape empirical scrutiny not only because of their impoverished socio-economic environment but also since toddlers are rarely the subjects of detailed public records.

¹ An example of research that adopts this approach is the Slovo Park Project, an initiative undertaken by the Health Psychology Unit and Centre for Peace Action at the University of South Africa.

While it is recognized that this research was published two decades ago and that there is an unquestionable need to conduct a present day epidemiological study of this nature, it is also noted that the profile of the burned child that is depicted here fits well with the readily observed reality of patients treated at the Hospital.

THE LONG-TERM PSYCHOSOCIAL ADJUSTMENT OF PAEDIATRIC BURN INJURY

The majority of citations in the burn literature have dealt with the pathophysiological sequelae of surgical management and only occasionally with the psychosocial aspects of burn injury. Within the body of psychosocial literature on burn injury, many researchers have focused on burns in adults, or in the case of children, on the emotional consequences of hospitalization. Given the paucity of South African research on the subject as explained above, the present state of knowledge is largely reliant on international research, the generalizability of which is questionable. To compound the problem, the existing international research evidence is limited in a number of ways: Study designs have been restricted by small sample size, high attrition rates, the exclusion of children thought to do poorly in adjusting to burns, the bias introduced by non-respondents, the lack of injury severity adjustments, variation in clinical judgements used in the measurement of outcomes, and a pattern of following subjects for an average of only one year. Indeed, by the year 2000, only one long-term (a follow-up of four years) outcome study on the psychosocial adjustment of paediatric burn survivors has been published in which the quality of life of these children was found to be acceptable but not well defined (Sheridan, Hinson, Liang, Nackel, Schoenfeld, Ryan, Mulligans & Tompkins, 2000).

Nonetheless, there is general consensus among researchers that most paediatric burn survivors are well adjusted, both psychologically and socially (Blakeney, Meyer, Moore, Broemeling, Hunt, Robson & Herndon, 1993; Blakeney, Meyer, Moore, Murphy, Broemeling, Robson & Herndon, 1993; Blakeney, Meyer, Robert, Desai, Wolf & Herndon, 1998; Herndon, LeMaster, Beard, Bernstein, Lewis, Rutan, Winkler, Cole, Bjarnson, Gore, Evans, Desai, Linares, Abston & Van Osten, 1986; LeDoux, Meyer, Blakeney & Herndon, 1996; Moore, Moore, Blakeney, Meyer, Murphy & Herndon, 1996; Zeitlin, 1997).

In terms of defining psychosocial adjustment, researchers have taken one of three approaches. The first is to characterize adjustment in terms of psychological or psychiatric disorders such as depression (Campbell, La Clave & Black, 1987; Stoddard, Norman, Murphy & Beardslee, 1989; Stoddard, Stroud & Murphy, 1992). The second is to define adjustment with regard to global variables like self-esteem (Bowden, Feller, Tholen & James, 1980; Broder & Strauss, 1989; Knudson-Cooper, 1981; LeDoux et al., 1996) and body image (Jessee, Strickland, Leeper & Wales, 1992; Orr, Reznikoff & Smith, 1989). The third, and arguably the most useful manner of conceptualizing adjustment is in terms of social competence and functional behaviour (Blakeney et al., 1993; Byrne, Love, Browne, Brown, Roberts & Streiner, 1986; Moore et al., 1996). Each of these three conceptualizations of adjustment is now considered.

Conceptualizing psychosocial adjustment in terms of psychological and psychiatric disorders

Sleep disorders

With the exception of studies by Kravitz, McCoy, Tompkins, Daly, Mulligan, McCauley, Robson and Herndon (1993) and Friedman, Plon, Martinez and Achauer (1989), the prevalence of sleep disorders as a consequence of paediatric burn injury has not received much empirical attention. A study by Meyer, Blakeney, LeDoux and Herndon (1995) revealed that 25% of parents of burned children perceive their children to have sleep disturbances. According to Kravitz et al. (1993), nightmares, enuresis, sleep walking and day napping occur commonly in children after burn injury, persist over time and do not diminish in relation to time elapsed since the burn injury. Furthermore, there is no relationship between cause of burn injury, family history of nightmares, patient history of enuresis and the incidence of nightmares (Kravitz et al., 1993). The dream content of the nightmares suffered by these children may relate to the actual burn incident (the children may smell smoke, relive the event, scream "fire", or dream of others who have died in the fire) or to procedural/treatment events (the children may dream that a burned hand will be amputated, that they will die under anaesthetic, or of the pain endured during dressing changes) (Kravitz et al., 1993). This study supports the notion of sleep as a coping mechanism during which cognitive processing of emotional stressors occurs. Further research into whether the

sleep disorders that are observed in children after burn injury might, in conjunction with other symptoms, meet the clinical criteria for post-traumatic stress disorder (PTSD) is required.

Depressive, anxiety and post-traumatic stress disorders

In the first major study of the quality of life of paediatric survivors of major thermal injury (>80% total body surface area), albeit on a small sample size of 12 patients, Herndon et al. (1986) found that one third of the children had excessive fear, regression and neurotic and somatic complaints. More recently, Stoddard et al. (1989) conducted research on the psychiatric sequelae of 30 children and adolescents with greater than 38% total body surface area burns. The participants in this study presented with significantly higher levels of DSM-III overanxious disorder and phobias, significantly higher lifetime levels of overanxious disorder, phobias and enuresis and more than one fourth of the severely burned children experienced full symptoms of PTSD in their lifetimes. While the presence of anxiety disorders changes little over time, enuresis diminishes as time passes (Stoddard et al., 1989).

The same study revealed that burned children are at risk for having depressive disorders, although these are thought to diminish over time and this did not reach statistical significance in this study (Stoddard et al., 1989). However, a more recent study by Stoddard et al. (1992) on depression in paediatric burn survivors revealed that unrecognized depression is common during the lifetimes of most burn survivors. The majority of children in this study were burned before the age of 7 and did not become depressed until an average of 4.4 years later. This finding makes intuitive sense in 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 (Stoddard et al., 1992).

A report by Campbell et al. (1987) found an incidence of clinical depression of only 11.9% in a sample of 285 acutely burned children (81% of whom had burns smaller than 40% of the total body surface area). This is lower than the lifetime rate found in the Stoddard et al. (1989) study, and also suggests that the DSM-III depressive order may not necessarily be common in acutely burned children with small to moderate

sized burns. Stoddard et al. (1992), however, report 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. It is also of interest to note that the comparison sample reports the same prevalence of present depressive disorder as the burned children. This is in keeping with other research that highlights the strengths and capacities of burned children for comparatively normal coping despite their histories of multiple trauma, severe scars and repeated surgery and hospitalization (Bowden et al., 1980; Byrne et al., 1986; Herndon et al., 1986). As a further complication, Stoddard et al. (1992) remind, however, that even though many severely burned children do not have any psychiatric symptoms, children with burns do seem to represent a population at risk for depression, and for a number of other comorbid complications. These include anxiety disorders, PTSD, attention deficit disorder, mania, bipolar disorder, dysthymia, conduct disorder and suicidal ideation.

In terms of causal explanations, there does not appear to be a definitive interpretation of the cause or causes of anxiety and depressive disorders in burned children. Some are clearly related to the burn trauma, such as the needle phobias, social phobias related to fears of social ridicule, or major depressions in response to disfigurement (Stoddard et al., 1989). These stresses appear to be lessened by successfully coping with the feared stimulus (e.g. having some control over the timing and frequency of medical procedures, attending school), and by cosmetic surgery. However, it is important to note that most of the burned children in these studies had those experiences to some degree and the majority did not receive psychiatric diagnoses. 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 (Blakeney, Herndon, Desai, Beard & Wales-Seale, 1988; Blakeney, Portman & Rutan, 1990; Bowden et al., 1980; Browne, Byrne, Brown, Pennock, Streiner, Roberts, Eyles, Truscott & Dabbs, 1985; Byrne et al., 1986; Davidson, Bowden & Tholen, 1981; Knudson-Cooper, 1984; LeDoux, Meyer, Blakeney & Herndon, 1998; Orr et al., 1989; Sawyer, Minde & Zuker, 1982) that are thought to be more significant determinants of depressive

illness in children with burns than the burn trauma or scarring. The significant contribution of family and social support in mediating against depression finds support in the study by Stoddard et al. (1992) since most of the participants reported a precipitant other than the burn itself as a cause for their depression, the most common of which were the family situation and social problems (such as beatings, not getting along with parents, sexual abuse, and alcoholism in parents).

The problem with conceptualizing psychosocial adjustment in terms of psychological and psychiatric disorders

The tendency for researchers to define adjustment in terms of psychiatric disorders such as depression may represent the application of an inaccurate model. This is so because although a burn injury represents an abnormal life stressor, defining its psychological impact in psychiatric terms may serve to exclude much needed intervention for those burn-injured persons who do not meet the narrow diagnostic criteria for a particular disorder (Patterson, Everett, Bombardier, Questad, Lee & Marvin, 1993). Patterson et al. (1993) suggest that the term *distress* used by Albee (1980), or the term *suffering* used by Cassell (1982) are more appropriate as they are more likely to capture the experience of burn survivors. Certainly almost every burn patient will experience some degree of distress or suffering and these variables are broad enough to reflect the spectrum of emotional response likely to be seen in this population. Using *distress* or *suffering* as a measure of adjustment also moves the conceptualization of adjustment away from a psychopathology model towards a more non-psychopathology model.

Conceptualizing psychosocial adjustment in terms of self-esteem and body image

In addition to the literature that conceptualizes the adjustment of paediatric burn survivors in terms of psychological disorders, a number of researchers have focused on global variables such as body image and self-esteem to measure psychosocial adjustment. This is particularly so in the case of self-esteem as an outcome variable. Self-esteem may be understood as the level of global regard that one has for the self as a person (Robert, Meyer, Bishop, Rosenberg, Murphy & Blakeney, 1999). The few published studies on self-esteem and paediatric burn survivors present contradictory and puzzling results: using standardized self-esteem measures, some investigators

have reported that the majority of survivors with disfiguring burn scars are within normal ranges of self-esteem, regardless of scar location, age at time of burn, length of time post burn, burn severity and percentage of total body surface area burned (Bowden et al., 1980; Knudson-Cooper, 1981; LeDoux et al., 1996; Orr et al., 1989).

Other investigators have compared measures of self-esteem for people with visible scars to people with non-visible defects such as congenital heart disease and found significantly lower levels of self-esteem among persons with disfiguring scars (Broder & Strauss, 1989; Goldberg, 1974). Some have reported deleterious effects of scar disfigurement on self-esteem consistent with the effects of other types of visible disfigurement on self-esteem e.g. children with craniofacial abnormalities (Pillemer & Cook, 1989).

Self-esteem is strongly related to self evaluation of physical appearance which in turn impacts on the affective state of the individual (Robert et al., 1999) It follows that burn survivors whose physical appearances are marked by disfiguring scars would be expected to have diminished self-esteem and saddened or depressed affect. This notion is borne out in the findings of Robert et al. (1999) that low self-esteem is associated with depression and anxiety in paediatric burn survivors. Similarly, Orr et al. (1989) found a strong correlation between depression, low self-esteem and poor body image in their study of 121 survivors of childhood burns, the scores of which were significantly influenced by perceived social support (more from friends than from family) and the participants' gender. When considering perceived social support, especially from friends, 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 reiterates the popular notion that physical attractiveness is more important for girls in terms of self-esteem.

The use of self-esteem as an outcome in measuring the psychosocial adjustment of paediatric burn survivors has yielded another interesting finding. Koon, Blakeney, Broemeling, Moore, Robson and Herndon (1992) reported that some paediatric burn survivors tend to present overly optimistic pictures of themselves, prompting the suggestion that their reports of high self-esteem may reflect a coping mechanism. This

notion is supported by findings of higher than normative self-esteem scores in some domains of self-esteem for boys with visible burn scars (Abdullah, Blakeney & Hunt, 1994) and by the results of a study by LeDoux et al. (1996) indicating that burned children's self concepts are better than the norm.

LeDoux et al. (1996) attribute these significantly high ratings to the positive use of denial as a functional coping strategy in which the burn survivors, although aware of their physical handicaps and disfigurement, attach minor significance to factors such as athletic competence and social acceptance. Instead, more emphasis is placed on areas unaffected by their burn injuries such as scholastic and job competence. Such an adapted value system appears to afford these children the hope necessary for post-burn adjustment by focusing on those factors within their control.

The importance of identifying positive personal strengths and enhancing the value attached to those strengths while simultaneously diminishing the value ascribed to disfigurement and impairment is reiterated in the study by Robert et al. (1999). These authors found that while adolescents with disfiguring burn scars possess an overall feeling of self worth similar to their peers, their levels of athletic competence and physical appearance were rated as significantly lower than the normative group. However, their levels of social acceptance and job competence were rated as significantly higher than the normative group. Although it is unclear as to why some burn survivors in this sample adapted their sense of self to their disfigurement while others did not, it seems that post-burn interaction with family and professionals that emphasizes positive personal traits prevents negative overall self perceptions and, in doing so, provides a protective factor to ward of debilitating depression.

The problem with conceptualizing psychosocial adjustment in terms of global variables

The contradictory results yielded by studies of self-esteem in paediatric burn survivors has prompted Knudson-Cooper (1981) to conclude that self-esteem is an inadequate measure of psychosocial adjustment. Furthermore, Patterson et al. (1993) argue that by characterizing adjustment with reference to global variables like self-esteem and body image, the complex and dynamic impact of burn injuries is not sufficiently

reflected. It is also suggested that by restricting the conceptualization of adjustment to one dimension (e.g. self-esteem), problems presenting in functional areas such as social relationships, recreational activities and the return to school are overlooked. The consequence of excluding functional outcome variables is that possibilities for intervention in these domains are diminished. Perhaps due to the limitations of conceptualizing psychosocial adjustment exclusively in terms of psychological disorder or a single global variable, a body of empirical research in which adjustment is characterized in terms of social competence and general adaptive behaviour has developed. This research is considered below.

Conceptualizing psychosocial adjustment in terms of social competence and general adaptive behaviour

The third approach to conceptualizing the psychosocial adjustment of paediatric burn survivors places greater emphasis on functional domains such as social and academic competence (Blakeney et al., 1993; Blakeney et al., 1993; Blakeney et al., 1998; LeDoux et al., 1996; Meyer et al., 1995; Meyer, Blakeney, Holzer, Moore, Murphy, Robson & Herndon, 1995; Moore et al., 1996). For the most part, the data in this research is collected from three separate sources: the burned child himself, the child's parent, and the child's teacher. The most commonly used instruments for this purpose are the Youth Self Report (YSR), the Child Behaviour Checklist (CBC), and the Teacher Report Form (TRF) respectively (Blakeney et al., 1993; Blakeney et al., 1993; Blakeney et al., 1998; LeDoux et al., 1996; Meyer et al., 1995; Moore et al., 1996). The simultaneous collection of information from three sources in a single study affords the opportunity to observe discrepancies of opinion in the extent and nature of the problems experienced by the burned child as well the chance to further explore the reasons for these discrepancies.

Blakeney et al. (1993) investigated the psychosocial sequelae of massive (>80% total body surface area) paediatric burns using the CBC, TRF and Piers Harris Children Self Concept Scale. By all reports, the children in this study were well adjusted, socially and psychologically: The children reported positive self regard and few problems, and the parents and teachers agreed that the children are as competent and plagued by no more problems than the normal reference group. These findings are

reiterated in the research of Moore et al. (1996) who investigated the extent to which the physical limitations of survivors of massive childhood burns result in social isolation and hamper psychosocial adjustment. Scored using the CBC and YSR, these children, despite their physical impairment, presented with no more problem behaviours than the published, clinically non-referred reference group and were as academically and socially competent as their peers, although unsurprisingly less athletic.

Like Moore et al. (1996) and Blakeney et al. (1993), Blakeney et al. (1998) investigated the long-term psychosocial adjustment of survivors of massive paediatric burn injuries and made use of the TRF, CBC and YSR. However, in this study, while the children as a group reported themselves as having neither more nor fewer problems than the reference population, the parents and teachers reported the burned children to have more problems than the reference population even though as a group their mean scores of current functioning fell within normal limits. The kinds of problems attributed to the children also differed with the observer – the parents identified more internalizing problems while the teachers reported more externalizing problems (i.e. acting out rather than being sad). Also unlike the results of Moore et al. (1996), the teachers and parents in this study reported that the burned children were mildly diminished in academic and social competence. This finding is supported by an earlier study of a sample of children with burns of moderate severity (Meyer et al., 1995).

Discrepancies between the opinions of teachers, parents and the burned children themselves regarding the extent to which the children are psychosocially adjusted post-burn were again revealed in a study by Blakeney et al. (1993). These authors investigated the social competence and prevalence of problem behaviour in 60 children with burns ranging from 15% to 70% total body surface area, and made use of the CBC, TRF and YSR as measuring instruments.

On the CBC, parents of boys aged 4 to 11 years indicated that their sons were less socially competent and had significantly more behaviour problems in the areas of somatic complaints, social interaction, and sexual identity than had the normative

group. The parents reported these boys to show more delinquent behaviour and less competence in social interactions and at school when compared with the reference group. Parents of girls aged 4 to 11 years reported behavioural problems and lack of social competence in almost every aspect. When compared with the normative group these girls were described as having more somatic complaints and more problems in interacting socially, in thinking, and in paying attention. They also tended to have more problems with delinquent and aggressive behaviour and with sexual identity (Blakeney et al., 1993).

Adolescent boys were reported by their parents as having more somatic complaints, more disturbances of thought, more problems with delinquent and aggressive behaviour and were perceived as being less competent in all areas when compared to the reference group. When compared with the reference group adolescent girls with burns were reported by their parents to have more somatic complaints, to be more withdrawn and less socially competent (Blakeney et al., 1993).

Quite on the contrary, the teachers generally reported fewer problems for the children with burns than for the reference population of children without burns as scored by the TRF. According to the teachers' report the only group with more problems than the reference group were the adolescent boys with burns in that they externalized problems (Blakeney et al., 1993).

On the YSR, the adolescents themselves noted few problems and usually described themselves as normal. This was especially true of the girls who reported having more difficulty only in the area of social problems and no differences in competency areas. The boys, however, had more difficulty with somatic complaints, thought problems and delinquent behaviour and had statistically significant decreased competency in both activities and social areas. The older children in this study acknowledged their delinquent behaviour, an acknowledgement, which, coupled with the parents' observations of tendencies towards delinquent and aggressive behaviour in the older boys indicates that the children may cope by externalizing (Blakeney et al., 1993).

In sum then, the parents of burned children expressed significant concern for the problematic behaviours and competence that they perceived in their children, much more so than the teachers and the burned children themselves. This was especially true in the younger age groups and for girls more than boys. Nonetheless, it is important to note that even though the scores differed significantly from the means of the normative groups, the group mean for the burned children was still within the normal range. In a sense this may be interpreted as reassuring evidence that burned children by and large do not suffer from major psychiatric disturbances or severe behavioural problems. On the other hand, however, it is disturbing to imagine that these children are, in fact, quite distressed and that this distress is not easily recognized by anyone except their parents. Along these lines, it may be that burned children deny to themselves and to their social world that they are feeling distressed. Perhaps these children perform so well publicly that only someone who knows them very well (i.e. a parent) can detect their unhappiness.

Another explanation for the discrepancies in perceptions described above is that the parents of burned children, for reasons of their own, misperceive their children's behaviour, attributing more difficulties to them than would another observer. They may also perceive their children to be less competent than they actually are. Other research has found that parents of burned children blame much of the stress in their own lives on the difficulties presented by their children (Blakeney et al., 1993; Meyer, Blakeney, Moore, Murphy, Robson & Herndon, 1994). For some reason, these parents need to believe that their children are troubled, incompetent and in need of extra attention. Parental well being as a factor in predicting the psychosocial adjustment of burned children is discussed in greater detail elsewhere in this chapter.

In order to clarify the findings of Blakeney et al. (1993) and to gather further information concerning the personal and social sufficiency and functioning of burned children as perceived by their parents, Meyer et al. (1995) administered the CBC and the Vineland Adaptive Behaviour Scales to 32 parents of paediatric burn survivors. Scores from the Vineland Scales indicated that parents view their burned children as being less personally and socially sufficient and deficient in adaptive behaviours when compared with the appropriate reference group. Those burned children with

significant behaviour problems as measured by the CBC differed from their peers with fewer problems by having less overall adaptive behaviour, fewer coping skills, and significantly more maladaptive behaviour. These results are surprising since several of the studies reviewed above have reported that most burned children have no more behavioural difficulties and are equally competent compared with normative unburned reference groups (Blakeney et al, 1993; Blakeney et al., 1993). The findings, however, are important as they elaborate on and differentiate among the difficulties that children have in adapting to post-burn life.

Although the CBC and the Vineland Scales seem to measure the same general trait of adaptation, they do approach the assessment from different angles and that alone may account for the discrepancies in the findings (Meyer et al., 1995). The CBC emphasizes the discovery of behavioural problems rather than performance and relies heavily on parental listings (without prompting) as a measure of competence. As such, the parent is to some degree the external standard of expectation. It is certainly plausible that a child could have few behavioural problems and be judged competent by parental standards, yet still be found to be lacking in skills and performance of tasks expected by others. Parental expectations may in another sense, be the source of the burned child's diminished adaptive behaviour scores on the Vineland Scales. Parents who are overly protective and do not encourage self-sufficiency in their children or parents who are overly stressed and too distracted to supervise their children will be likely to have children with lower scores of adaptation as measured by the Vineland Scales. There are at least two reasons why this should be so: Firstly, maternal stress and depression have been shown to predict maladaptive behaviour in the child (Hall & Fariel, 1988), and secondly, while the CBC is perhaps not affected by socio-economic factors, the Vineland Scales are affected by these factors (Meyer et al., 1995).

The conflicting and puzzling findings have different implications for the treatment and rehabilitation of burned children. The basic difference between the two sets of instruments is that the CBC shows that although two thirds of the sample are not maladjusted, all may be lagging in the development of behaviours and skills that promote good adjustment according to the Vineland Scales (Meyer et al., 1995). As

such domestic and community living skills should be taught in the psychosocial rehabilitation programme since a child's self-esteem rests largely on feelings of self-efficacy (Robert et al., 1999). This means that the children themselves must be the primary foci of the treatment. However, if it is true that parents only are privy to the distress behind the public façade of the children, it may also be that the parents of burned children should be instructed to adjust their expectations of their children and pay more attention to the consistent teaching, supervision and expectations of the burned child.

Predicting positive psychosocial adjustment in the paediatric burn survivor

Having provided a background to the research on how psychosocial adjustment is conceptualized in the burns literature, it is now useful to turn to the second component of the empirical literature on the psychosocial aspects of burn injury: the attempt to establish those factors that best determine positive psychosocial adjustment in the paediatric burn survivor. Several factors including the size, locus and severity of the burn, the length of time that has elapsed since the burn injury and the burned child's age, gender and level of intelligence have been considered. As the discussion below reveals, this research has yielded inconsistent results.

Size and severity of the burn injury

Andreasen, Noyes and Hartford (1972) and Bowden et al. (1980) report that adjustment problems are a function of burn severity. In contrast, Knudson-Cooper (1981), LeDoux et al. (1998) and Browne et al. (1985) found that the severity of the burn has no effect on adjustment. It is noteworthy that the latter study found that the less adjusted children were more often those with minor burns (Browne et al., 1985). Similarly, Byrne et al. (1986) and Blakeney et al. (1993) report that children with bigger burns have fewer problems. LeDoux et al. (1998), Meyer et al. (1994), Stoddard et al. (1992) and Blakeney et al. (1993) found that burn size has no effect on adjustment.

Locus of the burn injury

Facial disfigurement (Blakeney et al., 1988; Bowden et al., 1980; Knudson-Cooper, 1984; Sawyer et al., 1982) and disfigurement in other visible areas has also been

found to contribute to psychosocial adjustment (Sawyer et al., 1982). Stoddard et al. (1992) reported a trend toward an association between depression and the severity of cosmetic disfigurement. Clarke and Martin (1978) found that young girls who have sustained disfigurement to their breasts as a result of burns are especially distressed, particularly if an asymmetry is noticeable. It is also interesting to note that children with burns on their backs who do not directly or frequently view their considerable scars seem to integrate better into society (Clarke & Martin, 1978). Browne et al. (1986) suggest that maladjustment may be related to disfigurement and/or impairment of function of the hands or legs. On the contrary, Orr et al. (1989) report that there is no significant relationship between the locus of burn injury and adjustment.

Age at the time of the burn injury, gender and level of intelligence of the child

Age at the time of burn (Blakeney et al., 1988; Knudson-Cooper, 1981; Knudson-Cooper, 1984; Sawyer et al., 1989) and gender (Blakeney et al., 1988; Bowden et al., 1980) seem to contribute inconsistently. Level of intelligence has been considered as a possible contributing factor, but has not proved to be significant (Blakeney et al., 1990).

Length of time since the burn injury

The length of time that has passed since the burn has rarely been studied but may be an important variable (Blades, Mellis & Munster, 1982; Blakeney et al., 1993; Blakeney et al., 1998; Byrne et al., 1986; Orr et al., 1989). The findings of Browne et al. (1986) suggest that children do not seem to adjust with time, unlike adults (where 90% adjust as a function of time). Similarly, Blakeney et al. (1998) and Orr et al. (1989) report that there is no significant relationship between adjustment and the length of time following the burn, while LeDoux et al. (1998) argue that the length of time after the injury, if it is important to psychological healing, appears to be a factor only during the first two years after the burn injury. On the contrary, Blakeney et al. (1990) suggest that the first year after the burn injury is a time of hopelessness and despair, though adjustment improves during the first two years post-burn. Following that, although many children achieve self-acceptance others continue to despair. Blakeney et al. (1993) report that burned children seem to become more competent, less anxious, less withdrawn and more assertive with the passing of time after injury.

To this end, perhaps there is merit in the conclusion of Herndon et al. (1986) that the final outcome for these patients can only be assessed as they achieve late adolescence and young adulthood.

The emphasis placed on burn related variables such as the size, severity and locus of the burn in predicting psychosocial adjustment reflect the dominant medical model of conceptualizing adjustment (Patterson et al., 1993). As discussed below, the research on the long-term recovery from paediatric burns would be better served by models that take into account the potential of moderating variables such as social support from friends and family that have been shown to influence adjustment.

Social support as the most important predictor of psychosocial adjustment

The most consistently recognized contributing factor to the positive psychosocial adjustment of the burned child seems to be social support, particularly from the family. (Blakeney et al., 1988; Blakeney et al., 1990; Bowden et al., 1980; Browne et al., 1985; Byrne et al., 1986; Davidson et al., 1981; Knudson-Cooper, 1984; LeDoux et al., 1998; Sawyer et al., 1982). Peer support has also been recognized as having an important influence on adjustment (Orr et al., 1989). Both forms of support are in keeping with the buffering hypothesis proposed by Cobb (1976) in which social support is described as the variable that is most effective in mediating against the negative impact of other stressful variables.

The monolithic influence of the family in facilitating the recovery of the burned child has resulted in paediatric burn injury increasingly being understood as an assault on the family as a unit, not only on the child (Munster, 1993). It follows that it is 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. Of equal importance is to identify how maternal activities and the characteristics of the family environment contribute towards the child's long-term recovery.

Psychosocial effects of paediatric burn injury on the family

The long-term impact on the families of paediatric burn survivors has not been well studied, but clinical experience and scanty empirical data indicate the sequelae to be significant. Adriaessens, Boeckx, Gilles, Meertens, Nijs and Pyck (1987) describe the social isolation and withdrawal experienced by the family following a childhood burn injury. Family members may continue to experience symptoms of post-traumatic stress long after a burned child has returned home (Cella, Perry, Kulchycky & Goodwin, 1988; Cella, Perry, Poaz, Amand & Goodwin, 1988). In fact, families report less stress in the acute post-burn stage than do families several years after the burn (Cella et al., 1988).

Once burn-injured children are discharged from hospital, they are likely to require ongoing care and supervision in terms of compliance with pressure garments² and splints³. These children will be also be required to visit the hospital on a regular basis for follow-up appointments with the burns, plastic surgery and occupational and physical therapy clinics. If the burned child undergoes further corrective surgery after the initial hospitalization, the period of ongoing care can be lengthy. It makes sense that this presents yet another challenge to the family of the burned child. Indeed, parents of paediatric burn survivors report being stressed by concern for their unburned children whom they feel are slighted of attention and time, while the burned sibling requires the extensive devotion of both parents (Blakeney et al., 1993). The parents in this study also noted the personal financial difficulties attendant to the injury and treatment of the burned child even though their children received medical treatment at a hospital which provides care free of charge to the patient's family. Fortunately, these complaints seem to decrease over time as the parents become more accepting of their own children, less socially isolated and less confined in their parenting roles.

² Pressure garments are specially manufactured elastic garments used to prevent hypertrophic scarring by restricting the blood flow into the scar tissue.

³ A splint is a polymer and plastic compound that is shaped to fit over a burn-injured joint in order to provide proper positioning and prevent the formation of contractures.

A series of studies at the Shriners Burns Institute in Galveston, Texas investigated rates of depression in parents of recovering paediatric burn survivors (Blakeney et al., 1993; Blakeney, Moore, Broemeling, Hunt, Herndon & Robson, 1993; Meyer et al., 1994). Using the Parenting Stress Index (PSI), Blakeney et al. (1993) examined parental stress at various time periods after the child's burn. These investigators found that parents reported significant depressive symptoms at two years post-injury, that these levels appear to normalize after three years, and that after four or five years these levels of depression are significantly lower than both a normative sample and a group of parents of children with acute burns. The improvement in levels of parental distress has prompted the suggestion that parents of burned children may develop defensive coping strategies such as denial to minimize their depressed feelings, but which may exacerbate difficulties in other areas of their lives. Identifying and recognizing these defensive coping strategies may be critical, since burned children throughout their recovery depend largely on parental support.

Meyer et al. (1994) subsequently used the PSI and found that parents who report their children as troubled (more troubled than the children consider themselves and more than they are considered troubled by teachers) are themselves stressed, not only by their children's behaviour but in other areas unrelated to their children. Although these authors reiterate the finding that parental distress appears to improve with time for most, it was found that the parents of the most troubled burned children continued across time to be troubled themselves. These mothers report often feeling depressed and guilty, and compared with the reference parents, see their children as less acceptable, demanding, moody and behaving in ways that do not reinforce the role of the parent. These mothers do not acknowledge themselves as part of the problem or that external life stresses may be important. Similarly, the parents in the study by Blakeney et al. (1993) more often attributed their stress to their children than did normative parents.

These findings raise the question of whether the burned child's behaviour problems are caused by the parent or the converse as they are highly correlated. The risk of scapegoating of the burned child by the parent is certainly an issue. As such the

findings point to a need to provide psychosocial intervention for both the parents and the child in order to facilitate successful adjustment (Meyer et al., 1994).

Characteristics of the family environment and maternal activities as the most significant predictors of psychosocial adjustment

The involvement of the family, particularly the parents, in facilitating the successful psychosocial recovery of the burned child is an activity that begins as early as the hospitalization period. Benians (1988) cites the significant influence of parental visiting on the long-term survival and rehabilitation of extensively burned children; and Sheridan et al. (2000), in the most recently published study on the long-term outcomes of children who survive massive burns, identify consistent follow-up visits to the burn clinic after discharge as a significant predictor of a satisfying quality of life.

The characteristics of the family environment and the functional status of the family, particularly the mother, are of great importance in facilitating the long-term adaptation of the burned child (Blakeney et al., 1990; Browne et al., 1985; Byrne et al., 1986; LeDoux et al., 1998; Sawyer et al., 1982; Sheridan et al., 2000). Sawyer et al. (1982) report that the lack of a stable supportive home environment characterized by the emotional distress of the mother and multiple home moves by the family is related to the poor psychosocial outcome of the burned child. Browne et al. (1985) reached a similar conclusion about the role of the mother of the burned child in facilitating adjustment. The investigators in this study administered a variety of adjustment, coping and family environment scales to 145 mothers of children who had sustained major and minor burns in the previous 12 years. The findings revealed that children with major burns are no different from children with minor burns in the biological or psychological variables except on two dimensions of the mothers' Psychological Adjustment to Illness Scale adjustment score and Family Environment Score. Thus, the burned child's adjustment was more related to the mother's adjustment and social resources and her methods of coping than to the size of the child's burn or the time since the burn injury.

The 10% to 15% of burned children in this study who had poorer psychosocial adjustment had mothers with poorer psychosocial adjustment as characterized by tendencies to use avoidance to cope with problems; emotionally distancing themselves from problems, participation in few recreational activities, and coming from families with less moral or religious emphasis. The more socially adjusted children, on the other hand, were also not explained by burn severity. These children came from families with a high intellectual or cultural emphasis, and had mothers who participated in fewer organizational activities but belonged to more social organizations (Browne et al., 1985). Similarly, Byrne et al. (1986) reported that the most socially competent burned children are from families with greater participation in social and recreational activities, families of higher socio-economic status and larger families with mothers who viewed their children's adjustment more positively. These authors also stress the importance of an intellectual/cultural emphasis within the family.

A study by LeDoux et al. (1998) on the effect of the family environment on the psychosocial adaptation of 35 paediatric burn survivors revealed that children considered to be well adjusted have parents who score high on cohesion, achievement and organization and lower on conflict. The subject families in the study by LeDoux et al. (1998) were, as a whole, more cohesive, controlling and placed greater emphasis on moral and religious values than the normal reference population. The relationship between family cohesion and better psychosocial adjustment is a reiteration of the findings of Blakeney et al. (1990) that familial value patterns are critical in the prediction of psychosocial adjustment. In this study, the positive psychosocial adjustment of paediatric burn survivors was best predicted by a family environment in which commitment to each other is strong and where such cohesion allows expression of conflict and encourages autonomy and active mastery of the environment. This finding echoes the work of Beard, Herndon and Desai (1989) who found that by enhancing family commitment and self-sufficiency, the burned child's probability of well being is increased. Furthermore, Blakeney et al. (1990) found that poor psychosocial adjustment was predicted by a family environment that is characterized by conflict within the context of passive dependency and diminished cohesion.

To conclude the discussion on the importance of the family in facilitating adjustment, it seems that the enduring and pervasive positive relationship between adjustment and social resources calls for a refining of social support theory and its importance in identifying burned children at risk for maladjustment. This may be particularly relevant in the South African context where the burned population is characterized by abject poverty, which in turn has implications for the availability and use of organized social support structures.

The stigmatizing effect of disfigurement

The literature on the psychosocial adjustment of paediatric burn survivors rarely contains explicit reference to the aesthetic disfigurement that is the inevitable and arguably the most distressing consequence of a serious burn injury. The nature of a burn injury frequently implies extensive tissue loss that must be rectified with a skin graft⁴. Skin grafts have a meshed texture and are characterized by altered pigment formation and the absence of hair growth. This means that these grafts do not resemble normal skin in appearance (Hurren, 1995). Furthermore, even if the burn injury does not require skin grafting, burn scars can become extremely disfiguring due to hypertrophy⁵ and keloid formation⁶. This may occur despite appropriate aftercare. In addition, the contractile properties in the scar itself can cause crippling contractures⁷, leading to disability and deformity (Hurren, 1995). In cases of severe burns, it may be necessary to amputate digits or limbs resulting in significant disability. Skin appendages such as noses and ears may also be lost, causing a distortion of the facial features (Warden, 1996). Even the best of plastic surgery cannot restore burned individuals to their pre-burn appearance. Often the best that an individual who has sustained a burn injury can hope for is flat scars, unimpaired joint

⁴ A graft is a piece of skin taken from one part of the body and then transferred to a secondary site. Skin grafts are indicated for most deep dermal burns.

⁵ Hypertrophic scars are thickened and hard and develop between 3 and 12 months after the burn injury before reaching maximum prominence. Hypertrophic scars are confined to the site of the original burn injury and do not invade normal skin. *

⁶ Keloid scars, like hypertrophic scars, are thickened and hard, but grow in a tumour-like fashion, invading the normal skin outside the area of the original injury. Keloid scars may continue to grow for several years following the burn injury.

function and an approximation of normal facial features which leaves much to be desired.

Graphic examples of the disfigurement that results from burn injuries are provided in Chapter Three in the form of photographs. These photographs depict the aesthetic nature of skin grafts, hypertrophic scarring, keloid formation, contractures and amputations. All the photographs reproduced in Chapter Three are of participants in the present study and are used with their permission.

The aesthetic disability of disfigurement may result in profound social consequences for those afflicted. It is clear that society as a whole has considerable difficulty in relating to its disfigured members to the extent that there is a tendency to exclude them (Harris, 1982; Knudson-Cooper, 1981; McGregor, 1990; Pruzinsky, 1992; Robinson, Rumsey & Partridge, 1996). Although this basic psychological attitude towards disfigured persons is generally not discussed in the burn literature, it is something with which burn-disfigured individuals must deal on a daily basis and an issue that is familiar to all burn care providers.

Stigma refers to a painful, disfiguring mark that sets people aside from the usual. As such it is particularly suited to refer to a person who has sustained a burn injury. Stigmatization denies people full social acceptance. The contemporary connotations of the word 'stigma' are not really much different from its original meaning. For the Greeks, stigma referred to bodily signs that called attention to some moral failing on the part of the person who bore them. Signs, often cut or burned into the body, were intended to cause other people to avoid the bearer – the slave, traitor or criminal (Bernstein, O'Connell & Chedekel, 1992). Today stigma involves the same sense of moral disapproval, denigration and avoidance.

A body of sociological literature has been devoted to the effect of stigma on human behaviour. Goffman (1963) in particular has characterized the stigmatized individual

⁷ The pathological effect of the healing of scar tissue that results in the inability to move a joint fully because of tightness of the surrounding tissue.

as having a distinctive social role - a way of interacting with the larger society which differs in some way from the usual. He recognizes the reciprocal character of this interaction in that the larger society has particular ways of reacting to and interacting with stigmatized individuals. The emphasis is on the self-reinforcing system of behaviour where the difference that a disfigured person exhibits is perceived and reacted to by other persons in the larger society. The latter in turn interact in a way that reinforces the stigmatized individual's perception of the self as different.

While it is human nature to make assumptions about a disfigured person's intelligence, personality and psychopathology (Adler, 1992), the psychological and social burden of stigmatization cannot be underestimated. Social interactions for the disfigured person are often strained and unpleasant (Pruzinsky, 1992). McGregor (1990) describes how individuals with visible disfigurements are not accorded the same social respect as their non-disfigured counterparts in that their privacy is ignored. In their efforts to go about their daily affairs, disfigured persons are subject to visual and verbal assaults and a level of familiarity from strangers including naked stares, startle reactions, whispering, remarks, furtive glances, curiosity, personal questions, advice, manifestations of pity and aversion, laughter, ridicule or outright avoidance. Partridge (1990) uses the acronym SCARED to sum up the set of familiar and unenviable responses that the disfigured person has to come to terms with: Staring, Curiosity, Anguish, Recoil, Embarrassment and Dread. Similarly, in confronting others the disfigured person may also feel SCARED and can become trapped in a double bind: Self-consciousness, Conspicuousness, Anger, Reluctance, Embarrassment and feeling Different (Partridge, 1990). These strained social interactions result in feelings of shame (Lewis, 1987; Nathanson, 1987), impotence, anger and humiliation on the part of the person with the disfigurement (McGregor, 1990).

Stigmatization can be particularly painful for children. Although the burns literature does not offer very much on the subject, empirical research on children disfigured by cleft lips and palates and other craniofacial abnormalities provides extensive coverage of this topic (Houston & Bull, 1994; Pillemer & Cook, 1989; Tobiasen, 1989). Research on the responses of other children to disfigurement has revealed that facial

stereotyping begins as early as at age five years (Rumsey, Bull & Gahagan, 1986). In studies in which children have been asked to rate their preferences for companionship from photographs, the disfigured child tends to be placed at the bottom of the rating, along with the obese child (Sigelman, Miller & Whitworth, 1986; Lansdown, 1990). The disfigured child is described as having negative qualities and mood state, indicating a spread of stigma which reinforces a sense of aversion (Sigelman, Miller & Whitworth, 1986; Lansdown, 1990). Peer relations may be significantly hampered by teasing with the result that the disfigured child may plead not to go to school, feign illness or truant (Harris, 1982). Disfigured children are also inhibited recreationally, with a tendency to avoid communal changing rooms, public places like the beach, and organized sport and physical education activities (Harris, 1982). This self-consciousness and its concomitant social withdrawal can negatively affect children's social competence, predisposing them to later experiences of loneliness, depression and anxiety (Pillemer & Cook, 1989; Tobiasen, 1989).

The way in which burn-disfigured children deal with the world is thus profoundly affected by society's generally negative responses to their visible burn scars. The task of establishing a sense of personal worth and meaning in the face of the social rejection is an important part of the process of psychosocial recovery from a burn injury. To this end, a comprehensive rehabilitation programme has to address the issues of how the individual copes with this sort of social handicap.

CONCLUSION

The purpose of this introduction has been to contextualize the nature of paediatric burn injury in South Africa and to provide a comprehensive background to the literature on the long-term psychosocial adjustment of children who sustain thermal injury. According to the empirical research, the majority of paediatric burn survivors are well adjusted, both socially and psychologically. Moreover, adjustment appears to be positive regardless of whether it is conceptualized in terms of psychiatric disorder, global variables such as self-esteem, or in terms of social competence. If these findings are a true reflection of reality, then one may conclude that severe burn injury, disfigurement and physical impairment do not necessarily render children useless and unhappy, or overwhelm their defences, leaving them forever morose and angry.

Indeed, these findings would represent a striking testament to human resilience for it would seem that while some children cope with their moments of emotional and physical pain with relative ease, and others succumb to sadness and anger, most, nonetheless, have what might be called a satisfactory quality of life.

However, it must be pointed out that the findings reviewed in this chapter stem from research conducted predominantly at the Shriners Burns Institutes in Galveston, Texas and Boston, Massachusetts, both of which offer a comprehensive and long-term range of psychosocial services to burned children and their caregivers. The positive adjustment reported in these studies may therefore be a consequence of the psychosocial assistance provided, rather than the results of a spontaneous process of adaptation. This consideration, combined with the methodological flaws common to this body of research as discussed earlier and the fact that only one local study has been conducted on the subject, means that it is prudent to exercise caution when interpreting these findings and generalizing them to the South African context.

THE PRESENT RESEARCH

The Red Cross War Memorial Children's Hospital is the only paediatric hospital in sub-Saharan Africa and has the capacity to accommodate 293 inpatients. The Burns Unit at the Hospital is one of two dedicated paediatric burns facilities in South Africa. This unit has 22 beds and is staffed by a multidisciplinary team of health care professionals. The team comprises a surgeon, ten nurses, a dietician, a physiotherapist and an occupational therapist. Together these dedicated individuals provide a high standard of medical and surgical service to the burned child. It is therefore unfortunate that the scarcity of funding to date has meant that while the patients at the Hospital are given physical and occupational therapy so as to achieve maximum functional potential, no psychological or social services are available to facilitate the successful psychosocial rehabilitation of these children. The need for such rehabilitation has become particularly relevant as advances in medical and surgical management have dramatically decreased the mortality rate in paediatric burns, raising ethical questions regarding the residual quality of life of these young survivors.

The importance of rehabilitation is widely accepted within medical theory, but its profile in health care, particularly in South Africa, is heavily eclipsed by the acute services. Fortunately, growing public concern and the possibility of securing private funding for psychosocial rehabilitation purposes has prompted an interest in the long-term plight of the burned child. It is clear that the time has passed where all that can be done for burned children is to describe their misery, speculate on its origins and applaud their courage.

With the construction of a new burns rehabilitation centre pending, it is necessary for the Department of Paediatric Surgery at the Hospital to conduct a long-term follow-up of paediatric burn patients under its care so as to establish the extent to which these children are physically functional and psychosocially reintegrated. That burned children should experience difficulties during the recovery period following such a devastating injury makes intuitive sense. Once these children are physically healed and are ready to re-enter society, they begin to encounter new challenges and stresses. Accurately identifying those psychological and social stresses and the factors that most affect the quality of the recovery process for these children is crucial in finding ways to maximize their adjustment. Until these needs are determined, a suitable rehabilitation programme cannot be developed. Indeed, without this information, the very necessity and feasibility of such a programme is based only on the speculation and intuition of burn care professionals.

In light of these practical considerations and the fact that there is a paucity of local empirical research on the psychosocial aspects of paediatric burn injury, the aims of the present study were formulated as follows:

- (a) to determine the type of psychosocial sequelae of paediatric burns in a South African context;
- (b) to determine the type of obstacles to successful psychosocial integration encountered by paediatric burn survivors in a South African context; and
- (c) to make recommendations that will be useful in formulating a contextually appropriate, empirically informed rehabilitation programme aimed at

maximizing not only physical, but also psychosocial functioning in the paediatric burn survivor.

It is hoped that regardless of the nature of the findings, the knowledge produced by the results of this research will have value in promoting awareness of a hitherto largely unrecognized social problem.

FORMAT OF THE THESIS

This thesis comprises four chapters. Chapter Two contains a discussion of the research design and method employed in conducting the present research. As such, details regarding the sample criteria employed in selecting participants, the steps taken in recruiting the sample as well as the difficulties encountered in this process are discussed. The procedure followed and the measures used in collecting the data as well as important ethical considerations are described. Chapter Two also contains a discussion of the methods of data analysis employed in this study. A combined Results and Discussion section in Chapter Three follows this. Chapter Three is organized along thematic lines and in chronological order beginning with the burn injury itself, the hospitalization period, returning home with the burn-injured child and post-discharge treatment. The focus then turns to the effect of paediatric burn injury on the family and the caregivers' use of social support resources. The behavioural and emotional indicators of distress as evidenced by the participants are then discussed. This is followed by the findings related to the participants' scholastic adjustment and academic progress. The impact of disfigurement on the social relationships of the burned child is then explored. Here the focus is on the findings relating to the participants' coping strategies and their use of social support in mediating against the negative effect of strained social interactions. Chapter Three concludes with a discussion of the future prospects of the participants as voiced by themselves and their caregivers. Chapter Four contains the conclusion to the study as well as several recommendations for policy, research and practice that arise from the findings of the present study.

CHAPTER TWO

METHOD

SAMPLE

In order to investigate the long-term psychosocial adjustment of paediatric burn survivors it was thought necessary to study both the burn-injured children themselves as well as their caregivers. This rationale was informed by the empirical literature on the importance of the family in facilitating adjustment (Blakeney et al., 1988; Blakeney et al., 1990; LeDoux et al., 1998) as well as the value of collecting data from multiple sources (Blakeney et al., 1993; Blakeney et al., 1998; Meyer et al., 1995). By capturing the experience of both the burned child and those who have had to care for the child and are therefore privy to any distressing behaviour and emotions, it was reasoned that richer, more comprehensive data could be obtained. It follows that the more detailed the information gleaned from the research participants, the greater the possibility of designing appropriate interventions for the population under empirical scrutiny.

The paediatric burn survivors studied in this research are referred to as the participants or the children, while those responsible for their care are referred to as the caregivers.

Sample criteria

To be considered eligible for participation in the present research, several inclusion criteria were proposed for the participants. These criteria relate to the age of the child at the time of the burn injury, the time elapsed since the burn injury was sustained, the size, severity, locus and aetiology of the burn injury, and the present age and geographical location of the child.

First, in order to qualify as a *paediatric* burn survivor, the participant had to have sustained a thermal injury before the age of 13 years. This criterion makes sense when one considers that children older than 13 years are not treated at the Red Cross Children's Hospital and are instead treated at the Tygerberg Hospital in Bellville, Cape Town. The latter offers specialized facilities for the treatment of adolescents and adults who have sustained burn injuries.

Second, in terms of the size, locus and severity of the burn injury, the criteria were informed by the empirical literature on the subject and the admission protocol followed by the Burns Unit of the Hospital. According to this protocol, children require admission to hospital if they have sustained a burn injury that is greater than or equal to 10% of the total body surface area (TBSA) (H. Rode, personal communication, June 2000). Alternatively, if the size of the original burn injury is less than 10% of the participant's TBSA, but the injury has been sustained to the participant's hands, feet, face or perineum, the child would still require hospitalization. This exception is made because burns to these functional areas pose a significant risk in terms of impeding function and causing cosmetic disfigurement (Miller, Richard & Staley, 1994). These exact criteria were employed in the present study. With regard to the severity of the burn, since hospitalization is rarely prescribed for superficial⁸ burns except in the case of neonates (Miller et al., 1994) participants included in this study had to have sustained either a partial-thickness⁹ or a full-thickness¹⁰ burn injury. This criterion too is in keeping with the admission protocol followed by the Hospital (H. Rode, personal communication, June 2000).

Third, with regard to the aetiology of the burn injury, no distinction was drawn between participants who had sustained burns caused by hot liquid (scalds), flame, chemical substances, electricity or contact with a heated surface.

Fourth, since the present study constitutes an investigation into the *long-term* psychosocial adjustment of paediatric burn survivors, in order to be included in the

⁸ Superficial burns involve damage only to the outer layer of the skin. These wounds blister quickly and are very painful, but if allowed to dry out in sterile conditions, will spontaneously heal and return to normal skin within 10 days.

⁹ Partial-thickness burns are deep wounds that damage the nerve endings in the skin, thus making them extremely painful. If the wound is relatively shallow it will heal naturally within three weeks, however, deeper dermal burns will require skin grafting.

¹⁰ Full-thickness burns destroy all the layers of the skin, including sweat glands and hair follicles. Subcutaneous tissues such as fat, muscle, tendon and bone are often affected. These wounds do not heal spontaneously and are prone to infection. Skin grafting is always necessary for full-thickness burns.

study, a period of at least one year had to have elapsed between the time of data collection and the participant's burn accident.

Finally, to optimize the quality of the data collected, only participants older than 8 years of age that would be able to communicate verbally in either English or Afrikaans were included in the study. The latter prerequisite was thought useful in that it excluded the necessity of using translators or interpreters for Xhosa-only speakers.

The participants

The participants comprised 40 paediatric burn survivors ranging in age from 8 to 21 years (mean = 12.5 years; standard deviation = 3.2). The mean age at the time of sustaining the burn injury was 4.2 years (range 1 -13 years; standard deviation = 3.1) and the mean length of time that had elapsed between the injury and the interview was 8.3 years (range 2 - 19 years; standard deviation 3.5). In terms of gender, 20 participants were female and 20 were male. Regarding race, according to the official medical records, 32 participants classified as Coloured, six participants as African and two participants as White. The mean TBSA burned was 25.5% (range = 1% - 50%; standard deviation = 13.7) and the initial length of stay in hospital ranged from 0.5 weeks to 16 weeks (mean = 5.8 weeks; standard deviation = 3.9).

A brief summary of each of the 40 participants can be found in Appendix A.

The caregivers

The sample of caregivers was comprised mainly of the biological mothers of the participants (n=28). The primary caregivers of four participants who are permanent residents of the St Joseph's Home for Chronic Invalid Children in Montana, Cape Town were nurses. The remaining caregivers comprised one father, two grandaunts, one foster mother, one sister and three grandmothers. The caregivers ranged in age from 26 years to 72 years (mean = 43.6 years; standard deviation = 12.8) and in terms of education, caregivers had a mean of 7.3 years of education (range = 0 – 12 years; standard deviation = 3.1). Not including the participant, the caregiver was financially responsible for a mean of 2.6 children (range = 0 – 7 children; standard deviation =

1.7). With regards to employment, only 20 caregivers were employed. Six caregivers were supported by relatives or disability/pension funds and the remaining ten reported having no source of income.

Recruiting the sample

Recruiting the sample was perhaps one of the most challenging methodological aspects of this thesis. The sample was recruited from the admission records of the Burns and Plastic Surgery Units affiliated to the Red Cross Children's Hospital as well as the Plastic Surgery Unit affiliated to the Tygerberg Hospital. The rationale for recruitment from these databases is that children who sustain burns and are below the age of 13 years are treated at the Red Cross Hospital and continue to receive corrective surgical treatment at this hospital until they reach the age of 13 years. At that point, these children are transferred to the Tygerberg Hospital if further plastic surgery is required. The inclusion of the Tygerberg Hospital admission records was also thought useful since it is not unusual for children who sustain burn-disfiguring injuries to seek cosmetic treatment only in adolescence when they have a heightened awareness of their physical attractiveness (H. Rode, personal communication, April 2000). Thus, if perchance the admission records of the Red Cross Hospital archives were incomplete in the case of a potential participant, it was hoped that the information gleaned from the Tygerberg Hospital records would compensate for this error.

Once the records had been obtained from the respective hospital archives, a search of these records was conducted in order to locate potential participants eligible for inclusion in the study. Approximately 6200 admission records dating back to 1989 were scrutinized. Since these records are not available on a computerized database, this search was conducted manually, and proved to be a hugely time-consuming task. The task of searching the records was complicated by the poor quality of the records. In many instances, records had to be ignored in their entirety since they lacked crucial information such as the age of the child and the size and locus of the burn injury. The option of extending the search to records dating further back in time could not be exercised as neither hospital keep records predating 1989.

The search of the admission records yielded a total of 683 persons who met with the sample inclusion criteria discussed above. However, this initial cohort diminished substantially since meaningful contact details for these persons were provided in only 376 instances. The omission of contact details in the records can be attributed to several factors. Certainly, poor administration on the part of the ward staff could account for the scanty information provided in some instances. In addition, it is possible that at the time of admission, the burn-injured child did not have a fixed address that could have been documented. This would be in keeping with De Kock (1979) finding that the majority of burn-injured children are from impoverished, informal settlements.

Four participants who are permanent residents of the St Joseph's Home for Chronic Invalid Children were recruited immediately by arrangement with the social worker at the Home and then with the consent of the legal guardians of these children.

The admission records provided telephone numbers for a total of 41 candidates. Only four of these contact numbers were found to be valid and resulted in the recruitment of four participants. The many contact numbers that were considered invalid were classified as such when the number had been disconnected, the participants had moved home without providing a forwarding address or telephone number or the participant's caregiver was no longer employed at the workplace listed in the records. Given that in some cases as many as 11 years had elapsed since the contact numbers had been provided, it is understandable that so many of these numbers proved to be useless.

In an attempt to make contact with the remaining 368 candidates, telegrams were sent to the addresses provided in the medical records. The content of the telegram requested the caregiver of each potential participant to make telephonic contact with the author at the Hospital. Thirty-two responses were received. The low response rate could again be attributed to the length of time that had elapsed between providing these addresses and the time of sample recruitment. It is also quite likely that many of the potential participants and their families had subsequently relocated and did not receive the telegrams at all. Furthermore, even if a telegram was received, it may not

have been possible for the candidate to reach a telephone in order to make contact with me. Again, these speculations are consistent with the impoverished socio-economic environment in which the burned child is likely to live (De Kock, 1979). Further speculation as to the social fate of those children who did not reply to the telegrams is discussed in Chapter Four.

Once telephonic contact was established, the caregivers of the participants were informed of the nature and purpose of the study and that they would be financially reimbursed for any travel expenses incurred in making the trip to the Hospital where the study was conducted. All those caregivers who responded to the telegrams were enthusiastic about the study and there were no refusals. This means that every potential participant with whom contact was established was included in the study.

It is perhaps worth noting that from the time that the admission records were obtained to the time that the sample was finally recruited spanned a period of five months. Thus, although strictly speaking a convenience sampling approach was used to locate the participants for the study, it is clear that this is a misnomer in terms of the lengthy, expensive and tedious process that was involved. The difficulties encountered in the terms of recruiting participants as evidenced here may be what accounts for the burned population being understudied despite the magnitude of the problem. This challenge appears to be inherent in this type of research but also points the enormous necessity and practical value of conducting research of this nature.

PROCEDURE

Data was collected from the medical records of each participant and by conducting semi-structured individual interviews with each of the 40 participants and their respective caregivers. Many of the medical records were incomplete or illegible but provided at least some information regarding the participants' socio-demographic background, the aetiology, size and locus of the burn injury, and the participants' hospitalization and post-discharge treatment. The interviews were structured according to a *pro forma* questionnaire that included both open-ended and close-ended items. The interviews took the form of an informal conversation so as to minimize respondent anxiety. The measures are described in detail below.

The respondents who had been successfully recruited, whether via telephone or telegram, were informed that the study was to take place at the Hospital. The respondents were told that the interviews with the caregivers and the participants would take no longer than two hours and were urged to suggest days and times that were convenient for them. The decision to conduct the interviews at the Hospital was informed by the experience of De Wet et al. (1979), who, in order to collect data for the only other empirical study on the psychosocial adjustment of South African paediatric burn survivors, traveled distances of up to 600 kilometres in order to trace children who had been treated for burns at the Hospital. De Wet (personal communication, June 2000) described these trips to rural areas as dangerous in terms of physical safety and inordinately time-consuming. As such, the majority of the interviews were conducted in a private interviewing room in the Burns Unit at the Hospital. An exception to this standardized interview environment was made in the case of the four participants from St Joseph's Home who were not interviewed at the Hospital, but in a similarly private room at the Home. This arrangement was made to accommodate the fact that the caregivers of these children were nurses whose professional obligations did not permit them to leave the Home in order to be interviewed at the Hospital.

The interviews took place between 30 May 2001 and 24 July 2001. When necessary, letters were provided to explain an absence from school or employment. The duration of the interviews ranged from 30 to 90 minutes depending on the willingness of the participant and the caregiver to volunteer information and speak spontaneously. Consent to participate in the study was taken (see below). All the interviews were conducted in the mother tongue of the participants with the exception of the interviews with home language Xhosa speaking participants, which were conducted in English or Afrikaans if either language was well understood and frequently spoken by these persons. The assistance of a translator was not required. No attempt was made to standardize the language used in the interviews, and instead every effort was made to use register appropriate for the social and educational needs of the respondents.

The interviews were audiotaped using a standard cassette recorder. The decision to audiotape the interviews was taken since it was thought to be insensitive for the author to be writing while the respondents revealed their thoughts and experiences on such a sensitive topic. Photographs were taken of the burn-injured areas of the participant's body. It was explained to the respondents that these photographs would be useful both for comparative purposes if further surgery were to be undertaken and for the purposes of the present research. Several of these photographs are reproduced in Chapter Three with the permission of the respondents.

When possible and with the permission of the respondents, participants and their caregivers were interviewed separately. The rationale here was that caregivers often feel more at ease discussing their children and family background when the children are not present (Lavigne & Burns, 1981). Furthermore, by separating child and caregiver, the child could be spared from the exposure of intense criticism that often results from the tendency for caregivers to be unrelentingly critical when talking about their children. Separate interviewing was also thought to be more feasible in terms of facilitating disclosure on behalf of the child participants, particularly the adolescents, who may have felt awkward discussing sensitive subjects in the presence of their caregivers. In the case of younger children or those who appeared anxious, participants were not separated from their caregivers during the interview. Instead, these participants were supplied with drawing materials with which to occupy themselves during the interview with their caregivers.

Ethical considerations

Institutional review board approval

The necessary ethical approval to conduct the study was obtained from the Research Ethics Committee of the Faculty of Medicine at the University of Cape Town. This approval allowed access to both the admission records (required for sample recruitment) and the individual medical records. A copy of the official documentation to this effect can be found in Appendix B.

Informed consent to participation in the research

Informed consent has been isolated as the basic requirement for ethical practice in research (Carroll, Schneider & Wesley, 1985; Francis, 1999; Sieber, 1992) and is based on the ethical principles of autonomy, beneficence, non-malificence and justice (Englehardt, 1996; Kahn, Mastroianni & Sugarman, 1998). Since children under the age of 18 years are considered legally incapable of providing informed consent, consent had to be obtained from the caregivers not only for their own participation in the research but also, in their capacity as legal guardians, on behalf of their children (unless the children were of legal majority). Nonetheless, assent was obtained from the participant children since their meaningful understanding and co-operation was considered important.

In order to obtain the necessary assent and informed consent, the nature and purpose of the study was explained to the caregivers and to the participants. They were told that interviews were to be conducted with the aim of establishing the psychosocial adjustment of children who have sustained burn injuries in order to facilitate the development of a comprehensive rehabilitation programme for these young survivors. It was explained that it was possible to withdraw from the research at any time without incurring a penalty. This explanation was given to the caregivers twice: once telephonically when the original contact was established, and again directly before the interview commenced. In the second instance, the caregivers were asked to sign a document granting consent to their own participation in the research and to the participation of their children. Obtaining assent from the participant children took place at the interview only, however, when originally contacted, the caregivers were asked to discuss participation in the research with their children. This request was thought to encourage voluntary and willing participation in the research.

In the case of the four participants from St Joseph's Home, consent was obtained only telephonically from their legal guardians. Additional consent was obtained from the social worker at the Home.

Consent was given by both the caregiver and the participant to audiotape the interview and to take photographs of the burn-injured areas of the participant's body. It was

explained that these photographs become the property of the Hospital once the study is completed although copies would be available on request. There were no objections to audiotaping the interviews, but one participant refused to be photographed despite her mother's consent and encouragement.

A copy of the consent document signed by the caregivers and the participants who had attained majority status is contained in Appendix B.

Confidentiality

To protect the privacy of the participants under empirical scrutiny, both the participants and their caregivers were assured of the confidentiality of their disclosures. The names of the participants were replaced with pseudonyms and in terms of the photographs of participants reproduced in this thesis, every attempt has been made to obscure identifying features.

Responsibilities to the participants

Apart from providing payment to the caregivers for any travel expenses incurred in making the trip to the Hospital, every effort was made to provide the participants and their caregivers with as many benefits as possible arising from the research. The participants and their caregivers were informed that feedback regarding the research findings would be available in six months. Contact details were furnished for this purpose. It was also agreed that any problems reported by the caregivers or the participants at the time of the interview would be dealt with by the Hospital, if possible. In light of this agreement, when necessary, referrals were made by the author to the appropriate outpatient facilities either at the Hospital (if the participant was younger than 13 years) or if the participant was older than 13 years, to Groote Schuur Hospital or Tygerberg Hospital. It emerged that almost all the participants would benefit from some manner of formal intervention and as such a total of 43 referral appointments were made. All referrals were arranged personally by the author by making telephonic appointments with the relevant clinic staff. These appointments were made at the time that the interviews were conducted. Twenty six participants were referred for plastic surgery assessment where cosmetic scar revision or the release of contractures was required. Nine participants were referred for

scholastic/remedial assessment in cases where academic lag was evident. Eight participants who were thought to exhibit emotional and/or behavioural disturbances were referred for psychological/psychiatric evaluation.

MEASURES

As mentioned above, data was collected from three sources: the medical folders of the participants, the participants themselves and the participants' caregivers. The use of multiple sources has proved useful in other research of this nature (Blakeney et al., 1993; Blakeney et al., 1998; Meyer et al., 1995) and allowed for the verification of information in two ways. Firstly, although the medical folders were often incomplete, they did provide documented information regarding the nature of the participant's burn injury and hospitalization and post-discharge treatment that could be checked against the claims made in the interviews. Secondly, the participant's understanding of events could be compared with the caregiver's version, providing a more comprehensive overall impression.

The choice of a semi-structured, face-to-face interview with the participant and the participant's caregiver was thought to be the most appropriate method of data collection for this study. Although the vast majority of research conducted on the adjustment of paediatric burn survivors has relied on questionnaires such as the Child Behaviour Checklist, the Youth Self Report, the Teacher Report Form and various self-esteem inventories (e.g. Blakeney et al., 1993; Blakeney et al., 1998; LeDoux et al., 1996; Meyer et al., 1995; Moore et al., 1996), these instruments were deemed unsuitable for the present study. These standardized instruments were rejected for the purposes of this research because they are self-administered reports that require a high degree of literacy and sophistication on the part of the respondents. Given the educational and socio-economic status of the population being investigated in this study, it follows that the requirements for competent instrument completion would not be fulfilled. The choice of individual interviews is supported by the finding that many illiterate or partially literate respondents would prefer to complete a self-administered questionnaire rather than admit to their reading problems, resulting in a complete but meaningless set of information (Tripodi & Epstein, 1980). Similarly, this type of

instrument requires not only literacy on the part of the respondent, but a certain degree of fluency in the language in which the questionnaire is written.

The semi-structured interview schedule devised for the present research was structured in the sense that in order to answer the research question, the respondents were presented with specific questions representative of content areas that needed to be explored. Simultaneously, the interview was unstructured in that many open-ended questions were asked. This semi-structured approach was particularly useful for an in-depth investigation of a largely unexplored and sensitive subject. Questions could be rephrased in order to encourage, facilitate and guide the respondents to provide unbiased answers to necessary questions. This method was also suitably flexible to allow for probing and clarification questions that were required in order to elicit information from a socially unsophisticated population, whose literacy and confidence levels were likely to be low and who would perhaps be unaccustomed to self-reflection in the presence of a stranger.

The first component of the interview comprised the collecting of socio-demographic information about both the caregiver and the participant so as to establish a clear idea of the social and familial environment. A detailed medical history was taken in order to determine the existence of pre-morbid pathology. Participants and caregivers were also asked about the participants' current somatic complaints. The focus then turned to the burn injury with detailed questions being asked about the events surrounding the injury, the nature of the burn injury, the hospitalization period following the injury with its attendant surgical procedures, and any subsequent hospitalization for further surgery. Questions were also asked about compliance with post-discharge treatment in terms of attending outpatient's clinics and making use of pressure garments and splints, if these were indicated. Participants and caregivers were asked to elaborate on particular difficulties encountered with any of these aspects of the treatment process as well as to comment on what could have been done to assist them in overcoming these obstacles.

The section of the interview aimed specifically at eliciting information regarding the participants' current emotional and behavioural adjustment was partly informed by

literature on the subject and also loosely based on the Rutter Scale for Children (Rutter, 1967; Rutter, Tizard & Whitmore, 1970) and the Kiddie-Sads-Present and Lifetime Version (K-SADS-PL) Interview, as both instruments are widely used for this purpose (e.g. Kaplan, Sadock & Grebb, 1994; McGee, Williams, Bradshaw, Chapel, Robins & Silva, 1985; Schachar, Rutter & Smith, 1981; Venables, Fletcher, Dalais, Mitchell, Schlesinger & Mednick, 1983). Neither of the aforementioned instruments was used in their standardized format for two reasons. Firstly, both instruments are international in origin and have not been normed on the population being studied in this thesis. To this end, it was necessary to adapt the content to achieve contextual relevance. Secondly, the intended purpose of both these instruments is to provide clinical diagnoses with reference to a wide range of psychological and psychiatric disorders, ultimately for comparison with the normative population. These diagnoses are obtained by scoring the instruments in the prescribed manner which yields quantitative data in numerical form. However, the aim of the present study was not to formulate clinical diagnoses of psychosocial pathology, or to compare the findings to established norms, but rather to provide a detailed narrative description of adjustment following paediatric burn injury. Thus the nature of the information required would not be obtained by administering a questionnaire with a close-ended response format. Instead, open-ended questions that would encourage rich qualitative data were put to the respondents.

The abovementioned component of the interview focused on emotional and behavioural indicators of distress on the part of the participants. As such content areas included questions regarding the participants' mood, anxiety levels, control of bladder and bowel functions, sleeping and eating patterns, general anti-social conduct and scholastic progress. Questions were also asked regarding the extent and nature of formal psychosocial counseling received by the participants.

Participants and caregivers were also questioned about the participants' use of social support networks in terms of peer groups, the family and participation in recreational, sporting and religious activities. These questions were informed by the emphasis in the literature on the importance of social support in promoting the successful

psychosocial adaptation of paediatric burn survivors (Blakeney et al., 1988; Blakeney et al., 1990; LeDoux et al., 1998).

The identification of social support as the most significant factor in facilitating adjustment also provided the rationale for questioning caregivers and participants about the impact of the burn injury on family and sibling relationships. The extent to which social resources were available to and utilized by caregivers was also explored. As discussed in Chapter One, paediatric burn injury is increasingly being understood as a traumatic assault not only on the burned child, but on the family as a unit. It was thought that information obtained from the responses to these questions would be useful in formulating future interventions aimed at assisting the family in its entirety.

Much attention was paid to understanding the participants' attitudes towards their scars, how others react to the disfigurement and how the participants respond to these reactions. Equally, the actions of the caregivers in terms of encouraging the child and dealing with negative social interactions were probed. The effect of disfigurement and physical disability as a result of the burn injury on the participants' lifestyle and relationships was also explored. These questions were aimed at eliciting information on the effect of cosmetic disfigurement on psychosocial adjustment. Responses to these questions are of particular value since, as explained in Chapter One, the cosmetic disfigurement that is arguably the most significant legacy of a burn injury, has rarely been discussed in the literature on burns.

The interview concluded with a discussion of the participants' future prospects. Participants were asked about their employment and career aspirations as well as what they would wish for if they were granted any three wishes. Both the participants' and the caregivers' concerns for the future and their advice to those in a similar situation were explored. It was thought that this information would be useful in terms of formulating future therapeutic interventions and research projects.

A copy of the interview schedule is attached in Appendix C.

DATA ANALYSIS

Analysis of quantitative data

Since the vast majority of data in the study is not of a quantitative type, and those variables which are quantitative are continuous in nature, well known statistical measures of central tendency such as mean and standard deviation are thought to adequately reflect the nature of the spread of this data. The statistical software programme STATISTICA was used for these basic descriptive statistics.

Analysis of qualitative data

A process of thematic analysis (Bussis, Chittenden, Amarel & Carini, 1978; Ely, 1991) was used to analyze the qualitative data in this study. A theme can be defined as a statement of meaning that runs through all or most of the pertinent data, or one in the minority that carries substantial emotional or factual impact (Ely, 1991). The extraction of themes from the raw data can be understood as the researcher's inferred statement that highlights explicit or implicit attitudes toward life, behaviour or understandings of people and experiences.

The process of the thematic analysis began with the transcribing of the verbatim narrative of the interviews. Once transcribed, the raw data was read and re-read so as to develop a detailed, intimate knowledge of the nature of the data. During this phase, initial impressions and tentative analytic categories that emerged from the data were listed in the form of marginal notes. These categories and impressions were then refined by re-reading the entire body of raw data. The next step involved grouping data into themes both according to these tentative categories and according to the delineated content areas of the interview schedule described above. As such, both a 'bottom-up' and a 'top-down' approach were employed to extract themes from the data. The data was then reviewed for statements that were particularly revealing or expressive of the themes. These extracts of verbatim narrative were selected from the raw data and linked to the themes. The narrative that is reproduced in Chapter Three has been retained in its original form and excerpts taken from interviews with Afrikaans speaking respondents have not been translated into English. This is thought to be appropriate since the present study is targeted at a local audience. The findings

for each person were integrated and then compared to discover commonalities, patterns, differences and unique perspectives.

The mixture of monosyllabic responses to some questions and attempts made to keep the tone of the interview informal, thereby encouraging spontaneous discussion, served to complicate the analysis. Also, since the sample was relatively small, but the nature of the information elicited was in-depth, the analysis was a hybrid of survey type analysis and case study analysis. This means that while every effort was made to demonstrate the patterns common to the sample, it was equally important to reflect individually diverse experiences as authentic and valid in their own right. The responses of the caregivers and the participants were analyzed as a whole and only separated where a difference of opinion emerged.

CHAPTER THREE

RESULTS AND DISCUSSION

INTRODUCTION

This chapter comprises a combined Results and Discussion section that is organized both along thematic lines and in the chronological order of the interview schedule described in Chapter Two. The chapter begins with a discussion of the nature of the burn injury itself and includes several photographs illustrative of the cosmetic and physical sequelae of thermal injury as evidenced by the participants in this study. In order to contextualize the emotionally traumatic effect of a paediatric burn injury on the family, the experiences of the caregivers and the participants during the hospitalization period and upon returning home after discharge are explored. The findings relating to the participants' post-discharge treatment in terms of compliance with aftercare and subsequent corrective surgery are also reviewed. The remainder of the chapter follows the format of the interview schedule described in Chapter Two. This schedule is attached in Appendix C.

THE BURN INJURY

Aetiology of the burn injury

Twelve participants sustained scalds, eleven of which were accidental. The twelfth participant sustained a 50% total body surface area (TBSA) scald as a result of parental abuse. Two participants sustained contact burns by falling into hot coals or ash while playing outside. The remaining 26 participants sustained flame burns of various origins. In eleven cases, all of which were presumably accidental, a flammable liquid such as methylated spirits, petrol or turpentine was added to a wood fire in order to facilitate combustion, resulting in an explosion. Six participants were burned as a result of overturned candles; two participants were burned in paraffin-stove explosions and three participants sustained burns in shack fires of unknown origin. In terms of non-accidental flame burns, one participant was burned in a petrol bombing, two participants were burned as a result of the pyromania of a family member, and finally, one participant survived an attempt on her life after her father doused her in petrol and set her alight.

It is an interesting finding that the majority of participants in the present study had sustained flame burns as the incidence of scalds treated at the Hospital is generally much higher. For example, in the 12 months from January to December 2000, 684 children were admitted to the Burns Unit at the Hospital, 602 (88%) of whom had sustained scalds and only 76 (11%) flame burns. Similarly, the most recent statistics available from the Child Accident Prevention Foundation of South Africa indicate that of the 718 children seen at the Trauma Unit at the Hospital during 1999, 497 (69%) had sustained scalds and only 119 (17%) flame burns (N. du Toit, personal communication, August 2001). The most likely explanation for the preponderance of flame burn injuries in the sample is that this nature of burn causes more extensive tissue damage than a scald, resulting in more severe disfigurement (Morrow, Smith, Cairns, Howell, Nakayama & Peterson, 1996). It is quite possible that caregivers responded to telegrams based on the cosmetic appearance of the burn-injured child.

Locus of the burn injury

Table 1 reflects the breakdown of locus to burn injury to number of participants.

Table 1. Locus of the burn injury

Locus of burn injury	Number of participants
Face	24
Arm	22
Leg	19
Hand	16
Chest	15
Scalp	12
Stomach	11
Back	10
Perineum	8
Foot	5
Buttocks	3

Participants rarely sustained burns to only one area of the body. The higher incidence of burns to the face, arms, legs and hands is understandable in the sense that these areas are the most exposed (Cooper & Fenton, 1996). Unfortunately the resulting cosmetic deformity is therefore also very visible.

Scarring, skin grafts, tissue expanders¹¹ and amputations

The nature of the burn injuries sustained was such that all the participants were cosmetically disfigured by hypertrophic and/or keloid scars. Overleaf, Figure 1 of Greg and Figure 2 of Ncanisa are respectively illustrative of these types of scarring.

¹¹ A tissue expander is an inflatable balloon surgically buried under the skin and inflated over a period of months. The newly expanded overlying tissue is then moved to a tissue deficient area.

Figure 1. Greg: Hypertrophic scarring

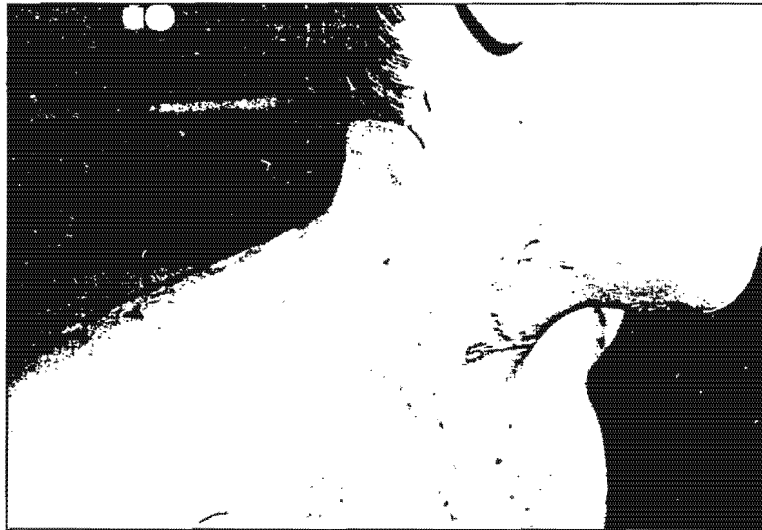
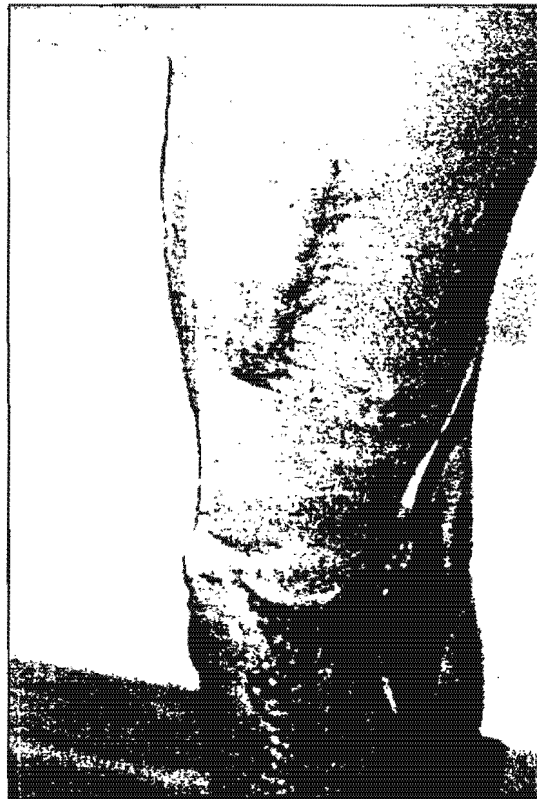


Figure 2. Ncanisa: Keloid scarring



All but four of the participants required skin grafting for their burn injuries. The aesthetic effect of a skin graft is depicted below in Figure 3 of Neville.

Figure 3. Neville: The aesthetic effect of a skin graft



Subsequent to sustaining the burn injury, eight participants had had a tissue expander implanted at least once. Figure 4 below of Sipho provides a graphic illustration of the nature of a tissue expander.

Figure 4. Sipho: A tissue expander



In terms of amputations, one participant had multiple limb amputations, three participants had at least one amputated limb and six participants had at least three digits amputated. None of the participants with extremity amputations had prostheses of any form although at the time of data collection, the Hospital had embarked on a fund raising venture to provide feet prostheses for the participant with multiple limb amputations (H. Rode, personal communication, September 2001).

Figure 5 below of Busisiwe shows a multiple digit amputation and Figure 6 below of Shannon depicts the amputation of both his legs.

Figure 5. Busisiwe: Multiple digit amputations



Figure 6. Shannon: Multiple limb amputations



Seven participants could be described as having been visibly deformed by the amputation of skin appendages: four by the loss of their ears, and three by the loss of their noses. Figure 7 below of Busisiwe illustrates the visible loss of her ear as well as the cosmetic effect of burn alopecia¹². It is interesting to note how the distortion of Busisiwe's facial features create a difficulty in identifying her gender.

Figure 7. Busisiwe: The cosmetic effect of skin appendage amputation and alopecia



THE HOSPITALIZATION PERIOD

Less than a quarter (n=7) of the participants could remember being in hospital since most were too young at the time. Those who did have memories of being in hospital, like Charlton quoted overleaf, described their daily debridements¹³ as the worst part of the experience.

¹² Alopecia is the loss of hair growth that results from damage to the hair follicles of the burned tissue.

¹³ Debridement involves the clearing of dead tissue, old creams and secretions from the burn wound.

"Die ergste was toe hulle my gewas het. Dit was rof. En daai reuk, dis soos 'n gebrande reuk wat 'n mens naar maak."

Charlton

All the caregivers, on the other hand, could recall the period of initial hospitalization with great clarity, regardless of how much time had subsequently elapsed. It was clear from these accounts that visits to the hospital were traumatic, both for the caregivers and for their children. Caregivers were unprepared for what they were confronted with on the ward, and reported being overwhelmed by the levels of activity and the unrelenting crying. Greg's mother describes her visits to the hospital below:

"I think I was most affected by his pain. It was terrible. The ward was too full and there was so much noise from the crying. There was children from the shack fires here that was totally burned. He didn't want to lay here – he screamed – he was scared – he didn't want to lay with the other children because they were so very bad. I came every day. He would run after me screaming because he did not want to lay here. And one day the nurse was cleaning him and I saw underneath the bandages. It was raw meat. It was terrible."

Greg's mother

The distress of the burn-injured child as observed by caregivers can be accounted for by several factors: the acute stress of constant pain, fever and disturbance of body chemistry (Kibbee, 1981); the suddenness of the transition from family to hospital environment; the severity of the physical trauma associated with the burn accident and the acute hospitalization; and the long duration of hospitalization (Knudson-Cooper, 1988). Furthermore, given that three quarters of the participants were pre-schoolers at the time of the burn (half of whom were younger than two years), separation anxiety was likely to play a significant role in the burned child's suffering. During this developmental stage children fear abandonment by the caregiver and are upset by the fact that the caregiver, who has always been the primary source of protection and control, is no longer in control (Knudson-Cooper & Thomas, 1988). The separation brought about by the hospitalization and the constant infliction of painful procedures by strangers may be viewed by the young child as a betrayal or as a punishment (Kibbee, 1981). The caregivers of older participants in the present study reported unusually immature behaviour on the part of their children during the hospitalization period. This can be explained by the widely recognized tendency for burned children

to regress during the acute hospitalization period (Knudson-Cooper & Thomas, 1988; Tucker, 1986).

The importance of visiting

The combination of serious thermal injury and the sense of abandonment that the burned child may experience during protracted hospitalization may have fatal results. Benians (1988) describes how regular visits from caregivers can literally make the difference between a burned child's decision to live or die. To this end it is imperative that caregiver visits be maintained on a prolonged and daily basis. In the present study, although all the caregivers said that the participants in their care had visitors while they were in hospital, ten caregivers emphasized the difficulties they encountered with obtaining transport to the hospital, taking time off from work and leaving their other children unattended. Some caregivers, like Donovan's mother quoted below, compensated for not being able to visit as often as she would have liked to by alternating between phone calls and visits.

"Ek het nie aspris weggebly nie. Ek moes reël vir die kleintjie om by die buurmense te bly. Ek het gekom toe ek geld gehad het of ek het gebel. Ek het geld geleen by die werk en naweke kom kuier, as ek kon."

Donovan's mother

Although the Hospital allows caregivers to remain with their children through the night and provides accommodation in the adjacent nursing residence for those caregivers who reside outside of Cape Town, it would be useful if a contingency fund were established to supplement the travel expenses incurred in making daily visits to the Hospital. This is especially necessary when one considers the caregivers' limited income (as described in Chapter Two) which necessitates a heavy reliance on public transport.

Only one of the ten participants who were already attending school was visited by his teachers and classmates while in hospital. For school-going children, regular contact with their peers is important in that it encourages a sense of peer empathy and facilitates a less traumatic return to school (Blakeney & Meyer, 1996). This points to the need for a strong hospital-school liaison that begins at the time of the child's

admission to the hospital (Blakeney, 1995). The importance of this form of co-operation in terms of ensuring the successful social reintegration of the burned child is discussed later on in this chapter.

Caregivers' guilt

All caregivers reported feeling guilty about the burn accident, whether they were actually involved or not. The literature on burn injury reiterates the finding that guilt is one of the main sources of emotional distress for caregivers of burned children (Bloomberg, 1998; Cromes, 1984; Knudson-Cooper, 1984; Rivlin, 1988). Possibly caregivers feel guilty that somehow they have failed in their role as the protector of the child. Caregivers like Leanne's mother quoted below may also harbour anger towards those responsible for the accident, feelings that have the potential to result in additional stress at home. The caregivers are going through a process of imagining what they could have done, or not done, that could have prevented the accident. Having to observe their children in pain and being powerless to put an end to it, accompanied by the knowledge that their children will be permanently disfigured and possibly disabled, compounds the caregivers' guilt. Francois' and Leanne's mother respectively describe their guilt about the burn accident:

"Dit was moeilik, nie om hom te behandel nie, maar omdat ek myself nie kon vergewe nie. Ek het skuldig gevoel want ek het nou nie geglo my kind gaan so 'n groot scar hê. Ek was mos nie by die huis nie. Ek moes werk en ek het nie 'n ander keuse gehad nie."

Francois' mother

"Daar was baie stryd in die woning na die ongeluk. Ek kon nie met my man oor die weg kom nie - elke keer wat ek na hom kyk sien ek net die vlamme. En nou dat hy die vuur gemaak het het Leanne nie maklik na hom gegaan nie. Sy het heelyd gesê 'dit is mos pappie se skuld'."

Leanne's mother

RETURNING HOME WITH THE BURNED CHILD

During the hospitalization period, burned children and their families have barely begun to deal with the meaning of the injury. This is partly because the hospital environment is a microcosm unto itself, a safe cocoon in comparison to the real work

of adjustment that begins when the child is discharged (Knudson-Cooper, 1984). While in hospital, the burned child's scars and injuries are not a subject of interest, remark or question. The outside world from which the patient has been insulated is a very different matter. Clearly both the burn-injured child and the caregivers need appropriate preparation for the challenges of returning home – both emotionally and practically in terms of continued burn care. Unfortunately, the lack of resources available to the Hospital means that none of the caregivers in this study received any form of instruction to this effect and were thus unprepared for the discharge phase. The resulting feelings of inadequacy as a caregiver, anger at the hospital staff and general distress are well illustrated by Greg and Olivia's mothers respectively:

"Taking his bandages off, the screaming. I also felt the pain that he was going through and then I hated the hospital and thought they should be doing this – I am not a nurse I can't even do this. I think I had a small breakdown or something".

Greg's mother

"Die eerste keer wat Olivia huistoe gekom het vir 'n naweek was terrible. Ek het vir hulle by St Joseph's gesê ek sal probeer om haar die behandeling te gee wat hulle vir haar gee maar ek is mos nie 'n verpleegster nie. Nou moet jy weet, wanneer sy die pressure garment by haar gesig afneem moes ek eers toilet toe jaag - toe sy die ding afhaal toe kom die velle so saam. Ek het my oë toegemaak en uitgejaag. Ek het so gehuil. Dit het vir my gelyk ek kan nie na my eie kind kyk nie. Ek kon dit nie hanteer nie en sy kon dit nie aanvaar nie. Dit was die moeilikste."

Olivia's mother

It is clear then that the caregiver and family of the burn-injured child experience a great deal of emotional turmoil both during the hospitalization period and once the child has been discharged. It is thought that these difficulties should be addressed as soon as possible to prevent these stresses from spilling over into the more challenging period of long-term adjustment that follows the hospitalization phase. Again, the scarcity of resources at the Hospital excluded the possibility of providing the caregivers in the present study with any form of psychosocial intervention at any stage during this ordeal. This is significant because taking the time to treat the family is of critical importance to the future of the burned child who needs expressions of care by loved ones (Blakeney & Meyer, 1996). A group therapy forum for caregivers in which

they can safely express their confusion, guilt and repulsion at the sight of the child's injuries as well as explore new ways of coping with the situation would be useful in normalizing the caregiver's distress (Rivlin, Forshaw, Polowyj & Woodruff, 1986). This recommendation is discussed in greater detail in Chapter Four.

POST-DISCHARGE TREATMENT

Compliance with clinic appointments

According to the medical folders, only ten of the 40 participants were compliant with their post-discharge treatment. This means that only ten patients attended the necessary follow-up outpatient burn, plastic surgery, occupational therapy and physiotherapy clinics for the required duration. Four of these ten were chronic patients at St Joseph's Home and two other participants had remained at the Home for this precise reason. There is no apparent common denominator in the remaining four compliant participants.

Interestingly, all but three caregivers claimed that they had kept every clinic appointment. Although it is possible that some of these caregivers were mistaken, this finding is more likely a reflection of social desirability bias. Caregivers like Tracey's mother quoted below who admitted to not keeping the clinic appointments cited reasons such as financial constraints and difficulties with transport:

"Ons moes teruggegaan het Oktobermaand maar met vervoer en finansies en so aan het dit bietjie moeilik gegaan, verstaan jy? Dis nou die rede daar ons nie by die hospitaal uitgekom het om die kliniek by te woon nie."

Tracey's mother

One mother added that she could see no reason to continue attending the clinics as her daughter was not in pain. This comment represents what is conventional wisdom in medical practice: patients discontinue treatment when their symptoms disappear, regardless of whether further treatment is required (H. Rode, personal communication, July 2001).

Compliance with wearing pressure garments and splints

According to the medical folders, the majority of the participants (n=35) required pressure garments and nearly three-quarters (n=27) required splints due to the nature and locus of their burns. Although most caregivers claimed that the participants in their care had complied with the necessary wearing of their pressure garments and splints, information gleaned from the medical records revealed this to be untrue. The few caregivers that admitted to non-compliance reported that they had not forced their children to wear the garments and splints because these were uncomfortable and evoked social ridicule. This comment from Bradley's sister illustrates this sentiment:

"Hy het gehuil en gesê hy wil dit nie dra nie want dit is styf en ongemaklik en dit jik en die kinders giggel agter hom as hy dit dra. Hy het net geweier en ek het hom nie gedwing nie."

Bradley's sister

Failure to comply with post-discharge treatment regimens prolongs the burned child's physical and emotional adjustment (Stern and Davey, 1985). To this end, these authors have suggested that the best way to hasten the burned child's physical and emotional rehabilitation is by early transfer from the Burns Unit to a homelike residential facility that embraces a multi-disciplinary team approach. This approach has been adopted in Adelaide, Australia with children from sparsely populated rural areas who will not receive the necessary post-discharge treatment in their local communities in terms of pressure garments, exercise and psychosocial stimulation. The intensive occupational and physical therapy offered at this facility results in significantly less hypertrophied scars and contractures and the children therefore require less corrective surgery. This in turn facilitates emotional adjustment. The local equivalent of the centre in Adelaide is the St Joseph's Home, however, this Home is not presently equipped to deal with the large numbers of burned children that would benefit from its services. It may be a worthwhile undertaking to determine the feasibility of improving the facilities as St Joseph's Home in the manner described here.

Subsequent plastic surgery

More than half (n=23) of the participants had returned for at least one plastic surgery procedure subsequent to their initial discharge. This may seem an impressive finding,

however, according to the medical records, only three participants had been formally discharged from the plastic surgery clinic. Furthermore, at the interview, 19 participants presented with contractures that were restricting mobility and required surgical correction. These contractures are the result of poor compliance with post-discharge treatment following either the initial hospitalization period, or a subsequent admission for plastic surgery. Figure 8 below of Shannon depicts the amputation of one of his hands and the digit contractures of the other, which prevent him from being able to straighten his fingers.

Figure 8. Shannon: Limb amputation and digit contractures



Figure 9 below of Nomawetu illustrates the nature of axilla contractures that prevent Nomawetu from raising her arms to 180 degrees above her head. The aesthetic effect of hypertrophic scarring is also well illustrated in Figure 9.

Figure 9. Nomawetu: Axilla contractures



Eleven year old Ncanisa serves as a good example of the importance of post-discharge compliance. Ncanisa, who sustained a 20% TBSA scald to the legs and feet when she was a year old, presented at the interview with contractures of the dorsum of both feet, causing her toes to be hyperextended. This hyperextension means that Ncanisa has to place all her weight on the balls of her feet when walking, resulting in an unnatural gait. When asked why she had not brought her daughter back to the hospital, Ncanisa's mother, like many other caregivers, cited financial reasons:

"On the leg she has some rough meat that needs to be cut and she is walking on her toes. She is crying that her skin is not smooth and it is pulling her. Then I tell her that to make it smooth sometimes baby is going to cost a lot of money and so long as she is better. Maybe if we can have money we can have it fixed one day."

Ncanisa's mother

Although it was not discussed in the interview, it is doubtful whether Ncanisa's mother is aware that such severe burns to the feet can disturb the growth of the feet. Thus, both ignorance of the potential harm that can result from poor compliance and limited financial resources are at play in Ncanisa's case. The same can most probably be said of the majority of cases. The need to educate caregivers of burned children as

well as the children themselves regarding the importance of compliance is therefore an important aspect of burn care rehabilitation. This point is discussed in more detail elsewhere in this chapter.

Referrals

The 19 participants who required contracture release as well as another seven participants who would benefit from cosmetic scar revision, were referred by the author to the appropriate outpatient plastic surgery units.

The reality of ongoing corrective surgery

With the exception of the four children at St Joseph's Home, only five other participants have been involved in the process of ongoing corrective surgery. All these children sustained burns to the face and hands. Although these children and their caregivers noted the improvements that had been made, they also expressed disillusionment and impatience with the lengthy process. Leanne, Lizette and James complained that after each surgical correction of their hands, they had to relearn use of the 'improved' hand. For them, the frustration involved in this process was more significant than the benefits derived from the surgery. Caroline, who has undergone 16 years of facial reconstructive surgery, is now demoralized and has lost faith in the power of plastic surgery:

"This name-calling makes me feel bad and sore and when I just think like I had such a lot of operations. They say they are going to take it away, you know, but by taking it away they just make another scar every time. In June 1999 I had a tissue expander here in my head but the skin wasn't enough or something and they ended up ruining my hairline as you can see. So every time they try and do something good, they just put another line or mark there. It is like everything is still the same. Every time I have an operation on my face its like I don't see a difference man. Look, like they reimplanted eyebrows for me and it didn't grow as they said it would and so I tweeze it with a tweezer. Then I thought fuck you, it is enough. The scars are not reduced".

Caroline

Busisiwe and Shannon, both residents of St Joseph's Home, spoke of their weariness of being "siek", of living in a place "waar net siek kinders bly" and of their overwhelming desire to return to their parents – and presumably to some semblance of

normal living: free of hospitals, operations and pressure garments. None of the participants from St Joseph's could recall the nature or purpose of their most recent surgical procedure, or had any indication of what the future held in terms of treatment. Moreover, not one of the four children would concede an improvement in their appearance or an enhancement of functionality.

The caregivers spoke of the necessity to provide their children with additional encouragement whenever the date for another surgical procedure approached. The participants described the days prior to surgery as being filled with apprehension of the impending physical discomfort and a preoccupation with thoughts of the cosmetic outcome of the procedure. According to the caregivers, the children become more withdrawn and depressed during this time resulting in parental doubt about the appropriateness of ongoing surgery. Lizette's mother articulated these sentiments:

"Die Sondag voor die operasie is sy nou weer depressief en teruggetrokke en toe sê sy 'Mammie, nie alweer' en toe sê ek vir haar 'Ons is nou daarin en ons moet daar uitkom. Alles het goed afgeloop, kyk die verbetering'. Ek weet self hulle kan dinge verbeter maar lyk vir my is dit die beste as hulle dit so los soos dit is. Ek voel sy het al so baie geopereer en dit is genoeg. Sy sê baie sy wil nie eintlik hê hulle moet haar hand regmaak nie want sy ken 'n kind wat net een vinger het en hy kom goed reg. Nou sê sy sy het nie nog operasies nodig. Ek wil altyd hê hulle moet vir haar ook vra".

Lizette's mother

Thus it would seem that the very recipients of the surgery, the children, are seldom, if ever, meaningfully consulted about whether or not they actually wish to continue with reconstructive surgery. Equally, the extent to which the caregivers of these children actively participate in decisions and are informed as to the long-term surgical treatment plan is doubtful. It is suggested that an interplay of at least three different dynamics is responsible for bringing about this situation. The first is the undeniable existence of an overwhelming power differential between doctor and caregiver: while the doctor is educated and in possession of the technical expertise needed to treat the child, the caregiver is from a socially disadvantaged background and is poorly educated. Moreover, as the doctor has been socialized into a dominant role (Lidz, Meisel, Zerubavel, Carter, Sestak & Roth, 1984) in which he or she does what is

considered to be in the best interests of the disfigured child; the caregiver assumes a passive role, entrusting his or her child to the care of the doctor who it is believed will exercise the most appropriate remedy. Although it is not being suggested that medical professionals regularly exploit this differential, it would be naïve not to recognize that the act of intervention is a fundamental component of surgical training and practice, and doctors are more likely to encourage than advise against it.

The second factor is an unwritten assumption that disfigured persons will continue with plastic surgery until as much as possible of their previous visage is recaptured. In a society that prizes attractive appearance, it is incomprehensible to many that a disfigured person would elect to forego further surgery. This assumption draws power from the widespread misconception that advances in reconstructive surgery are such that even the most unsightly blemishes and asymmetries that are the legacy of a burn injury can be erased (Partridge, 1999). This remark by Caroline illustrates the perpetuation of this myth:

"You watch the movies and you see all the technology and I wonder man, why don't they just use a laboratory that grows skin, like different colours of skin and then at a certain age they can use that skin and then at a certain age they can use those lasers and take the marks away."

Caroline

The third factor is one of parental responsibility to a child: A caregiver like Lizette's mother quoted above who has misgivings about the appropriateness of ongoing surgery echoed the fear that if she decided (on behalf of her child) to forego further cosmetic surgery, then she would effectively be denying her child the opportunity of social acceptance. Consequently, she would be blamed for any subsequent social rejection that the child would experience as a result of her disfigurement:

"Dit is mos nie lekker om so in die wêreld te gaan, so geskend. Ek wil nie eendag vorentoe hê sy moet my blame, of by my kom kla oor hoe sy lyk en ek het niks daaroor gedoen nie."

Lizette's mother

The point is that reconstructive surgery is a long-term treatment process, particularly in the South African context where waiting lists are long and very small areas are corrected at any one time. If disfigured children grow up to believe that their social acceptance is dependent on recapturing their good looks, the possibility exists that the crusade for a surgically repaired appearance will supercede meaningful attempts at social rehabilitation (Partridge, 1990). Once surgery is completed to restore the child to maximum functionality, continued cosmetic surgery is a choice that can only be made if there is a communicative relationship between the burned child, the child's caregivers and the surgical team. The benefits and disadvantages of any proposed surgery need to be discussed openly and realistically in terms of what can be done and the resulting drain on time, lifestyle and finances. It may be useful to commit to a phase of surgical procedures towards a particular end point. The psychosocial aspects of continuing surgery should ideally be discussed with a social worker or psychologist who has experience in burns. It is interesting that burned children tend to be better adjusted when their surgery is completed: Giljohann (1979) found that whilst surgery is still being planned, burned children and their families entertain unrealistic fantasies that the scars will magically be replaced by 'normal' skin, but when no further surgery is contemplated, there is no room for such fantasies. It may also be useful to consult with other burn survivors and their caregivers in order to benefit from their experiences. This form of networking would need to be facilitated by the Hospital.

The need for education regarding the nature and consequences of burn injury

The findings presented above relating to poor compliance with post-discharge treatment highlight two points: the first is the financial expense incurred, and the second is a lack of education regarding the importance of such compliance. While knowledge cannot compensate for inadequate funds, information about the long-term benefits of compliance with exercise, positioning and pressure garments may serve as much needed motivation. It is likely that once the burned child has been discharged from hospital and the trauma of the acute phase of treatment has passed, caregivers assume the worst part to be over and that any follow-up treatment is of relatively minor importance. Information regarding compliance should therefore be emphasized not only upon discharge, and at any subsequent clinic appointments, but should also be available during the inpatient phase. Posters or pamphlets could be used for this

purpose. Ideally, caregivers should be given verbal information regarding continuing burn care and the importance of post-discharge compliance, perhaps within the forum of a caregiver support group (Quay & Alexander, 1982) as discussed in Chapter Four.

The need for quite basic education regarding the nature of burn injuries and their consequences for the burned person was highlighted by three cases in particular. Rasheeda and Taryn, both of whom sustained burns to the lower abdomen believe that they will be unable to tolerate pregnancy as their 'skin will tear open'. Perhaps more disturbing is that Rasheeda and Taryn's respective caregivers share this erroneous belief. Another participant, Leanne, was apprehensive that her children would inherit her disfiguring marks, a concern reiterated by her mother, quoted below:

"Leanne het vir my gevra na een van die operasies toe sy by die huis kom of sy eendag kinders gaan kry wat merke het – toe dink ek daaroor vir die eerste keer en toe sê ek, ek sal maar dink dit is die geval maar ons moet maar die dokter vra of die kinders ook hierdie lelike letsels gaan hê."

Leanne's mother

PAEDIATRIC BURN INJURY AND THE FAMILY

Caregivers' levels of education and socio-economic status

As per the socio-demographic information provided in Chapter Two, the caregivers of the participants are poorly educated group with a limited source of income. This information is in keeping with the findings of De Kock (1979) who reported that the incidence of paediatric thermal injury is higher in deprived families. The socio-demographic characteristics of the caregivers as evidenced in this study are important in light of the empirical literature that the most psychosocially competent burn-injured children are those from families of higher socio-economic status in which there is an intellectual or cultural emphasis (Browne et al., 1980; Byrne et al., 1986). Thus, if levels of caregiver education and socio-economic status are to be used as predictors of the long-term adjustment of the participants in the present study, it is likely that such psychosocial adaptation will be poor.

Family environment

The family backgrounds of the participants were notable in the sense that few conformed to the conventional notion of a stable family structure. Excluding the four participants from St Joseph's Home, only 10 of the participants were from two-parent homes. In five cases, the father of the participant was deceased, in 16 cases the whereabouts of the father were unknown and in a further three cases the father of the participant had no contact with his child although his whereabouts were known. In the case of two siblings, the mother of the participants was deceased (she had been killed in the fire that injured her children) and the participants resided with their grandmother. In three cases the whereabouts of the participants' mothers were unknown: two of these women were described as suffering from a mental illness and one from alcohol and drug addiction. As a result, one participant lived with her grandaunt, another with her grandmother and a third was in foster care. One other participant lived with his grandaunt, as his mother is mentally handicapped.

Within these family structures, nine caregivers described their home environment as affected by the alcoholic problems or abusive behaviour of one member of the family, usually the participant's father.

The above description of the participants' caregivers resonates with the finding that parents of burned children have a substantially high rate of dysfunction as defined by a history of psychiatric disturbance, substance abuse or involvement with child welfare services (Kendall-Grove, Ehde, Patterson & Johnson, 1998). Furthermore, in light of the research that the psychosocial adjustment of the burned child is best predicted by a stable home environment (Saywer et al. 1982) in which conflict is low and commitment and cohesion are high (Blakeney et al. 1990; Byrne et al. 1986; LeDoux et al. 1998), the prospects for the participants in the present study appear rather bleak.

Caregivers' use of social resources

According to the empirical literature the psychosocial adjustment of the burned child depends largely on the caregiver's adjustment and use of social resources in terms of

participation in social, recreational and religious activities (Browne et al., 1980; Byrne et al., 1986; LeDoux et al., 1998). To this end, caregivers were asked about the extent to which they have access to and utilize social support networks, whether these are within the family or external i.e. friends and religious and recreational organizations.

Eleven caregivers said that they could rely on at least one person in their family for support, and in two cases friends were cited as the main source of support. Seventeen caregivers said that their source of support was religious belief, although only two had received direct assistance from their respective religious communities. Only one caregiver had a recreational interest outside of the home. The remaining caregivers, it seems, are without any form of social support. Germaine's mother is one such caregiver and she describes her feelings of isolation below:

"Ek kan met niemand gesels oor die ding. Om so alleenig te wees kan maar moeilik wees, ek moet sê."

Germaine's mother

The majority of caregivers reported being supported during the crisis of the admission period, but that this support waned when the child returned home and life continued. The lack of support experienced by the caregivers was evidenced in that eight caregivers expressed their gratitude for having been contacted to participate in the study. It seems that these caregivers took heart in the continued interest of the Hospital in the recovery of their children, even though in some cases the burn accident had occurred several years before. The interviews provided a forum for these caregivers to express their concerns about the emotional and behavioural problems that they perceive their children to have. Neisha and Hassiem's grandmother summarized these sentiments:

"Af en toe wonder ek wat gaan gebeur met hierdie twee. Daar is soveel probleme en niemand stel eintlik belang nie. Mense het mos lank gelede vergeet dat hulle ma dood is en so aan. Ek was dankbaar toe Lesley gebel het want ek het weer moed geskep. Ek het gedink Lesley sal vir my kan sê wat om met hulle te maak nou dat hulle so anders is."

Neisha and Hassiem's grandmother

Burn-injured children rely on their caregivers for support and encouragement throughout the recovery process. The stress of caring for a burned child must not be underestimated, particularly where limited social support is available. Given the paucity of such support as evidenced in this study and the importance of the caregiver's emotional state in facilitating psychosocial adjustment (Blakeney et al., 1993; Meyer et al., 1994; Saywer et al., 1982), the implications for the child's psychosocial recovery are once again presented as bleak. The need for some form of intervention to assist caregivers is well illustrated by this comment from Olivia's mother:

"Daar is tye waar Olivia nie so goed voel nie en daar is tye waar ek self nie so goed voel nie. Dis die stress. Kyk sy kry behandeling, maar ek kry nie behandeling om vir haar te help nie."

Olivia's mother

The effect of the burn injury on the siblings of the burned child

Eight caregivers reported having difficulties with their other children as a result of the burn injury sustained by the participant. According to these caregivers, the siblings of the participant complain that the burned child receives more attention from the caregiver, or that the siblings are required to adjust their lifestyles in order to accommodate the needs of the burned child. Lizette's mother describes the challenge of caring for a burned child without depriving the child's siblings of affection:

"Dit is moeilik by die huis met drie kinders en werk en so aan en Lizette voel sy kry te min aandag. Dan moet sy iets probeer doen om aandag te kry en dit is nie die geval - sy kry baie aandag. Die punt is die ander kinders sê ons skenk meer aandag aan haar as aan hulle en dan sê ek vir die anders hulle verbeel hulle net. Ek probeer al drie kinders dieselfde hanteer."

Lizette's mother

In the case of Tracey, who has an identical twin sister, the effect of the burn injury on the other twin was particularly interesting. It seems that Tracey's twin identified strongly with her sister's pain during the hospitalization period and subsequently developed academic problems. In addition, the tendency for twins to dress in the same way is problematic for Tracey's sister since Tracey refuses to wear clothes that would

expose her burn scars. Tracey's mother describes the unburned twin's reaction to Tracey's burn injury:

"Die ander tweeling het baie erg gereageer. Toe Tracey in die hospitaal was het die ander een by die huis gelê en aan pyn gely. En met die skoolwerk, presteer Tracey beter as die ling wat nie gebrand het nie. Daai een het gedruip na die brand. En nou met klere koop, kan ons mos nie shorts of 'n mini koop want Tracey sal dit nie dra nie. So die ander ling moet maar by die een inval. Dit is nogal 'n probleem."

Tracey's mother

Although Blakeney et al. (1993) reported parents of paediatric burn survivors being stressed by their concern for their unburned children, the feelings and reactions of siblings have rarely been examined in the empirical literature on burns. It is clear from these accounts that the siblings of the burned child may feel neglected and excluded or that they occupy a peripheral position within the family. When one considers the impact of a burn injury on the family as a unit, it seems that an investigation of this aspect of psychosocial recovery will yield interesting findings.

EMOTIONAL AND BEHAVIOURAL INDICATORS OF DISTRESS

In keeping with the suggestion made by Patterson et al. (1993), the psychological sequelae of burn injuries as established in this study are not defined using narrow clinical diagnoses, but instead are more broadly conceptualized as emotions or behaviours that cause distress (Albee, 1980) or suffering (Cassell, 1982) to the burn survivor. Conceptualizing the psychological sequelae in this form means that the findings of the present study cannot meaningfully be compared to the research results discussed in Chapter One since those findings relied on pre-established, clearly defined diagnostic criteria. Similarly, clinical terms have not been used to present the findings here as the information is intended to be descriptive rather than diagnostic.

Depressive behaviour

The majority of participants (n=28) described themselves or were described by their caregivers as depressed, withdrawn, irritable and unhappy. The following extracts from the interviews with Tracey's mother, Charlton's mother, Katrina and Carla respectively are examples of behaviour and emotion categorized as depressive:

"Tracey het uitbarstings. Ek kan nie eintlik verduidelik nie, maar sy raak so gefrustreerd oor enige iets en dan huil sy vreeslik."

Tracey's mother

"Hy is baie kort van draad vanaf die brand. Charlton was nooit so nie. Hy is baie gespanne. En hy skryf maklik mense af want hy is kleinlik."

Charlton's mother

"Ek weet ek is depressief. Daar is net tye wanneer ek nie lus is om met ander mense te wees nie. Ek sal liewers alleen wees. Dis maar hoe dit is."

Katrina

"Ek voel deurmekaar en ongelukkig. Miskien is dit as gevolg van my letsels maar ek weet ook nie meer nie."

Carla

Since participants and caregivers were asked about current behaviour and changes in behaviour subsequent to the burn injury, it is assumed that this depressive behaviour is as a result of the burn injury and its subsequent disfigurement. Of course it is not possible to exclude the effects of pre-existing symptomology, a problem common to research of this nature (Patterson et al., 1993). Also, it must be borne in mind that since more than half ($n=21$) of the participants were three years old or younger at the time of the burn, it was not possible for the caregivers of these participants to speculate on their behaviour prior to the burn injury.

Suicidal behaviour

In some cases, the depressive behaviours and emotions described above have culminated in suicidal thoughts: three participants reported that they have contemplated killing themselves although their caregivers are not aware of these sentiments. More dramatically, two other participants have attempted suicide, one by throwing himself on the railway tracks and the other by taking an overdose. Caroline describes her attempt to end her life as follows:

"I tried to commit suicide when I was 11 or 12. I drank my mother's asthma tablets. She came into the room and I was vomiting and then she saw the tablets. She took me to the hospital and they gave me charcoal and it made me vomit. I just felt like giving up man, every day it was a battle from the morning I got up till I got home from school - it was just every day a battle and I just couldn't handle it anymore."

Caroline

Changes in eating behaviour

All the participants were described as having a healthy appetite before the burn injury and changes in eating patterns were reported by the caregivers of only three participants. These three participants were also described as depressed as per the above section. In the case of two participants, caregivers reported a diminished appetite and steady weight loss since the burn injury. Both participants are reported to eat only under protest and one caregiver has threatened to admit her child to hospital. The third participant, Rasheeda, has steadily gained weight since the burn injury. Rasheeda admits that she seldom leaves the house or exercises and that she eats to console herself when she is lonely:

"Ek suppose ek eet om myself te troos. Ek weet ek is vet en my ma sê altyd ek moet gewig verloor, maar daar is niks wat ek daaraan kan doen nie because why ek oefen nie eintlik nie. Ek bly meestal by die huis."

Rasheeda

Control of bladder and bowel functions

Five participants suffered from loss of control of their bladder functions and one experienced lack of control of both his bladder and bowel functions after returning home from the hospital. Mostly, these symptoms disappeared within several months. However, two participants still do not have control over their bladder functions even though several years have elapsed since the burn injury. Twelve year old Celine, who was a year old when she sustained a 10% TBSA flame burn to her feet, is one such participant and describes her poor bladder control as follows:

"My ma sê altyd ek moet probeer om wakker te skrik of iets of haar roep as ek toilet toe wil gaan maar ek maak nogsteeds my kooi nat en dit gebeur ook in die dag by die skool. Sê nou ek moet skryf, dan kan ek die pie net nie inhou."

Celine

Disturbed sleeping behaviour

More than half of the participants (n=22) suffered disturbances of their sleeping behaviour following the burn injury. Nightmares, day napping, talking, shouting, crying or shivering during sleep appear to be common sequelae of paediatric burn injury. As in the Kravitz et al. (1993) study, the dream content of the participants' nightmares related to the actual burn incident and its social consequences thereby supporting the notion that sleep is a coping mechanism during which cognitive processing of emotional stressors occurs. The following excerpts illustrate these sleep disturbances as well as the ways in which aspects of the burn incident are relived during sleep:

"Sy het baie sleg geslaap vir drie of vier maande – so gebewe en geruk. Een aand het sy geskree 'ek wil nie brand nie'."

Anthea's mother

"Hy het nie mooi geslaap nie. Hy het in die nag geskree en nou nogsteeds. Hy skree name uit as hy slaap, dis name wat die kinders vir hom sê."

Karl's mother

"She has nightmares. She used to scream in the night and cry 'dit brand, dit brand' - but not anymore."

Nina's fostermother

"Ek het gereeld nagmerries oor my pa. Ek droom hy kom terug en brand ons weer."

Olivia

"Sy slaap onsettend baie in die middag en sy praat ook onsettend baie in haar slaap in die nag - sy praat volle sinne. Dan huil sy ook in haar slaap, soort van 'n huil-snik. Ek maak haar altyd wakker as dit gebeur."

Olivia's mother

"Sy het baie in haar slaap gehuil en as ek haar wakker maak dan hou sy aan met huil - sy het omtrent elke nag so huilgeslaap. In haar slaap ruk en bewe sy nogsteeds."

Leanne's mother

Situation specific anxiety

In terms of situation specific anxious behaviour, eight participants have a fear of fire since the burn injury and seven participants are afraid of the dark, insisting on sleeping with a caregiver or a sibling, even though in most cases such behaviour is not age appropriate. Refusing to sleep alone may be interpreted as a continued form of separation anxiety that also manifests in reluctance to part from the caregiver in other situations, such as attending school. (The reluctance to attend school as a response to disfigurement is discussed elsewhere in this chapter). Indeed, four caregivers reported unusually clinging behaviour on the part of the participant after the burn injury. The following quotes illustrate the situation specific anxiety experienced by the participants:

"Hy sal nie eers die vlam van 'n kers doodmaak. As ons buite vuurmaak, dan sal hy hele nag binne sit en by die gordyne uitloer".

Andrew's mother

"Ek is vreeslik bang vir vuur. Ek is bang vir die donker en ek wil nie alleen wees nie. Ek wil nie alleen slaap nie. Die deur moet altyd oop wees, en ek gaan ook nie alleen in die nag toilet nie".

Rasheeda

"Leanne het op die ou end weer soos 'n baby geraak. Ek moes haar orals rond dra net soos toe sy 'n baby was. As ek haar gelos het dan het sy eers begin te skree."

Leanne's mother

Seven participants reported becoming extremely anxious when meeting new people, an understandable reaction considering the high incidence of social ridicule evoked by the disfigurement of the participants as discussed later in this chapter. Dion describes his fearful feelings when confronted with meeting strangers:

“Ek is bang om nuwe mense te ontmoet want hulle sal miskien nie van my hou nie omdat ek gebrand is, ek is nie dieselfde as hulle, ek is maar altyd eenkant.”

Dion

Caregivers’ concerns about general antisocial conduct/delinquency

In terms of other antisocial conduct, the caregivers of four participants reported that since the burn injury, their children have taken to telling lies more frequently. Furthermore, three participants have stolen money from their caregivers on at least one occasion and one child has stolen goods from a convenience store. One mother described her son’s tendency to break and destroy toys and furniture without any apparent provocation. Another caregiver reported that since the burn injury, her son has developed a violent temper, threatening to kill his parents when they scold him. This particular child has also developed a fascination with fire and in response to being reprimanded for disobedience, has set various objects alight. Neville’s mother describes this delinquent behaviour:

“Lyk vir my Neville is baie, baie deurmekaar. Hy is so aggressief. As iemand hom iets gemaak of as ek of sy pa vir hom sê hy moet nie iets doen nie dan vat hy sommer ‘n mes en sê hy gaan ons doodmaak. Hy maak ook aanmekaar vuur – hy is soos die duiwel met die vuur sodra ons hom uitskel vir stoutigheid. Hy het onlangs amper weer gebrand.”

Neville’s mother

The caregivers of two participants voiced the concern that their teenage daughters are engaging in sexually promiscuous behaviour. Fifteen year old Katrina left school in grade seven because she did not want to wear a skirt to school as it exposed her scarred legs and now, according to her mother, she has befriended a group of girls several years her senior and wanders around at night. Similarly, Celine’s mother complains that her 12 year old daughter goes out at night without giving an indication of where she is going, and only returns in the morning before school. She claims that Celine likes to wear “*kaal klere*” to show off her body despite her scars. Unfortunately, Celine’s mother responds to this conduct with violence:

*"Ek moet nou eerlik wees, as dit nou sulke tyd kom vat ek my vuïs
en dan slat ek haar want ek kan dit nie vat nie, rêrig waar."*

Celine's mother

It is suggested that the reason for the behaviour described here is related to the need for attention expressed in a defiant and provocative fashion. It is clear from this study that these paediatric burn survivors are regularly subjected to social ridicule and peer rejection, no doubt resulting in feelings of isolation. It may well be that these children, by acting out as they do, are only seeking to compensate for that humiliation. De Wet et al. (1979) and Giljohann (1979) similarly found that promiscuous behaviour in adolescents burned as children is related to insecurity about appearance and sexual desirability, and to a poor self-image related to disfigurement.

Perhaps the most distinct case of attention-seeking behaviour as compensation for emotional and social distress is that of Nina, who, as an infant sustained a 50% TBSA scald when her alcoholic mother plunged her into boiling water. Nina's current fostermother describes her defiant and aggressive behaviour as follows:

"Nina is very aggressive. Most of the time we find the dolls without heads and now she attacks the legs as well. You know the Barbie dolls heads don't come off – she cuts them off. . . She likes to show her scars to shock strangers – she will show them when strangers are in the house because she thrives on the attention. She shows everybody who hasn't already seen it and she likes to say that her mother burned her on purpose and that she was in hospital. She loves the attention. Dinnertime is the time for attention – she will put all her food in her mouth at one time and then she will start laughing. She laughs when there is no joke and she won't stop laughing. It is like she doesn't allow herself to feel something sad. She says she wants to be a model. She wants to be in that environment with all that attention focused just on her."

Nina's fostermother

Nina's psychosocial reality is undoubtedly influenced by her deprived social background and the fact that her previous foster environment was cruel and punitive. It is not unreasonable to imagine that a person who has suffered a traumatic burn injury resulting in permanent scarring and who is victimized again through social rejection in so many forms, would seek attention of whatever nature. Nina appears to be mutilating the dolls according to her own image, by attacking their faces and legs,

the loci of her own burn disfigurement. Similarly, Nina expresses the wish that others should suffer as she has: when asked how she responds when other children tease her about her burn scars, she replied that she tells them *“eendag gaan jy groot raak en dan gaan jy ook jou kinders brand.”*

In a similar way, the participants who have taken to violent behaviour may well be influenced by the cultural norms of the communities in which they live. The Cape Flats, the area in which most participants reside, is a notoriously crime-infested area in which violence is a widely used method of problem solving. It is understandable that children exposed to aggression on a daily basis should model these behaviours in their own interactions.

Professional psychological counselling

Despite the problems described above, and the clear need for therapeutic intervention, the majority of participants have never received any professional psychological counseling to deal with the trauma of the burn injury and its consequent disfigurement. There are, however, a number of exceptions: The four participants from St Joseph's Home presumably benefit from the services of the Home's resident social worker, although the extent and nature of the attention that they receive is unknown. Furthermore, according to the medical records, five participants were referred to the Child and Family Unit affiliated to the Hospital at some stage during their treatment. The records indicate only that these participants required evaluation for 'suspected conduct disorder'. Unfortunately, two participants did not follow through with these referrals and the remaining three made short term use of the Unit's services. Two of these participants were given prescription medication, one for hyperactivity (Ritalin) and the other for depression (Fluoxetine), and continue to take this medication even though such use is dangerously unsupervised. One participant received counseling from a psychiatric registrar for a period of three years, although it is unclear how this arrangement came into existence. The only other participant who has received professional counseling consulted a private occupational therapist, but this arrangement was short lived due to financial constraints.

Referrals

In cases where the participants presented with suspected behavioural or emotional pathology, the author made referrals for psychiatric/psychological evaluation. A total of eight participants were referred either to the Child and Family Unit at the Hospital, or to the Department of Psychiatry at Tygerberg Hospital. It seems that several of the participants with their efforts to avoid situations related to trauma, nightmares, irritability or outbursts of anger, social impairment, and difficulty concentrating would meet the diagnostic criteria for Post Traumatic Stress Disorder.

SOMATIC COMPLAINTS

Participants and caregivers were asked about the participant's general health and medical history. All but seven participants had unremarkable medical histories. The exceptions were single cases of congenital syphilis, meningococcal septicaemia, exomphalos minor, club foot and enlarged liver. Two participants suffer from congenital hearing problems. In terms of current somatic complaints, ten participants complained of itching in the areas in which they have scars. Itching is a normal consequence of scarring since grafted skin has no oil glands (Cooper & Fenton, 1996). Unfortunately there is no cream or ointment that offers complete relief from this discomfort. Four participants complained that their scars 'leak'. This poor reabsorption of fluid is as a result of damage to the normal lymphatic drainage system and little improvement can be expected (Warden, 1996). Three participants reported experiencing pain when undertaking physical activity, one of whom had formerly been diagnosed with an enlarged liver, which would account for his discomfort. The other two participants have severe contractures of the feet with resultant loss of joint range of motion, thereby accounting for their pain. One participant was described by his mother as having a poor appetite, sweating excessively and coughing. This participant was referred to the medical outpatient's clinic for suspected tuberculosis.

SCHOLASTIC PERFORMANCE

Although there is a small body of research on behavioural problems of burned children at school (Sawyer et al., 1982), scholastic performance has received relatively little attention in the empirical literature (Blakeney et al., 1998; De Wet et al., 1979; Giljohann, 1979; Moore et al., 1996). An overwhelming finding of the

present study is that more than a third (n=15) of the participants have failed at least one grade at school. The extended period of hospitalization required following the burn injury accounted for five of the ten participants who were of school going age at the time of the burn having to repeat a grade at school. The academic lag experienced by the remaining ten participants could not be justified by lengthy absences from school, indeed, seven of these participants were toddlers at the time of the burn injury. The poor progress at school was explained by participants and their caregivers in terms of having difficulty concentrating in class and/or understanding instructions. These quotes from Gershwin, Natalie and Germaine's mothers respectively illustrate the remedial problems experienced by these participants:

"Hy sukkel baie by die skool. Hy was twee jaar in Sub A en dan twee jaar in Sub B en toe plaas hulle hom oor. Dit lyk vir my hy wil die ding doen, maar sy konsentrasie is sleg. Ek sal iets sê en dan sal hy terug kom en vra 'wat het mammi gesê ek moet doen?' Ek moet drie of vier keer vir hom iets sê voor hy dit doen."

Gershwin's mother

"Sy is baie swak by die skool met lees en so aan. I will say to her 'here is the word picnic. Now write it down ten times and say each time picnic'. Then she will do that, 'picnic, picnic'. En dan na 'n tyd vra ek haar weer. 'What is this word?' En dan sê sy sy weet nie. Lyk my sy leer nie so then I make her write it fifty times so aaneen – picnic, picnic, picnic, en dan vergeet sy sommer. Sy is baie agter so."

Natalie's mother

"Hy is baie stadig in die skool. Hy druipe elke keer. Hy sit twee keer in elke standerd en dan stoot hulle hom vorentoe."

Germaine's mother

Hyperactivity

Six caregivers described their children as having a short attention span, constantly fidgeting, easily distracted, impulsive and reluctant to remain seated. One participant has been formally diagnosed as hyperactive and had been transferred to a remedial school. This participant's problem came to light when he was admitted for a contracture release that had to be abandoned when the wardstaff could not restrain him.

Preventing academic lag

Although difficult, it is not impossible for burned children to cope academically even if they miss lengthy periods of school or have to be admitted to hospital on a regular basis. However, to accomplish this, a strong liaison is needed between the school, the hospital and the child's caregiver. While it is unfeasible for children to be tutored during the hospitalization period, they should be kept informed of happenings at school; and once they return home, their homework should be brought to them to prevent unnecessary academic lag. Although only one participant had contact with his classmates during the initial admission period, three participants maintained their scholastic performance by having schoolwork brought to their homes. Thirteen year old Leanne, who sustained a 30% TBSA flame burn when she was in Grade 1, was hospitalized initially for five weeks and has subsequently been admitted several times for corrective surgery. Nonetheless, according to her mother, Leanne is progressing well at school:

"Oor die jare het sy baie skool gemis maar sy vang gou aan en sy bly nie agter nie. Die juffrou of die kinders bring haar werk vir haar huistoe. Ek sal sê dis die rede waarom sy nog nooit 'n standerd gedruip het nie."

Leanne's mother

The option of having a child institutionalized in a residence such as St Joseph's Home where he or she can receive ongoing care is not a decision to be made easily or taken lightly, and this alternative is rarely exercised. However, one of the merits of this arrangement is that residents receive specialized academic attention to compensate for their ongoing admissions to hospital, thereby preventing academic lag. Two participants, James and Olivia, lived at St Joseph's Home for several years before returning home and attending regular schools. Both agreed that although living at the Home was difficult in other aspects, the schooling system was preferable to their current arrangement. Seventeen year old James who attended the Astra School at the Home for four years explains as follows:

“Dit was aanvanklik moeilik by die nuwe skool. Nie net omdat ek al een wat gebrand is, maar omdat by Astra, as ek skool misgeloop het, was dit nie ‘n probleem nie want die onderwysers het seker gemaak dat ek alles inhaal. Hulle het tyd gehad vir sulke goed. Daar was spesiale aandag. Nou as ek skool mis moet ek maar alleen sukkel as ek iets nie verstaan nie.”

James

Thus, the attention required by a burned child who has to attend hospital on a regular basis and may have to wear splints and pressure garments for protracted periods must be carefully negotiated with the child's school. The need for a formal, organized school entry or reintegration programme for the burned child is discussed below.

Referrals

Nine participants were referred by the author to the Child and Family Unit for remedial assessment. These referrals were made on the basis of inexplicably poor scholastic performance or a suspected learning disability. A comprehensive developmental evaluation would also serve to determine whether the academic difficulties experienced by the burn-injured child are partly determined by a family history of learning disability, an aspect which was not explored in this study.

THE IMPACT OF DISFIGUREMENT

In McGregor's (1974) terms, many disfigured individuals are consigned to a 'social death' because of the poor quality of their social interactions. The negative impact of disfigurement on the burned child was clearly evidenced in this study.

Social ridicule: teasing, name-calling and bullying

Perhaps the most significant finding of the present research is that survivors of paediatric burn injury are subjected to persistent social ridicule in the form of teasing and name-calling, regardless of the severity or visibility of their disfigurement. Although peers are the main culprits, two participants have been ridiculed by adults (both of whom are the respective participants' teachers) and five participants are also teased by their siblings. Five participants are not only humiliated with name-calling, but are physically bullied by other children. Even the four children who reside permanently at St Joseph's Home where each child is disabled or disfigured in some form or another, were not exempt from this form of social humiliation. The most

popular names for children who are disfigured by a burn injury are 'kentucky', 'KFC', 'gebrande chicken' and 'gebrande ding'.

School as the site of social ridicule

Attending school is problematic for the participants as this is where the most social ridicule is endured. Three participants have changed schools for this reason and three have dropped out because they could not tolerate the teasing any longer. Below, Caroline, Anthea, Natalie and Greg's mother provide descriptions of the distress and humiliation that burn-disfigured children experience at the hands of their peers:

"Primary school was the worst years of my life. I had to go to school with a tissue expander in my head and people used to stare at me and call me names like 'chicken' and 'burned thing' and things like that. When you with your friends and now people say horrible things I felt so embarrassed. No matter where I am there is always that certain amount of people that will mock and growing up until the age of 15 was the toughest time."

Caroline

"Ek hou niks van skool nie want elke dag by die skool skree die kinders vir my name soos 'gebrande chicken', of 'Kentucky' of 'gebrande nar'."

Anthea

"Die kinders by die skool en in die pad stamp my en slat aan my. Hulle skree vir my name soos 'gebrande nek', 'KFC', 'gebrande chip' en sulke goed."

Natalie

"The big problem is other children. At his school there is children from preschool to standard five and mostly the standard fours and fives starting calling him names like 'alien from Mars' and 'bubblegum neck' and when school comes out, hitting at him and smashing him against the poles. Twice already we had to buy him new bicycles because it was folded in half."

Greg's mother

It seems that this victimization does not dissipate with time, although several of the older participants reported that others do become accustomed to their disfigured appearances. Nonetheless, as Olivia indicates, this does not signal an end to the ridicule:

"Die kinders raak gewoon aan jou. Dis net as die nuwe standerd sesse begin, dan begin die hele ding van vooraf."

Olivia

Introducing a formal school entry/reintegration programme

Outside of the family, school is the community that dominates a child's life and it is in this domain that the child develops socially appropriate behaviour, academic skills and a sense of self-worth. It is clear from these accounts that the participants are not receiving the feedback necessary to reassure them of their value and competence. The combined effect of both academic lag and peer rejection on the burned child's self-esteem must surely be overwhelming. Knudson-Cooper (1984) describes a vicious cycle in which the child's declining scholastic prowess results in feelings of low self-worth which compound the loss of self-confidence that results from teasing, causing the child to become less motivated to 'catch up' at school. It seems that a formal school entry or reintegration programme for burned children is urgently required to alleviate the situation.

Three participants benefitted from some form of school reintegration programme. In Leanne's case, her persistent complaints of teasing resulted in the psychiatric registrar writing a letter to the school principal. Leanne reports that school life was much improved afterwards. In Greg's case, the principal of the school addressed all the learners before Greg's return to school. As Greg's mother explains, the effects were positive.

"When Greg went home the first time we still lived in Ottery and the children from his school came to visit him here at the hospital. The teacher organized this visit. Even the principal in the big hall spoke to everybody and to the whole school to tell them what happened to him and they were very nice. Greg had no teasing when he went back to his old school."

Greg's mother

However, Greg's move to a new school where the principal was not as co-operative or understanding proved to be quite traumatic, as his mother explains:

"About a year after Greg burned we moved to Parow and Greg went to a new school. Now that is when the shit with the other children started. And that I think we have got a big mistake because they also hit at him and he was only in standard two and I said 'if they smack or hit you, hit them back – don't just stand still'. So after that there has been lots of fighting. I did speak to the new principal and asked him what Ottery school done to speak to the whole school but he never done that neither. He says they are children and children are like that."

Greg's mother

The reaction of the principal of Greg's school is disappointing, but similar reactions have been reported in other research (Cahners, 1979). It is likely that school personnel, like most other people, 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. Like the child's home caregivers, teachers no doubt have concerns about the specialized attention that a burned child will require and that they will be inadequate in meeting the child's needs. Teachers may choose to distance themselves from the problem as Greg's principal did. On the other hand, even with the best intentions, this uncertainty and lack of instruction on the part of teachers may translate into an inappropriate handle on the situation, as is illustrated in Bradley's case:

"Ek het met die onderwyser gaan praat en verduidelik die kind het gebrand en hy moet gereeld hospitaal toe gaan en so aan. En die onderwyser het meer tyd vir hom gehad en die kinders het hom een kan gesit en toe begin hy nou die bed natmaak."

Bradley's sister

The consequences of 'being put aside' as described above by Bradley's sister may be dramatic: Not only has Bradley failed two grades, but he also is one of three other participants who dropped out of school citing their reason as being unable to cope with the persistent teasing that their disfigurement evoked. It is clear then that teachers need to be equipped with the necessary information and skills to address both the burned child's anxieties and to deal with the social ridicule that the child's disfigurement evokes from others.

In order to prepare burn-injured children, their caregivers, classmates and teachers for school, a variety of formal school reintegration programmes have been implemented

with great success in the United States and Australia (Blakeney, 1995; Doctor, 1992). Regardless of the context in which these programmes are implemented, the content remains consistent and serves three basic aims: The first aim involves providing burned children with an opportunity to deal with their fears and anxieties about returning to school, such as the reaction of classmates, perceptions of body image and participation in schoolwork and sporting activities. Secondly, these programmes provide school peers and personnel with a forum in which to express their concerns and feelings about the returning learner's injury, hospital experience and likely expectations of the future. Finally, and perhaps most importantly, a comprehensive school reintegration programme comprises an educational component dealing with burn care, pressure garments, splints and perhaps most importantly, the need to prevent burn injuries.

Sandra King (personal communication, May 2001), President of the Australia New Zealand Burns Association and a pioneer in paediatric burn care in Australia, explains that a successful programme is one that facilitates empathy on the part of the burned child's peers, satisfying their curiosity in such a way that acceptance of the burned child is encouraged. In the absence of medical contraindications, the idea is not to secure specialized treatment for the burned child which would undoubtedly lead to a sense of entitlement (Shields, Abrams & Stuart, 1985). As a valued and contributing member of society, the child cannot shirk academic or social responsibilities. This attitude is endorsed by Olivia's mother in her explanation of Olivia's informal school reintegration programme:

"Ek en die psigiatriese verpleegster het vooraf met die hoof gaan praat en vir hulle gesê waardeur sy gegaan het en waardeur sy nog moet gaan, en voor die skool begin het hy met die kinders en die onderwysers gesels en vir hulle alles verduidelik. Dit is belangrik dat hulle beseft dat Olivia nie spesiale behandeling kry nie – sy moet haar werk doen, sy moet haarself gedra soos tevore, maar daar is een juffrou wat haar hanteer as daar enige probleme is met die kinders of die ander onderwysers. Natuurlik is daar kinders wat vir haar name skree, maar sy hanteer dit nou beter."

Olivia's mother

In the local context, Horwitz (1998) has developed and evaluated a pilot school reintegration programme for use in South African primary schools. This programme was designed to meet the three basic aims outlined above as well as to be resource-efficient, flexible and compatible with the Outcome Based Education (OBE) principles as set out in Curriculum 2005. The efficiency of the project was evaluated through an embedded case study of a single 11 year old burn-injured child with a mild disfigurement. Horwitz (1998) found that the programme and its accompanying manual served to engage the learners and the burn-injured child in such a way that the incidence of social ridicule decreased. Unfortunately, the implementation of the programme did not prevent academic lag. Nonetheless, Horwitz's (1998) study provides a good example of the way in which limited resources can be creatively utilized to bring about a more positive process of school reintegration for the burn-injured child.

A final observation on the subject of school reintegration programmes: It is interesting that the literature has concentrated on those children re-entering school after a burn injury to the exclusion of those children who have a pre-existing disfigurement as a result of a burn injury sustained as a toddler. Contrary to Giljohann's (1979) finding, the present study revealed that children injured at an earlier age are no less distressed by their scars than those injured in middle childhood. As counter-intuitive as it seems, the participants in the present study who grew up with the scars being a familiar part of their body and had no recollection of their pre-burn appearance experienced as many difficulties at school as those injured at a later age. This means that even if a disfiguring burn is sustained during infancy, a similar school programme is required for when the child enters school albeit that this is several years later. Such a programme would be particularly useful if the child is engaged in a long-term process of corrective surgery as it would encourage post-discharge compliance. The upshot is that contact between the caregivers and the hospital must be ongoing so that the issue of school entry can be dealt with as it arises. In instances where the child is already at school when the burn injury is sustained, a strong hospital-school liaison is an essential part of post-discharge planning and is required to facilitate the transition back to school (Blakeney, 1995).

Given the limited resources available to the Hospital, a contextually appropriate school reintegration programme will require the support of the local education administration. Suggestions to this end are described in greater detail in Chapter Four.

Participants' immediate reactions to teasing

The participants respond inconsistently to the name-calling and bullying and with a variety of reactions. Fourteen respond by remaining silent or walking away, six respond by crying, seven react with swearing and 13 participants resort to aggressive behaviour such as hitting. Five of these participants rely exclusively on violent means to deal with teasing. In two cases, the preferred mode of retaliation is stabbing: one participant has stabbed his brother twice. Three quarters of the participants said that they tell their caregivers when they are teased and 16 said they report the teasing to their teachers. Natalie's response to how she deals with teasing illustrates that participants do not rely on a single organized strategy:

"Somtyds huil ek of ek bly stil, of ek los hulle en ek sê my ma of ek sê die juffrou dan skel sy hulle."

Natalie

Only six participants respond to teasing with a straightforward answer, five of whom say that they adopted this approach only after several years of responding in the ways described above. Three of these participants, Anthea, Caroline and Francois, describe how their reactions to teasing evolved:

"In die begin het ek gehuil of geskel maar nie meer nie. As kinders nou met my soek dan sê ek vir hulle 'los my uit ek kan dit nie help dat ek gebrand het nie. Ek is nie so gebore nie en ek het nie daarvoor gevra nie'."

Anthea

"When I was younger I was always fighting or crying. In high school sometimes I used to walk away and sometimes I used to backchat and say that 'I might be burned but I am cleverer than you' or things like that. They would shout names at me and I would say 'if it makes you feel better than you must say those things'. With age I am very straight with people, very honest. I am who I am. It's funny because some of those people that were so nasty now want to be my friend. I will greet them, but I don't need them."

Caroline

"Toe ek jonger was het ek baie baklei maar ons was almal jonk en ek neem daai kinders nie kwalik nie. Ek kan eerlik sê ek het baie geleer. Deesdae sal ek sê 'ek het jou gehoor en ek het jou gesê ek het gebrand', en as hulle aangaan dan raak ek eers kwaad. Mense sal nie maklik met my soek nie, en daar is baie wat my gespot het wat nou my vriende wil wees."

Francois

It is interesting that both Francois and Caroline remark on how children who once ridiculed them now wish to befriend them. It is suggested that the reason for this change in the attitude of others is that Caroline and Francois have accepted their 'different' appearance. This acceptance leads to a decrease in preoccupation with the possible effect of their appearance on social interactions. Rumsey, Bull and Gahagen (1986) have discussed the possibility that disfigured people themselves are in part responsible for the problems encountered during social interaction. By harbouring the belief that they are the object of unwelcome attention and in anticipation of negative reactions from others, disfigured persons can behave defensively, in an aggressive or a shy manner. These communication patterns tend to elicit negative behaviour from others (Snyder, Tanke & Berscheid, 1977). The idea that others perceive disfigured people in a negative way is therefore reinforced and a cycle of spiraling problems may begin.

Robinson et al. (1996) suggest that disfigured people can achieve more satisfying social interactions by strengthening their social skills, which is precisely what Caroline and Francois have done over the years: their strategy has evolved to one in which they challenge remarks, stand up for themselves and give straight-forward answers to questions about their disfigurement. This new repertoire of social skills

elicits a more positive response from others and the resulting feedback bolsters self-esteem. This in turn is rewarded with more effective social behaviour.

The lesson to be learned here is that the burn-disfigured child must be formally taught how to deal with the staring and teasing that accompany disfigurement. This is particularly true of the participants in this study as few evidenced an organized strategy for coping with negative social feedback. As Goffman (1963, p. 104) suggests: "Individuals with a stigma may have to learn about the structure of interaction if they are to minimize the obtrusiveness of their stigma." Similarly, Partridge (1990) has proposed that since disfigurement is a social handicap, the onus is on the disfigured person to adopt new strategies in order to relieve the strain of social interactions.

Participants' general strategies for coping with disfigurement

Camouflage

The most popular strategy employed by the participants for coping with disfigurement is camouflage, a finding that is supported by the empirical literature on disfigurement (Harris, 1982). Nearly all the participants were markedly self-conscious of their burn scars and took steps to avoid exposing the disfigurement to others, in some cases, even to family and friends. Six participants who sustained burns to the scalp resulting in alopecia, wear caps and scarves to disguise their uneven hairlines and bald heads. Francois' mother explains:

"Francois steek die ding weg. Niemand kan dit sien nie. Hy sê mense sal skrik as hulle dit sien. Hy dra 'n cap - hy raak onsteld as hy nie die hoed aan het nie. Hy is nie gewoond om uit te stap by die deur sonder die hoed aan nie."

Francois's mother

Two participants have experimented with different hairstyles to hide their facial scars and one participant wears a concealing foundation.

Nine participants with burn scars on the trunk or limbs, wear long sleeves and/or pants when participating in sports or going to the beach. In more extreme cases of self-

conscious behaviour, some participants will not remove their camouflaging clothing or reveal their disfigurements even in front of their families and close friends.

Wearing a skirt to school proves to be extremely stressful for the girls who sustained burns to their legs. Most adapt to this situation by wearing two pairs of pantihose with their uniforms, however, in one case, the headmaster of the school would not allow this concession and the participant cites this as the reason that she dropped out of school.

While it may seem discouraging that so many participants use camouflaging techniques to avoid exposing their scars, it is also possible that this strategy is a healthy and acceptable response in that acknowledges the scar (Harris, 1982).

Non-avoidant cognitive coping strategies: positive self-talk and social comparison

Three participants used non-avoidant cognitive strategies such as positive self-talk and making social comparisons about how much worse off they could have been. According to Janoff-Bulman (1992), the benefit of social comparison is that it allows burn survivors to minimize the threat and malevolence of their own trauma experiences. The participants who made use of these strategies, Francois, Caroline and James, were mature, both in age and in outlook on the burn and its consequences:

"Ek het vir myself gesê die merk is klaar daar. Of die merk kan my afhou of ek kan van myself hou en verby die merk kyk. Toe besluit ek dat ek van myself hou en ek gaan verby die merk kyk. As ek op myself afkyk, sal ander mense ook op my afkyk."

Francois

"You know I would never want to change what I am and who I am. I have a nice job and a supportive boyfriend and a baby that is so beautiful. The only thing I would like to change is the scars, just to have it gone, or it can still be there, but just be lighter so that people can't much notice it."

Caroline

"Ek vertel myself gereeld dat dit maak nie saak wat mense van my dink nie, dit is net belangrik wat ek van myself dink. Ek het by St Joseph's geleer daar is nie so 'n ding soos kan nie – 'n mens moet altyd probeer."

James

Although these three participants are in the minority in the present study, they provide testament to the notion that it is quite possible to survive a disfiguring burn trauma and still create a meaningful life. Too often the negative images of burn survivors perpetuated by popular culture allow one to lose sight of this possibility. As Petro and Salzberg (1992) point out, the burn injured person is conceptualized in one of four ways in prevailing discourse: He is alternatively evil personified; the arch enemy opposing the hero; a tragic figure whose injury transforms him into something less than entirely evil; or a victim. In terms of the latter, burn related academic literature and empirical reports are also often guilty of referring to the burn survivor as a victim, (e.g. see Kibbee, 1981; Tucker, 1986) thereby implying weakness and helplessness. By adopting the understanding of the burn injured person as a victim, someone who is not responsible for himself, burn care professionals unconsciously support the rejection of the individual as reflected in the inadequate progress of burn rehabilitation.

James Partridge (1999), a burn survivor himself and founder of Changing Faces, a London based organization devoted to promoting the general well-being of the facially disfigured, argues that use of the word 'victim' negates the possibility of personal growth after a major trauma. He asserts that the loss of one's good looks, like any other loss, can result in a sense of positive personal evolution. Similarly, Giljohann (1979) found that the participants in her study of adolescents burned as children felt some resistance to being placed in a subgroup of 'burn victims'. Instead, they preferred to see themselves as normal individuals and the fact that they had been burned as no longer being a central theme in their lives.

Although most participants could not think of any redeeming features of being burned and tended to focus on their losses, again Francois, Caroline and James offered a refreshing perspective and were able to conceptualize their unusual appearances not only in deficit terms. Both Caroline and Francois said that their life-long

disfigurement has made them less judgemental and more empathetic in their approach to others. James remarked that if he had not been burned, his social circumstances would most likely have culminated in him becoming a gangster. Francois and James' sentiments are presented below:

"Ek suppose die scar het my iets geleer. As 'n mens te perfek is sien jy nie baie dinge nie. Jy kan nie 'n mens wat minder bevoorreg is verstaan nie. Jy kan beter oor die weg kom met anders as jy nie perfek is nie."

Francois

"Miskien gaan dit nou snaaks vir Lesley klink, maar as ek rondkyk na die ander seuns wat in my nabyheid woon besef ek dat as ek nie gebrand het nie sal ek seker 'n gangster of iets gewees het. Ek sal seker rof gewees het soos die ander."

James

Avoidant coping strategies: Social withdrawal and shrinking from contact

Eight participants cope with their disfigurement by withdrawing socially, for example, staying indoors and avoiding meeting new people. Leanne's mother describes how Leanne reacts when visitors come to their home:

"Sy is baie mens-sku, so teruggetrokke en in haar dop. Sy sal nog agter my rug sit as daar mense is al sê ek vir haar sy moet uitkom. Dit neem tyd om gewoon te raak aan mense, om met mense te meng."

Leanne's mother

Situations such as going swimming or participating in sporting activities that would draw attention to disfiguring marks are avoided in the case of four participants. Since school is the primary location in which the participants interact and the source of the majority of social distress, it follows that reluctance to attend school is common. Indeed, in 16 cases caregivers reported that the participants report somatic complaints such as headaches, stomachaches and leg cramps in the mornings before school. Karl's case represents a good example of this form of school reluctance, and the reasons behind it.

"Karl kom sê vir my die kinders terg hom en slat aan hom. Hy kom altyd dit vir my sê. Hy wil nie skool toe gaan nie. As ek vir hom sê hy moet skool toe gaan dan sê hy sy maag pyn of iets en dan begin hy te huil en dan somtyds los ek hom of somtyds vat ek hom self skool toe. Ek vat hom na die hek toe en dan gaan hy maar huil-huil skool toe."

Karl's mother

As discussed elsewhere, three of the four participants who have dropped out of school – the ultimate form of school refusal – cite their reason as an inability to cope with the persistent teasing and name-calling that their disfigurement evoked. It is intended that the school entry/reintegration programme outlined above would deal with these issues.

Caregivers' reactions to disfigurement

Caregivers' immediate reactions to teasing

A minority of caregivers was unaware of the social problems that their children experience. Those who were aware of the situation reacted to reports of teasing in several ways, none of which were resorted to exclusively. Five caregivers had sought out the parents of the offending children and explained the situation to them. Six caregivers had been to the child's school and addressed the matter with the participants' teachers. Twelve caregivers have chosen to deal with the offending children themselves, either by hitting them (in four cases) or like Greg's mother quoted below, by speaking to them:

"Once I went to the school and I was just fed up and so I was cross and so I called all the children and explained to them what happened and they said 'I'm sorry auntie, we won't call him that again'."

Greg's mother

Five caregivers reported taking no action and cited their reason as 'children being children'. Only two parents had specifically instructed their children as to how to deal with teasing for example, by ignoring or challenging remarks or explaining the cause of the disfigurement.

Caregivers' general strategies for coping with the participants' disfigurement

Encouragement and reassurance

In terms of more general strategies for coping with the child's disfigurement, most caregivers reported having to reassure and encourage the child on a regular basis. The nature of this reassurance takes a variety of forms. Some caregivers employ social comparison arguments to emphasize that the disfigurement could have been worse. Many caregivers often remind their children that the burn injury was accidental, that they are not blame for it and should therefore not be embarrassed. A few caregivers reassure the children that they are loved and still beautiful to their caregivers. These quotes from Francois and Zolani's mothers respectively illustrate the nature of the encouragement given to their children:

"Ek sê vir hom elke dag hy is 'n baie mooi kind. Ek sê vir hom hy het baie om voor dankbaar te wees want die scar kon soveel erger gewees het. Ek sê vir hom hy moet gewoonnd daaraan raak want die mense sal nie gewoonnd daaraan raak nie as jy nie self dit doen nie."

Francois' mother

"When I walk around with him in town or something people and children like look at him, especially the children, and they call him 'chicken thing', and he feels different from the other children. I say he must not mind because he is still beautiful like he is and he is my son and I love him. He didn't make himself to be like this, it was just an accident."

Zolani's mother

Restricting social interaction and encouraging camouflage

The caregivers of six participants thought it more appropriate for their children to conceal their disfigurement when in public and a further four caregivers actively restricted the child's social activities (e.g. keeping the participant indoors after school). The reasons given were the need to protect the participant from social ridicule and to avoid insensitive questions from other adults who would assume that the disfigurement is as a result of negligence on the caregiver's behalf. This rationale is demonstrated in the following excerpts from the interviews with Olivia and Celine's mothers respectively:

"Ek weet ek kan mos nie my eie kind wegsteek nie maar ek wou Olivia nie saam dorp toe neem nie omdat mense so kyk en die kinders giggel agter haar en ek kry seer vir haar. As ek sy was sal ek baie skaam gewees het, eerlik waar."

Olivia's mother

"Ek sê gedurig vir haar sy moet die goed toemaak. Die mense is bietjie grillerig as hulle dit sien en 'n paar het my al gevra of ek nie my eie kind kan oppas nie."

Celine's mother

The tendency for caregivers to be overprotective of the burned child finds support in the empirical literature (Knudson-Cooper, 1981). Adriaessens et al. (1987) describe how caregivers feel embarrassed by the child's appearance and withdraw socially to avoid hostility from the outside world. Unfortunately, this approach does little to facilitate positive adjustment since a good recovery depends on both internal acceptance and a pro-active external participation in society (Knudson-Cooper, 1981; Sheridan et al., 2000). Neither goal can be attained if the child's social activities are restricted and the child's appearance is made out to be a source of shame.

Forming romantic relationships

Forming romantic relationships is a dominant theme in the lives of most adolescents. Given that even healthy adolescents are insecure about the normal changes that are happening to their bodies as they begin to develop secondary sex characteristics, it follows that disfigured teenagers have many complex body image issues to resolve especially because they are at a high risk for social exclusion. The literature on disfigurement points to a process of downgrading the self-concept resulting in disfigured adolescents viewing themselves as unlovable (Harris, 1982). To this end the effect of the disfiguring scars on sexuality and the formation of romantic relationships was explored with the adolescent participants and their caregivers. Although most participants were non-committal at best and defensive at least while discussing the topic, the information gleaned did reveal a variety of perspectives.

The most significant example of perceived attractiveness providing an obstacle to developing a romantic liaison was Rasheeda, a 20 year old young woman who sustained a 50% TBSA flame burn when she was nine years old. Rasheeda's problem

is a multi-faceted one: she believes that she has suffered internal injuries that would render her incapable of conceiving a child and as discussed elsewhere, she believes that her skin will 'tear open' if she does fall pregnant. She is also self-conscious about her weight and the fact that her breasts are asymmetrical and disfigured as a result of the burn injury. Moreover, Rasheeda feels unduly pressurized to find a partner as she is from a devout Muslim family in which she is the only unmarried person of her age. This combination of factors has culminated in Rasheeda taking a dim view of her romantic prospects:

"Al wat ek weet is dat ek nooit gaan trou nie en ek sal ook nie kinders kry nie. Ek wil nie 'n man hê omdat ek gebrand het. Ek is veronderstel om al getroud te wees maar hulle verstaan nie. Ek wil nie eendag trou nie. Ek kan nie. Ek sal nooit 'n outjie kry."

Rasheeda

Eighteen year old Francois' approach to members of the opposite sex is cautious but sensible.

"Ek kom goed met meisies oor die weg maar ek sal nie sommer met 'n meisie praat. Ek sal wag. Ek sy my nog so kyk en sy weet ek het die merk, dan sal ek met haar praat. Dan weet ek sy weet ek het nie 'n karakterfout nie."

Francois

Social comparison with other adolescents can be painful for the burn-disfigured teenager. Olivia's mother describes her 17 year old daughter's eager attempts at forging a romantic relationship as awkward and inappropriate.

"Sy sal nou byvoorbeeld sê die kinders van haar ouderdom het almal outjies en dan vergelyk sy haarself met hulle. Daar het 'n jong man by haar kom kuier maar ek dink sy was 'n bietjie ernstig of miskien 'n bietjie te haastig. Sy het sommer op sy skouer gelê. Hy is nie terug nie. Ek weet nie of die brand hom afgeskrik het nie of hy net nuuskierig was of wat. Ek kry haar maar jammer want hy kom nie meer nie."

Olivia's mother

These sorts of rejecting experiences must be dealt with tactfully and carefully to avoid the teenager spiralling into a depression as result of poor self-esteem. Burn-disfigured

children must be reminded that they too are capable of developing loving relationships with suitable partners. For instance, Caroline, the oldest participant in the sample has a devoted boyfriend and a two year old child. Individuals such as Caroline are a useful resource in terms of motivating other young people to believe in their potential for happiness, perhaps by addressing disfigured teenagers in the safe forum of a support group. This suggestion is explored in Chapter Four.

A final word on the emerging sexuality of disfigured teenagers: Anecdotal evidence suggests that young women disfigured by burns will seek affection by whatever means, including resorting to prostitution (R. Albertyn, personal communication, January 2001). This is similar though not identical to the defiant and provocative behaviour that disfigurement can produce as was discussed earlier on in the cases of Katrina and Celine. It follows that these young people need reassurance regarding their dignity and self-respect, and that loving contact can be achieved through less desperate avenues.

The effect of disfigurement on sexuality is a largely unexplored area of research and further investigation in this field is likely to yield lucrative results.

PARTICIPANTS' USE OF SOCIAL SUPPORT

Given the emphasis in the literature on the importance of social support in facilitating the long-term psychosocial adjustment of paediatric burn survivors (Blakeney et al., 1988; Blakeney et al., 1990; Bowden et al., 1980; Browne et al., 1985; Byrne et al., 1986; Davidson et al., 1981; Knudson-Cooper, 1984; LeDoux et al., 1998; Sawyer et al., 1982), participants were questioned about their access to and use of social support resources.

Religious support

Religious belief is an important source of strength for five participants, particularly where the participant is involved in a church youth group. This sort of involvement can open doors for friendship, encourage acceptance from peers and in doing so, facilitate self-esteem. Olivia's mother describes the boost in self-confidence that catechism has brought to her daughter:

"In die begin was daar tye waar sy net in die huis gesit het, maar nou met die kateiseer en die jeuggroep het dit vir haar baie self vertrouwe gegee."

Olivia's mother

Recreational activities and sports

Most of the participants reported involvement in some sort of sporting activity at school or have an extra mural activity. Few participants refrain from these activities because of their disfigurements. The importance of recreational activities is that they can be a great source of satisfaction for the disfigured child, providing an opportunity to socialize with non-disfigured children and to experience a sense of accomplishment from participating in activities like other unburned children. Francois, who is an avid dancer, describes the sense of fulfillment that he derives from dancing and how it detracts from his disfigurement:

"Ek weet ek is 'n goeie danser. Dit gee my sterkte want ek doen iets wat anders nie kan nie al het ek 'n swakpunt."

Francois

The value of emphasizing positive personal traits and abilities while simultaneously diminishing the value ascribed to disfigurement has been recognized as facilitating self-esteem and adjustment (Robert et al., 1999). It follows that it is important for caregivers to encourage their burn-disfigured children to attempt new activities in order for these children to discover their own talents.

Peer support

Although most participants reported having friends, either from school or from participation in extra mural activities, only ten participants said that they could rely on support from their friends in dealing with their problems. Anthea is one such participant:

"Ek praat met my vriende as ek unhappy is. Hulle sê vir my altyd ek moet myself nooit so aftrek nie en ek moet vorentoe kyk en nie dink aan wat ander mense sê of dink nie."

Anthea

Interestingly, excluding the participants from St Joseph's Home, two participants are friendly with other burn-disfigured children and two others have friends that are physically handicapped by congenital conditions. While it is understandably safer to be surrounded by those who are also 'different' in one way or another, this form of socialization does not encourage normalization or acceptance.

The reticence of burn-disfigured children to interact with other children is well founded, particularly in the case of adolescents. The importance of physical appearance during this developmental stage is such that any adolescent who detracts from the perceived attractiveness of the group is a threat to each individual in the group and is therefore likely to be excluded. To this end, it may be a worthwhile exercise for volunteers who are close in age to the burned adolescent to join in support groups and express their willingness to socialize with these children. This is particularly so in light of the finding that peer support is likely to be more important than family support when dealing with adolescents since teenagers are especially susceptible to the positive and negative influences of their peers (Orr et al., 1989).

Family support

Most participants said that they could speak a member of their family if they were troubled. Given the importance of family support in facilitating psychosocial adjustment (Blakeney et al., 1988; Blakeney et al., 1990; Bowden et al., 1980; Browne et al., 1985; Byrne et al., 1986; Davidson, Bowden & Tholen, 1981; Knudson-Cooper, 1984; LeDoux et al., 1998; Sawyer et al., 1982), this is a heartening finding. This quote from Caroline succinctly illustrates the value of family support:

"My mom, she always stood by me, this is one thing that I can remember. I could always turn to her and I know that if she weren't in my life to stand by me and talk courage into me I would not have been what I am today. I can honestly say thank you to my mother for always being there for me, especially during school years."

Caroline

The pitfalls of seeking support

Although the value of social support from friends and family is important, it must simultaneously be recognized that the burn-injured child may become weary of

turning to others for help. Indeed, ten participants said that they would not talk to anyone about their problems and would prefer to deal with these issues themselves because of the fuss and embarrassment that results from complaining. Caroline, who conceded to making extensive use of her mother's advice explains why social support is not an infallible approach to dealing with problems:

"I did have my mommy and the teachers were also aware because it was such a big thing at school. But there also came a time when I didn't tell anybody what was happening because I wanted to avoid all the trouble and problems it caused. The thing with people sticking up for me is that then I feel like they are pitying me and I always tell them that 'I don't want your pity and I don't want you to feel sorry for me. I want you to like me for who I am'. If people stick up for you all the time then there comes a time when you are so dependent on them and you feel that you cannot defend yourself and people will think you are a scaredy cat or things like that. It is so complicated you can't actually really explain it."

Caroline

FACING THE FUTURE

Employment and career aspirations

Empirical research on the employment and career aspirations of paediatric burn survivors is meagre and possibly outdated. Nonetheless, this research indicates that burn-injured adolescents evidence lower vocational aspirations, poor career planning and a lack of confidence in success at work (Chang & Herzog, 1976; Goldberg, 1974). In the present study, many of the younger participants had not devoted much thought to a career choice, but responses from the older participants reiterated Rivlin's (1988) finding that vocational aspirations can be profoundly affected by disfigurement. More than a third ($n=15$) of the participants said that they would choose law or medicine as a career and usually cited their reasons as wanting to be of some form of assistance to others. A possible interpretation of this finding is that the participants have developed empathy as a result of their traumatic experiences. These quotes from Olivia and Yolanda respectively would certainly support such an interpretation:

"Eendag wil ek 'n laywer wees. Ek wil vir die judge sê van die kinders wat in rolstoele is en dan skel die mense hulle in die winkels."

Olivia

"Ek wil 'n dokter wees om die gebrande kinders te help."

Yolanda

Advice for other caregivers of burn-injured children

Both the caregivers and the older participants were asked to share their thoughts on how other caregivers should approach the problem of a burn injury in the family. There was consensus that caregivers must exercise patience with burn-injured children, reassure them of their worth and remind them often that they are loved, irrespective of their appearance. Some caregivers emphasized the importance of reminding burn-disfigured children that the burn accident was not their fault and that they should not be ashamed of their looks. A few caregivers responded that the only course of action is prayer. These various viewpoints are expressed by Leanne, Natalie, Taryn and Donovan's mothers respectively:

"Ek sal sê gee hulle baie liefde want dit is al wat hulle kan help."

Leanne's mother

"Hulle moet baie patience hê met hulle kinders. Hulle moet baie moed inpraat en vir die kind sê dis nie haar skuld dat sy gebrand het, dis mos 'n ongeluk wat sy nie kon help. Sy is mos nie so gebore nie."

Natalie's mother

"I would say that as a parent make sure that your child stays happy and doesn't feel self-conscious and the best way to do this is to show them that you care and that you love them and make them feel loved irrespective, make them feel as though what they look like is not what is going to make them as a person – it is what is inside of them and how they deal and feel about other people – that is what is ultimately going to make them as a person. But it is very difficult to teach children that because children haven't reached that level of maturity to know that what is inside that counts- but I think constantly you have to instill in them a positive outlook – that is what I have been doing with Taryn."

Taryn's mother

"Ek sal sê die hele ding is net 'n gebedsaak. Jy raak moedeloos en jy wonder hoekom en waarom, maar met geloof in die Here kom jy maar deur."

Donovan's mother

One participant, Francois, raised an important point in his advice about caring for the burn-injured child:

"Hulle moet nie vir hom hanteer asof hy gebrand het nie because why as jy iemand hanteer teenoor die fout wat hy het dan kyk hy baie terug op die fout - hy sal altyd dink dat hy verkeerd kan doen omdat hy gebrand het - 'hulle sal verstaan, ek het gebrand, ek is mos nie perfek nie'. Sy ouers moet hom presies dieselfde hanteer soos die ander kinders wat perfek is. Soos my ouers - hulle het baie omgee oor die brandwond, maar as ek verkeerd was het ek pak gekry soos die anders - ek het nie spesiale behandeling gekry nie."

Francois

Francois' insightful comment highlights the dangers of human response to ill or injured children - to shower them with attention and special privileges in an effort to compensate for their suffering. An unfortunate consequence of this behaviour, if it is not time limited, is the possible creation of a sense of entitlement. Instead, burn-injured children, like other children should be encouraged to develop independence, autonomy and the self-actualization of their potential. As mentioned elsewhere, if one is treated as a victim, one will never learn to take responsibility for one's life.

Advice for other paediatric burn survivors

While health professionals may aid in the process of successful adjustment, it has been suggested that the burn survivors themselves are the experts on post-burn concerns (Robert, Berton, Moore, Murphy, Meyer, Blakeney & Herndon, 1997). As such, the participants were asked to dispense advice that they thought would be useful for other paediatric burn survivors. The responses yielded two extreme perspectives: while most participants focused on the negative aspects of their experiences and felt that other burned children should be warned of the social humiliation that awaits them, others were more positive in outlook and emphasized the importance of self-acceptance. These two viewpoints are expressed by Rasheeda and Caroline respectively:

"Ek sal vir hulle sê hoe dit gaan wees met die lelike goed wat kinders vir jou skree en die hartseer. Mense moet gewoon aan jou raak. Die hartseer is daar as jy ouer is, maar dit is nie so erg nie."

Rasheeda

"Dealing with it and coping with it and accepting it is most probably the best remedy that there is. As long as you don't deal with it and talk about it, it is a living hell. You must talk about it. You must express yourself as much as possible. You don't need to speak to a shrink, speak to a friend or to a teddy bear, or like I used to express my feelings by writing, just to get that heavy load off my shoulders. Do whatever, just to get that off and once that is off, just accepting it really helps. You must make the most out of life. If you don't do it, nobody else will."

Caroline

Of course, care should be taken not to overgeneralize post-burn response patterns at the expense of an individual's personal experience. Nonetheless, the words of advice quoted above succinctly summarize the different ways in which children learn to cope with disfigurement.

Caregivers' concerns for the future of the participant

All the caregivers were asked about their primary concerns regarding the future of the participants in their care. In the five cases where the caregiver was older than 65 years or in frail health, the chief concern was expressed as there being nobody to take care of the participant in the event of the caregiver's death. This sentiment is reflected in a comment by Rasheeda's mother:

"Ek is bekommerd oor Rasheeda se toekoms. Wat gaan eendag gebeur as ek doodgaan? Wat gaan van haar word? Wie sal vir haar sorg? Sien, sy is nooit weg van my af nie - waar ek is in die huis, is sy."

Rasheeda's mother

Eight caregivers reported financial concerns such as providing food, housing and education as being of the utmost importance. For example, even though 13 year old Nomawetu is both severely physically disfigured and presents with many behavioural problems, her mother did not mention these issues as a concern:

"My only worry is that I am struggling because there is no father so I am really struggling with the money. I owe the school the school fees and I can't afford and I must eat and I must pay for the bus for school and I am really struggling. We need another place to live also because in our shack in Nyanga you don't know if it can happen again."

Nomawetu's mother

This finding can be interpreted as a simple operationalization of Maslow's (1970) hierarchy of needs. It is understandable why Nomawetu's mother, a single parent with a menial job who lives in abject poverty in a criminally violent informal settlement, would emphasize fundamental physiological needs and the need for safety and security, rather than focus on the needs for social acceptance or self-esteem. Once more one is reminded of the stark reality of the South African socio-economic situation and the many obstacles that need to be overcome before issues of tertiary health can be adequately addressed.

Only in seven cases was the burn injury the focus of the caregiver's concern. These concerns centred mainly around the participant's disfigurement and the effect that it will have on feelings of self-consciousness, social acceptance, finding employment and forming romantic relationships. Zolani's mother is one caregiver who harbours these apprehensions:

"I think his face is the only problem. I don't know, but I am thinking maybe he won't have any girlfriends when he is big because he has got a burned face. Maybe he will not get a job because the people think he is ugly."

Zolani's mother

Two caregivers were worried that their children would hold them responsible for the disfigurement later on in life. In terms of behavioural concerns, two caregivers voiced their fears that their respective children's aggression and promiscuity would ultimately result in criminal activity.

Only three caregivers were optimistic about the future and could not see their children being held back by their disfigurement. Anthea's mother remarked:

"Anthea het groot drome. Sy sal nie maklik opgee nie – ek gun haar dit. Niks gaan haar terughou nie."

Anthea's mother

The general lack of optimism portrayed here highlights the necessity to encourage both participants and caregivers to have faith in a good outcome. A positive attitude towards the future enables burned children to focus their energies on pursuing the goal of successful adjustment (Beard et al. 1989). However, if the child's caregivers are bereft of hope for the future, it follows that the child's potential sources from which to garner strength are diminished.

Sophistication, passivity and complacency

One quarter of the caregivers declared that they have no concerns for the future of the participant in their care. This finding was somewhat surprising, particularly since the caregivers who claimed to have no real apprehensions were mostly those who had attributed many emotional and behavioural problems to their children. This finding is open to at least two interpretations. The first is that the caregivers and I do not share a common understanding of what constitutes problematic behaviour. The second, more interesting interpretation is based on the overall passivity reflected by the caregivers during the interviews. Few caregivers volunteered information to general questions or spoke spontaneously. In some cases, caregivers seemed to know very little about the children in their care. The following is taken from the interview with Shane's mother and demonstrates this pattern of complacency:

- Lesley: *"Is daar enige iets oor Shane se gedrag wat mevrou pla?"*
Shane's mother: *"Nie eintlik."*
Lesley: *"Dink mevrou hy sou anders gewees het as hy nie gebrand het nie?"*
Shane's mother: *"Ek sal self nie kan sê nie."*
Lesley: *"Dink mevrou hy is 'n gelukkige kind?"*
Shane's mother: *"Ek weet ook nie."*
Lesley: *"Het Shane probleme by die skool met sy onderwysers of sy skoolwerk?"*
Shane's mother: *"Ek weet self nie wat by die skool alles aangaan nie."*
Lesley: *"Het hy vriende by die skool of in die buurt waar mevrou-hulle woon?"*
Shane's mother: *"Lesley moet hom maar self vra."*
Lesley: *"Is mevrou bekommerd oor Shane se toekoms?"*

Shane's mother: *"Nee, alles is oraaait."*

Perhaps the perceived passivity can be attributed to feelings of anxiety arising from being interviewed or the fact that the population under empirical scrutiny is not one that is accustomed to self-reflection, particularly in the presence of a stranger (Bulmer, 1993; Mitchell, 1993). It is also possible that the historical context of racial subjugation and differential power relations may have contributed to the apparent complacency of the respondents.

According to Bulmer (1993), the difficulties encountered in the present study in terms of passivity on the part of the participants are common to the process of conducting social research in developing countries with an unsophisticated population. In poor and uneducated communities, social research is not well established, requests for interviews are rare, and the problems of illiteracy and cultural differences between the researcher and the respondent render the latter quite ignorant of the activity of social research and the role of the interviewer. This lack of familiarity with the interview process means that the respondents are unlikely to have an understanding of what is being asked of them. In addition, Bulmer (1993) argues that respondents are often not particularly interested in providing accurate answers since the benefits of the research are not apparent to them. In the present research, it is hoped that the aims and benefits of the research were explained sufficiently well to the respondents to minimize this sort of bias.

Furthermore, one could speculate that some caregivers deliberately chose not to disclose their concerns regarding the participants' psychosocial problems, perhaps thinking that such disclosure would introduce the threat of intervention by a social welfare agency.

Wishful thinking

At the conclusion of the interviews, participants were asked what they would wish for if they had any three wishes. The purpose of this question was to assess the relative impact and importance of the burn injury and its subsequent disfigurement on the participant's daily functioning. With few exceptions, and regardless of the visibility of the scarring, the participants wished that the burn had never happened, that the scars

would disappear and that they could be 'normal'. These quotes from Greg, Caroline, Carla and Nina illustrate the nature of this wishful thinking:

"I wish that my burn would go away then I wouldn't be affected by the look of it. I would have more friends because people wouldn't mock me and things like that."

Greg

"I would wish for the scars to go away. Sometimes I look in the mirror and I don't see the scars anymore, but I still wish, even if it is just for a minute or for a day, that I could live a normal life. A normal life without burns, even if it is just for a day so that I can feel what it feels like to be without burns. The burns covers a part of me that I will never be able to uncover and sometimes I just wish I could wake up and it will all be gone."

Caroline

"Ek sal wens die brand gaan weg en dan sal ek 'n mooi meisie wees. Ek kan sien van die fotos hoe ek sou gelyk het. Ek wens ek kan sommer oorsee gaan om net weg te gaan van almal. Ek wil nie tussen mense wees nie want ek wil nie he mense moet my pla nie. Ek wil op my eie wees, alleen."

Carla

"Ek sal wens ek het my regte bene gehad. Dan sal ek 'n skirt skool toe kan dra met sokkies. Niemand sal vir my iets kan sê nie."

Nina

These excerpts express a form of whimsical nostalgia reminiscent of a grieving process in which the children mourn the loss of their natural good looks and normal social interaction. However, as in the discussion with the caregivers regarding their concerns for the future, the participants' responses also revealed the relative insignificance of the burn injury and its disfigurement in comparison to other, more pressing psychosocial problems. For instance, the four children from St Joseph's Home wished that they could return to their families. Nomawetu, who lives in Nyanga wished that she could live elsewhere because it is *"dirty and scary outside in Nyanga"*. Yolanda, who lives with her grandaunt because her mother suffers from mental illness, wished for her mother's health, and that they could be reunited.

CHAPTER FOUR

CONCLUSION AND RECOMMENDATIONS

CONCLUSION

According to the limited epidemiological information available, paediatric burn injury represents a significant social problem in South Africa. Despite the magnitude of the problem and its potentially devastating physical, psychological and social consequences, the plight of burn-injured children in the local context is an unrecognized one, and has thus escaped empirical scrutiny to date. The purpose of this study has therefore been to explore the long-term psychosocial sequelae of children who survive thermal injuries with a view to determining their obstacles to optimal psychological functioning and social integration. It is intended that the findings of this research be utilized in the development of a contextually appropriate rehabilitation programme for these children.

The literature reviewed in Chapter One represents the state of empirical knowledge of the psychosocial adjustment that follows thermal injury suffered in childhood. The general consensus appears to be that such adjustment is positive (Blakeney et al., 1993; Blakeney et al., 1993; Blakeney et al., 1998; Herndon et al., 1986; LeDoux et al., 1996; Moore et al., 1996; Zeitlin, 1997), regardless of whether it is conceptualized in terms of psychological disorders (Campbell et al., 1987; Stoddard et al., 1989; Stoddard et al., 1989), global variables such as self-esteem (Bowden et al., 1980; Orr et al., 1989) or in terms of social competence and functional behaviour (Blakeney et al., 1993; Byrne et al., 1986; Moore et al., 1996). However, the methodological flaws common to this body of research as discussed in Chapter One and the fact that only one South African study has been conducted on the subject, call for prudence when interpreting and generalizing these findings to the local context.

The respondents interviewed in the present study chronicled many difficulties with post-burn adjustment, both psychologically and socially. The emotional and behavioural difficulties experienced by most of the burn-injured child include depressive, suicidal and anxious behaviour; changes in sleeping patterns; lack of bladder and bowel control; and general delinquent conduct such as lying, stealing and

promiscuity. Furthermore, many participants in the present study evidenced poor scholastic adjustment and significant academic lag. The abovementioned problems are no doubt compounded by the enduring barrage of social ridicule experienced by the participants in response to their disfiguring burn scars, and their lack of adaptive strategies for coping with these strained social interactions.

The many challenges faced by burned children and their families in adjusting to paediatric burn injury were also demonstrated by the caregivers interviewed in the present study. The traumatic nature of the hospitalization period and the emotionally daunting task of caring for a burn-disfigured child in the long-term are complicated by the limited social resources available to these caregivers. The responses of the caregivers in this research provide testament to the notion that paediatric burn injury is an assault on the family as a unit, and has ramifications that extend beyond the burned child. Such a burn injury is a drain on an already limited income and has psychosocial consequences for the siblings of the burn survivor.

intervention

The findings of the present research therefore clearly indicate that children who sustain burns as well as their caregivers are a population greatly in need of intervention. (This is particularly so in light of the fact that to date the paucity of resources at the Hospital's disposal has meant that no formal psychosocial assistance has been available to these children or their caregivers) Thus, while medical and surgical advances in the management of paediatric burns have progressed to such an extent that even extensive burns are no longer necessarily fatal, burn survivors, their families and society at large are inadequately prepared for the psychosocial consequences of such an injury. It is in light of these considerations that burn care professionals at the Hospital have embarked on a psychosocial rehabilitation initiative that is aimed at promoting the acceptance of the burn-disfigured child into the wider community. Such a process requires a mutuality that includes the openness and responsiveness of the society into which the burn survivor attempts re-entry, and mental and emotional preparedness on the part of the child and his or her caregivers (Doctor, 1992).

The process of facilitating the successful psychological adjustment and social reintegration of the burn-injured child in the South African context is likely to be fraught with difficulties. The complications encountered in recruiting and interviewing the sample of the present study are indicative of the challenges inherent in conducting social research in developing countries like South Africa. Simultaneously, however, these difficulties highlight the very necessity of such research in that the importance of understanding the experiences of the poor and less educated population likely to be affected by burn injury is emphasized. It is only by achieving a rich, contextualized understanding of the reality of the problem of paediatric burn injury as voiced by those afflicted that meaningful and appropriate steps can be taken to alleviate the situation. For this reason the present research is thought to be of practical and empirical value.

The combined effect of the magnitude of the problem, the (scarcity of resources) available to health care professionals in order to deal with the problem and the impoverished (socio-economic nature of the population) that is affected by burn injury mean that recommendations that could be implemented with relative ease in more developed countries, present a (formidable challenge in the local context.) Thus, any recommendations for improving the plight of the burned child will have to be addressed with a great deal of effort and creativity.

In light of these considerations, the following recommendations are thought to represent a (realistic response) to the problems experienced by the paediatric burn survivors as described in this thesis. These suggestions are intended to facilitate both increased environmental receptivity to burn-disfigured children and to encourage these children to present themselves to others with more confidence.

RECOMMENDATIONS

Recommendations for policy and practice

Support for the burn-injured and disfigured child

The need to provide support for the burn-injured child during hospitalization and particularly once the reality of disfigurement has set in, is clearly evidenced in this study. While little can be done with young children in terms of 'talking cures' and

interventions are confined to play therapy, once the child reaches adolescence, the need for support is likely to increase. To this end it is proposed that support groups be made accessible to adolescents with disfiguring scars. As the Hospital only treats children up until the age of 13 years, such a group would be best accommodated at Tygerberg or Groote Schuur Hospital. To promote a viable referral process, this means that contact between the child and the Hospital must be maintained in the years following the burn accident.

Little has been written about the impact of having a burns support group attached to the Burns Unit. Partridge and Robinson (1995) advocate the value of such a support group, whether as a supplement to individual counseling or as a stand-alone intervention. The significance of such a group is the facilitation of the flow of empathy and experience from one burn survivor to another. It is thought that within the safety of such a group, those attending can normalize their feelings and reactions and gain self-esteem and confidence. Ultimately, the idea is to reduce the sense of isolation and its related anxiety as experienced by the participants in this study. The setting of such a support group would also be an appropriate forum in which burn survivors who have created meaningful lives subsequent to sustaining their injuries are able to provide comfort and advice to those less experienced (Pearson, 1984). An individual such as Caroline, the 21 year old participant in the present study who is frequently quoted in Chapter Three, would be ideal for this purpose.

In addition, a variety of group social activities can flow from such support groups. This occurs as members of the group develop informal networks of support outside of the group setting (Munster, 1993).

In light of the singular paucity of organized strategies for dealing with social situations as evidenced in this study, it is clear that the disfigured child must be taught a repertoire of socially appropriate skills for handling difficult situations. Changing Faces, a British based support programme for disfigured individuals has developed the REACH OUT model, an acronym of eight skills devised to facilitate social interaction between disfigured persons and others (Barbour, 1996; Barbour, 1997; Barbour, 1999). These strategies are explained below:

1. *Reassuring others* with a smile, nod or eye contact allows the disfigured person to appear more confident and to feel in control of the social interaction.
2. *Engaging with others* in a general conversation beginning with an open-ended question shifts the focus away from the awkwardness of being confronted by a disfigured person. Open-ended questions are those that begin with words like 'how', 'where', 'when', 'what' and 'who'. These types of questions encourage others to elaborate and continue talking to the disfigured person by giving them an opportunity to talk about themselves.
3. *Asserting oneself* with confidence means that the disfigured person must accept that being disfigured is not a reason to be apologetic towards others. Without adopting an aggressive stance, the disfigured individual should relay to others that their staring is inappropriate or hurtful.
4. *Courage* is undoubtedly required in order for the disfigured person to overcome the obstacles of low self-esteem and heightened self-consciousness that accompany a disfiguring injury. It is important for disfigured individuals to recognize that they have been presented with a challenge and that it is appropriate to congratulate themselves each time they succeed in tackling a difficult social situation.
5. *Humour* is a powerful tool for the disfigured individual. Being able to laugh at oneself and treating one's disfigurement in a light-hearted fashion puts others at ease by making them realize that the disfigured person is comfortable with his or her appearance.
6. *Over to you* is a skill that the disfigured person should employ to shift the attention to other people in the social group by encouraging them to talk about their own interests.
7. *Understanding* that others are naturally curious about unfamiliar appearances is an important skill for the disfigured person. The best way to overcome the awkwardness created by this lack of experience with people who look 'different' is for the disfigured person to put others at ease and allow them permission to ask about the cause of the disfigurement. Direct references such as "I noticed you looking at my hands. You are probably wondering what happened to me" are

appropriate for dealing with the uncertainty that is likely to arise when a disfigured person encounters a new social contact.

8. *Trying again* is an important skill for the disfigured person. Not every social encounter is a success. The importance of this skill is that disfigured persons must give themselves credit for having attempted a difficult task and not blame themselves for failing to engage others in conversation.

Other useful skills suggested by Changing Faces include rehearsing one or more simple explanations for the cause of the disfigurement that can be readily called upon when others ask about what happened to cause the scars (Barbour, 1996). The constant use of positive self-talk is also suggested as a useful strategy in dealing with disfigurement (Barbour, 1997). The underlying theme of these skills is the recognition on behalf of the disfigured child that disfigurement is a social handicap with which the majority of the population has little experience. In a sense, the onus is shifted to the disfigured person who has more experience with these situations.

The implementation of these strategies requires a great deal of effort on behalf of the disfigured child and will initially have to be practiced first in the confines of a safe environment. If it is not possible to teach and rehearse these skills on a one to one basis due to limited staff resources, then then the group forum described above would be an ideal setting in which to practice these new behaviours. The assistance of caregivers in this regard is also important. This point is reiterated later on in this chapter.

Burn-disfigured versus disfigured

In terms of the social problems that result from disfigurement as described in Chapter Three, there seems little point in drawing a distinction between children disfigured by burns and those who have been disfigured by other causes e.g. congenital craniofacial abnormalites, port wine stains, motor vehicle accidents or other traumatic events. While children who are disfigured by means other than burns do not have medical and surgical procedures in common, the fact that they too look 'different' would mean that they too are stigmatized. The suggestion to include children with other forms of visible disfigurement in a support group is proposed in that it may seem more

financially feasible to potential fund-raising ventures if a more diverse population is seen to benefit.

Caregiver support groups

Given the influential role of caregivers in the emotional recovery of the burned child, it is necessary to help caregivers cope with their children's reactions. To gain strength though, caregivers first need to deal with their own situation and feelings of guilt, anger, shock, fear, and helplessness (Blumenfield & Schoeps, 1992). At a later stage, they must come to terms with their own and the community's reaction to the child's disfigurement. Simultaneously, caregivers need to be aware of the importance of post-discharge compliance in terms of attending outpatient clinics, wearing pressure garments and splints, and the likely changes in behaviour that can be expected from the child as a result of the burn injury.

In recognition of these issues it is suggested that a support group be established for the caregivers of burned children. It is recommended that caregivers would have access to these groups during the inpatient phase. The availability of caregiver support groups have been found to be useful in facilitating adjustment to the child's burn-injury (Broadland & Andreason, 1979; Rivlin et al., 1986; Rizzone, Stoddard, Murphy & Kruger, 1994). These groups are an effective forum for educating families to cope with the new situation that they face by enabling caregivers to realize that they have common concerns and by providing the stimulation and support that individual counseling cannot offer (Rivlin et al., 1986). Input from caregivers whose children sustained burn injuries in the past and who have coped successfully with the experience has also been found to constitute a valuable contribution to such caregiver groups (Pearson, 1984). The group process enables caregivers to develop positive attitudes and abilities that would assist in the child's adjustment (Doctor, 1992). Simultaneously, the caregiver group is an ideal setting in which to provide information about the surgical and medical treatment of the burned child and the nature of continued care that will be required once the child is discharged from hospital (Munster, 1993).

The context of the caregiver group is also a suitable forum in which to discuss the REACH OUT model described above and the ways in which caregivers can reinforce the principles of this model. Caregivers of burn-disfigured children need advice on how to listen to, spend time with, comfort and praise their children in ways that bolster their self-esteem and diminish self-consciousness (Barbour, 1997; Robert et al., 1999). Rehearsing explanations about the cause of the disfigurement and learning ways in which to discuss the burn injury and its consequences in an honest fashion are also issues that can be addressed within a caregiver support group.

Ideally, support groups are facilitated by a psychologist or social worker (Munster, 1993). However, the caregiver group is different from therapy in structure and purpose since no contractual obligations or requirements for consistent attendance are necessary (Fowler, 1979). Another difference is that such support groups are not intended to work out the complicated roots of underlying feelings, but are aimed at dealing with the crisis of the burn injury. It is thought that the introduction of a caregiver support group would also relieve the boredom of the protracted hospitalization period as well as provide an opportunity for informal support networks to develop (Munster, 1993).

The need for education and burns awareness

The need for education in terms of the significance of compliance with post-discharge treatment was discussed in Chapter Three. It is thought that caregiver support groups will fulfill this function, however, failing that, it is the responsibility of burn care professionals to specifically instruct caregivers as to the importance and proper use of pressure garments and splints. If personal instruction is not possible, posters and pamphlets should be available both during the inpatient phase and at subsequent outpatient clinics. It is thought that once caregivers are aware of the serious nature of the problem, they will be more likely to comply with post-discharge regimens.

Given the magnitude of the problem as described in Chapter One, education regarding the prevention of burn injuries is clearly a priority. At present, the Child Accident Prevention Foundation of South Africa does provide a service to schools and other community organizations which focuses on burn prevention. However, staff at the

Prevention

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Foundation is limited and it is therefore suggested that local education departments enlist the assistance of municipal fire departments to become involved in this endeavour.

Debunking disfigurement

Education is also required in order to address society's collective beliefs about the life prospects of a person with disfiguring scars and the way in which these myths serve to stigmatize members of the disfigured population. Popular culture as perpetuated through the media encourage the notions that plastic surgery can miraculously correct any cosmetic imperfection and that one's physical appearance is intricately linked to one's personality and future success (Partridge, 1990). These uninformed viewpoints are dangerous for disfigured people as they may become self-fulfilling prophecies (Barbour, 1999) thereby exacerbating the social withdrawal, self-consciousness and pessimistic worldviews that were evidenced by the participants in the present study. To this end, it is suggested that those involved in the visual media be encouraged not only to refrain from perpetuating these myths, but also to make a concerted effort to dispel them by shifting away from stereotypical casting. Similarly, school education should comprise more scope for appearance issues (Barbour, 1997). The pervasive problem of school as the site of social ridicule as highlighted in this study point to the need to introduce anti-bullying policies (Partridge, 1990). Such a step is intended to convey the message that prejudice and discrimination on the basis of appearance is unacceptable behaviour in a humane society. Public campaigns aimed at perpetuating a more comprehensive ethos of fairness are required if the environment into which the burn-disfigured child is to be reintegrated is to be truly receptive.

School entry/reintegration programme

The importance of infrastructure and organization in terms of the burned child's school entry or reintegration is described in Chapter Three along with the basic principles of such a programme. However, given the limited resources available to the Hospital, a local programme is unlikely to take the form of similar programmes developed elsewhere in the world. For instance, it would not be possible for a social worker, nurse or doctor from the Burns Unit to visit the school personally at the time

that the programme is launched. Nonetheless, the same content can be conveyed to the school authorities in writing, by telephone, or on videotape.

A useful suggestion is to obtain the endorsement of the local education authorities in such a way that teachers are able to facilitate the school reintegration programme (Horwitz, 1999). Posters, handmade puppets and other materials can be employed to effectively communicate the nature of the returning learner's burn injury, the significance of pressure garments, splints and other appliances, and the importance of preventing burn injuries.

It is important to bear in mind that the child should return to school as soon as possible to prevent unnecessary academic lag and that the caregivers should be empowered to actively participate as appropriate advocates for their child. While in hospital, burn-injured children should be treated as though they will return to school on discharge (Doctor, 1992). To achieve maximum benefit, schools should be contacted when one of their learners is hospitalized for a burn injury so that peer visits can be arranged and other preparations can begin. Where the child is not of school going age at the time of the burn, a strong hospital-school liaison is necessary so that the burns team can be alerted when the disfigured child is ready for school entrance.

Burn camps

Regular outpatient follow-up may be supplemented with recreational camps for burn-injured children. Numerous camps have been developed in the United States, Australia, New Zealand, the United Kingdom, Australia and Belgium (Munster, 1993). These camps provide continuity of care and support to facilitate post-burn adaptation, particularly for children who have limited access to psychosocial support systems because of geographical constraints – a typical problem in the South African setting.

Specialized camps for children with specific diagnoses have been in existence for many years (Doctor, 1992). Each camp has taken the basic premise and tailored a programme unique to the talents and creativity of the staff members and the particular resources of the community. The goals of treatment are consistent at burn camps,

regardless of the setting in which they take place. The programme aims to provide a safe and supportive environment where the development of self-esteem, a sense of community and the importance of peer support are the primary foci (S. King, personal communication, May 2001). With the encouragement of caring and knowledgeable staff, children at the camp are exposed to challenging physical and social situations. These activities allow burn-injured children to overcome their frustrations and fears and to maximize their potential. It is theorized that success in one arena, the camp, can be translated into success into the more significant environments of home and school.

It is believed that for many burned children, the camping experience represents the only opportunity to openly share the true depth of their feelings with individuals, peers and counselors who can tolerate and understand the intensity of their emotional responses. Shields et al. (1985) describe a camp for children with cancer and state that they do not attempt to compensate for what cancer has brought to the lives of these children or treat them as if they are special or different from the rest of their peer group. Instead the programme is designed to overcome preoccupation with illness and feelings of isolation thereby providing these children with an opportunity to experience as many aspects of normal childhood development as possible.

Campers are encouraged to develop their independence, autonomy and self-actualization (Doctor, 1992). The environment should be designed in such a way that no one is isolated, shamed or ridiculed because of disfiguring scars or physical disability. Campers should be encouraged to challenge previously conceived limitations: the idea is for burn-injured children to risk 'failure', learn new social skills, and reach beyond their own pain to help one another.

The staff contingency of the burn camp should ideally comprise a multi-disciplinary team. Staff need to be carefully selected and may include fire fighters, psychologists, social workers, nurses, doctors, occupational therapists, physiotherapists and those trained in facilitating particular activities (Munster, 1993).

An expected reaction to the suggestion of a burn camp is the financial cost involved. Clearly it would be unreasonable to expect the families of the children to pay for the camping experience given the already limited income on which they subsist. However, this is no different to the situation in the United States and Australia where burn camps are funded by hospital affiliations, private donations and grants. It is suggested that what is required in order to fulfil the goal of a burn camp is creativity and motivated fundraising. Local community organizations such as the Lions and Rotary Clubs, the Freemason Lodges, religious organizations and private individuals should be approached with suitable funding proposals aimed at eliciting sponsorship for burn-disfigured children to attend these therapeutic excursions. It is believed that once the wider community is made aware of the significant social problem of paediatric burn injury in South Africa and the fact that the affected population is characterized by poverty, these organizations would willingly direct funds towards this cause.

The creation of a full-time post for a psychologist/social worker in the Burns Unit

In order to actualize the recommendations suggested above, it is strongly urged that a full time post in the Burns Unit be created for a psychologist or a social worker. The role of this person would be both therapeutic and administrative and would include co-ordinating the many aspects of rehabilitation described above. As such the job description of the psychologist or social worker would include:

- Maintaining long-term contact with patients treated at the Hospital so as to monitor their progress and deal with problems as soon as they arise (this would include discussion regarding the benefits and disadvantages of further corrective surgery)
- Being available to reassure and encourage both children and caregivers during the inpatient phase
- Being available to provide psychosocial support to the nursing staff in the Burns Unit
- Developing a range of posters and pamphlets that contain information regarding the correct use of pressure garments and splints, the importance of post-discharge compliance and advice on what can be expected when the child is discharged

- Monitoring the post-discharge compliance of the patients who have been treated at the Unit
- Organizing and facilitating support groups for the older burn-injured children and adolescents in which coping issues are explored and social skills are taught
- Organizing and facilitating support groups for caregivers during the inpatient phase
- Inviting those burn-injured children and their caregivers who have coped successfully with the psychosocial challenges of post-burn adjustment to address the respective support groups
- Developing and co-ordinating fundraising and sponsorship proposals to local community organizations in order to finance activities such as outings into the community, burns camps and a transport contingency fund to assist caregivers while their children are in hospital
- Developing and co-ordinating a contextually appropriate burn camp
- Developing and co-ordinating a contextually appropriate school re-entry programme
- Creating and maintaining a strong hospital-school liaison in order to organize peer visits to the hospital, the school reintegration programme, and ongoing availability to deal with issues as they arise at school
- Recruiting and training volunteers to assist with burn camps, school reintegration visits and excursions into the community.

Recommendations for further research

The findings of the present research present several opportunities for further research. On a lesser scale, further investigation into the psychosocial effect of paediatric burn injury on the siblings of the burned child is required, as is an examination of the way in which disfigured adolescents perceive and negotiate their emerging sexuality. It may also be useful to explore the possibility of improving the facilities at the St Joseph's Home in such a way that more burn-injured children can be accommodated in a residential facility that will meet their physical and psychosocial needs.

On a larger scale, the paucity of epidemiological information regarding paediatric burn injuries calls for a researchers to turn their attention to collecting and

disseminating this kind of data. Although the present study was not epidemiological in nature, information regarding the incidence, distribution and control of burn injuries in the South African population would have been most useful as a starting point for the study. Regional burns units such as the one at the Red Cross Children's Hospital as well as community day hospitals will be required to co-operate in this process.

As a final recommendation for research, it is suggested that an ideal study of the long-term psychosocial adjustment of paediatric burn survivors would most likely be a prospective, longitudinal investigation of burn-injured children of varying developmental ages. Such a study will yield the kind of information that is necessary to design a comprehensive psychosocial rehabilitation programme aimed at promoting the optimal recovery of the young burns survivor. Unfortunately, the resources required to conduct a study of this nature were well beyond the scope of the present study, both in terms of time frame and with regards to locating participants. It is recommended, however, that further research on this topic should include the following methodological considerations in order to maximize the usefulness of the findings. Firstly, the inception cohort of participants would have to be early, say at the time of admission, and at a uniform point in time. Secondly, the follow-up of the participants must account for all persons. Hopefully, with an improved regimen of post-discharge compliance (as recommended above), less burn-injured children will be 'lost to follow-up'. Thirdly, in terms of assessing the outcome of the participants' adjustment, the clinical status of the participants needs to be known and the criteria used to judge their psychosocial adaptation must be replicable and accurate. These criteria must also be amenable to blind assessment and adjustment for extraneous variables (e.g. severity of the burn and the time elapsed since the burn injury was sustained).

CHALLENGES

Conducting this research was challenging in several aspects. I believe, however, that the lessons learned are valuable personally and professionally in terms of informing future interventions and research practices.

Recruiting the participants

As has been emphasized elsewhere in this thesis, the process of recruiting the participants was lengthy, tedious and expensive. The resulting response rate was both disappointing and disconcerting given the magnitude of the problem and the nature of its consequences that have been described in the present study. Chapter Two contains several thoughts on the whereabouts of the non-respondents in terms of not having received the recruitment telegrams due to relocation or being unable to make contact with the Hospital. More disturbing though, is the speculation of the burn care staff at the Hospital regarding the fate of the children who escaped the empirical scrutiny of this study: anecdotal evidence suggests that many burn-disfigured children commit suicide (H. Rode, personal communication, August 2000), leave home or resort to prostitution in response to their social rejection (R. Albertyn, personal communication, August 2000). To this end, it is hoped that by imposing a more stringent post-discharge regimen, the number of children who are 'lost to follow-up' will be reduced.

Striking a balance between empathy and detached inquiry

Perhaps the most challenging aspect of the present research was the data collection phase. Although rewarding, the interviews with both the caregivers and the participants were emotionally exhausting. The mental strain that I experienced was no doubt as a result of the disclosures of human suffering and cruelty that were revealed during the interviews. Many interviewees cried throughout their interviews and despite my intentions, I found myself moved to tears on several occasions.

At these times, it was difficult to retain my composure. I realized that the balance between empathy and detached inquiry is not easily attained when dealing with such a sensitive issue. It occurred to me that my post-graduate training in research psychology had not adequately prepared me for this eventuality and that this should perhaps be amended in future curricula. It seems that research psychologists need some instruction in basic counseling skills in that it is surely unethical to elicit a participant's painful memories and yet, have limited means with which to provide closure. Similarly, I too was personally affected by the content of the interviews and considered the possibility of debriefing. Unfortunately, research psychologists do not

benefit from the supervision that clinical psychologists do, and perhaps this is an issue that needs to be further explored.

LIMITATIONS OF THE STUDY

The present study is hampered by at least two limitations. Firstly, the sample size was relatively small. However, given that every attempt was made to contact potential participants as detailed in Chapter Two, it is difficult to suggest ways in which this situation could have been remedied. Furthermore, it is thought that in light of the socio-demographic characteristics of the population most likely to be affected by paediatric burn injury as described elsewhere in this study, those respondents who did participate in the research reflect an adequate representation of the larger population. It must also be noted though, that despite the small number of participants, the sample was large enough to allow for trends to emerge. At the same time, the sample was small enough to permit a rich and contextualized analysis of individual diversity.

Secondly, the investigation into the psychosocial sequelae was limited in that it was purely descriptive and failed to quantify problems in terms of their frequency, duration and precipitating factors. This was intentional in the sense that the aim of the research was not to provide psychiatric diagnoses of the participants or to compare their functioning to a norm-referenced population. However, the lack of clear diagnostic outcomes means that the findings of the present study cannot be compared to the research findings of previous work conducted on this topic.

Nonetheless, this thesis provided an opportunity to work with members of an impoverished community whose difficulties have hitherto been ignored. Every effort has been made to report the participants' stories and social contexts in the way that they are lived and understood by these individuals. Furthermore, it is believed that this study provided a valuable opportunity for the participants to benefit from the research process in that the majority received referrals for much needed surgical and/or psychological intervention. It is therefore argued that the manner in which this research was conducted was appropriate for the local context, the purpose and scope of the study and the available resources.

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APPENDIX A

THE PARTICIPANTS

THE PARTICIPANTS

This appendix contains a brief summary of each participant detailing information such as current age, age at the time of the burn injury, the aetiology of the burn injury and any other remarkable aspects of the participant. The participants are discussed in alphabetical order.

Andrew

Andrew is a 12 year old boy who sustained a 35% TBSA flame burn to his face, scalp, back and arms when he was nine years old. Andrew and his cousin Charlton (discussed below) were burned when the latter's three year old brother set fire to the mattress on which they were sleeping. Since the burn injury, Andrew has run away from home on several occasions, truants regularly and has been caught shoplifting.

Anthea

Anthea is a 15 year old girl who sustained a 12% TBSA flame burn to her face and hands when she was three years old. Anthea was burned when gangsters (who are now incarcerated) threw a petrol bomb into a shebeen that her mother was frequenting. Anthea's mother sustained very serious burns in the attack. Anthea is markedly self-conscious about her scars, particularly those on her face, and is very socially withdrawn. Unfortunately, Anthea's adjustment is hampered by the knowledge that her father deserted her mother as a result of the burn injury because he was ashamed of his wife's appearance. Anthea has not seen her father for 12 years.

Bradley

Bradley, a Tygerberg Hospital recruit, is a 15 year old boy who sustained a 15% TBSA scald to his arm, hand and chest when he was five years old. The scald occurred when Bradley pulled a pot of boiling water off the stove. Bradley's primary caregiver is his older sister and he appears to relate to her as his mother. Bradley suffered from a lack of bladder and bowel control for six years following the burn injury. He is also a good example of a child for whom a burn injury and its subsequent disfigurement has lasting implications for scholastic progress: he has failed two grades at school, the first because of his initial hospitalization and the second because

he had to return to hospital to repair a torn skin graft. Bradley has subsequently dropped out of school because he could not tolerate the ongoing teasing and name-calling, although he has deceived his family into believing that he still attends school.

Bridget

Bridget, a Tygerberg Hospital recruit, is a 12 year old girl who sustained a 1% TBSA contact burn (hot coal) to her hand when she was four years old. Bridget's hand is severely contracted and she is not able to straighten her fingers, thereby hampering the use of her hand. Bridget's father is deceased and she lives with her mother and older sister.

Busisiwe

Busisiwe is a ten year old girl who sustained a 35% TBSA flame burn when she was three years old. The burn injury was as a result of a shack fire of undetermined origin. Busisiwe sustained burns to her face, scalp, neck, hands, stomach and legs. The burns to her hands were so deep that all her digits had to be amputated. Her facial features have been severely distorted and she also has alopecia as a result of the burn to her scalp. Busisiwe has had several dozen surgical procedures for cosmetic and functional purposes and has been living at St Joseph's Home for seven years.

Carla

Carla is a 15 year old girl who sustained a 25% TBSA flame burn to her face, hands and arms when she was five years old. The fire occurred when a candle fell over and set a carpet alight in the room in which Carla was sleeping. Carla is struggling academically and has failed a grade at school. Her mother describes her as an aggressive and defiant child. Carla claims that her scars do not worry her, but admits that she swims in a tracksuit. Carla is the only participant who refused to be photographed.

Caroline

Caroline is a 21 year old young woman who sustained a 30% TBSA flame burn to the face, scalp, hands and arms at age two years. The fire occurred when a candle fell over and set light to the room in which Caroline was sleeping. Caroline is the oldest

participant in the sample and has lived with the sequelae of the burn injury for 19 years. To this end she proved to be a wealth of information. Caroline has undergone many surgical procedures and has now lost faith in the power of plastic surgery to improve her appearance. Depression has been a lifelong problem for Caroline. She attributes this to her appearance and the social ridicule that it evokes. Caroline attempted suicide as a teenager when she felt that she could no longer cope with the constant barrage of name-calling. She works as a security guard, has a son of two years old, and is unmarried.

Celine

Celine, a recruit from Tygerberg Hospital, is a 12 year old girl who sustained a 10% TBSA contact burn to both feet when she was a year old. The burn injury occurred when Celine walked into a pile of hot ash in order to retrieve a toy. Celine has not yet gained control over her bladder function and has therefore been suffering from enuresis for 11 years. Furthermore, Celine's mother is concerned that her daughter is engaging in sexually promiscuous behaviour as she wanders around late at night without disclosing her whereabouts. Academically, Celine is struggling although she has not failed a grade. Unfortunately Celine's mother responds with physical violence to what she perceives as laziness on her daughter's behalf.

Chantal

Chantal, a Tygerberg Hospital recruit, is an 11 year old girl who sustained a 12% TBSA scald when she was three years old. The burn injury arose when Chantal pulled a kettle of boiling water off the kitchen counter. Her back and buttocks were burned. Chantal's is currently living with her grandmother as her parents have been declared unfit to raise her (both suffer from alcohol and drug addictions and have been physically violent towards Chantal in the past). Chantal is an interesting instance of a child in denial about the extent of her disfigurement: her career ambition is to be a photographic model.

Charlton

Charlton is a 16 year old boy who sustained a 26% TBSA flame burn to his face, back and both arms when he was 13 years old. Charlton and his cousin Andrew (discussed

above) were burned when the former's three year old brother set fire to the mattress on which they were sleeping. Charlton seems to be making good progress at school, but the extent of his self-consciousness regarding his scars is such that he will not wear a short sleeve even in front of his family.

Dion

Dion, a Tygerberg Hospital recruit, is a 16 year old boy who sustained a 15% TBSA scald to his face, neck, arm, chest and stomach when he was a year old. The burn occurred when Dion pulled a jug of boiling water off a table. Dion was the only participant who was accompanied by his father to the interview. Academically, Dion is struggling and has failed two grades. Furthermore, he wants to drop out of school because he feels that he cannot cope with the constant teasing and name-calling that his disfigured appearance evokes.

Donovan

Donovan is a nine year old boy who sustained a 35% TBSA scald to his face, chest, stomach and both hands when he was two years old. Donovan sustained the scald when he pulled a kettle of boiling water off the stove. He presents with serious contractures in both hands that require surgical correction as he is unable to straighten his fingers and cannot make full use of either hand. Donovan has had no plastic surgery in the past.

Francois

Francois is an 18 year old boy who sustained a 2% TBSA scald (hot oil) to the scalp when he was eight years old. The scald was a result of an accident in the kitchen. Francois is one of the few participants who did not require skin grafting for his burn, but has undergone other cosmetic and corrective surgery. As one of the older participants in the study, Francois provided a uniquely mature perspective on the life of a paediatric burn survivor.

Germaine

Germaine is a 14 year old boy who sustained a 14% TBSA flame burn to his stomach, leg and arm when he was nine years old. The burn injury occurred when methylated

spirits was thrown on a fire in order to facilitate combustion. Germaine is struggling at school and truanting on a regular basis. He also appears to be depressed and recently attempted suicide by throwing himself onto the railway tracks near to his home.

Gershwin

Gershwin is a ten year old boy who sustained a 36% TBSA flame burn to his face, back and both arms when he was three years old. Gershwin was burned when a neighbour made a fire in a used glue pot, resulting in an explosion. Gershwin frequently refuses to go to school because of the teasing that he is subjected to. He also suffers from disturbed sleeping behaviour and has fears of being alone, the dark and fire. Furthermore, Gershwin has been caught stealing money from school.

Greg

Greg is a 12 year old boy who sustained a 27% TBSA flame burn to his face, neck, chest, arm and back at age seven years. The fire occurred when petrol was thrown onto a fire to encourage combustion, resulting in an explosion. Greg is a good example of the benefits of an informal school reintegration programme: his classmates and teacher visited him in hospital and the headmaster prepared the school for his return. As such Greg experienced very little teasing or name-calling when he returned to school and even though he missed six months of school, he still managed to achieve good marks at the end of the year. However, since Greg has moved to another school where no such arrangements were made in advance, he has been bullied and teased about his disfiguring scars and his grades have deteriorated.

Hassiem

Hassiem is an eight year old boy who sustained a 30% TBSA flame burn to his hands, scalp, face, legs, arms and face when he was two years old. The burn injury occurred when a candle fell over setting fire to the room in which Hassiem, his sister Neisha (discussed below) and their mother were sleeping. Neisha was also burned in the fire and their mother died in hospital as a result of her burn injuries. Hassiem has had several digits on his one hand amputated and has alopecia as a result of his scalp burns. He is a hyperactive child (he is currently taking Ritalin) and has serious

learning problems, resulting in his transfer to a remedial school. Hassiem is in the care of his grandmother.

James

James is a 17 year old boy who sustained a 13% TBSA flame burn to his face, scalp and both hands when he was a year old. The fire occurred when a candle fell over, setting fire to the room in which James was sleeping alight. James' face is badly scarred and he has had several digits on both hands amputated. James' familial background is a troubled one: his mother is mute and was raped by his father, who despite knowing James, rejected him after the burn accident. Due to these circumstances James was a permanent resident at St Joseph's Home for ten years (an arrangement that enabled him to continue with much needed surgery) before being transferred to the care of his grand-aunt.

Karl

Karl is an eight year old boy who sustained a 25% TBSA flame burn to his face, scalp, back and both arms when he was three years old. Karl was burned when petrol was thrown onto a fire to encourage combustion, resulting in an explosion. His mother describes Karl as an aggressive, nervous and hyperactive child. His sleeping behaviour is disturbed in that he screams in his sleep since the burn injury. Karl is reluctant to attend school because of the teasing that his appearance evokes. It became apparent during the interview that Karl was suffering from tuberculosis. His mother admitted that her two younger children are receiving treatment for tuberculosis, but since Karl is over the age of five and therefore does not qualify for free medical care at the clinic, his mother had decided to leave the condition untreated.

Katrina

Katrina, a Tygerberg Hospital recruit, is a 15 year old girl who sustained a 3% TBSA burn to both feet when she was a year old. Katrina was burned when a candle fell over and set fire to the curtains in the room in which she was asleep. Katrina's self-consciousness about her scars is such that she has dropped out of school because she refused to wear a skirt to school (as this exposed her disfigurement), and the principal of the school would not grant her a concession to wear pants. Katrina's mother is

concerned that her daughter is engaging in sexually promiscuous behaviour because since she has left school, she has befriended girls several years her senior and she wanders around at night without disclosing her whereabouts.

Leanne

Leanne is a 13 year old girl who sustained a 30% TBSA flame burn to her face, chest, stomach and buttocks when she was six years old. The burn occurred when Leanne's father poured turpentine onto the fire to encourage combustion, resulting in an explosion. Leanne is one of the few participants who had the benefit of several years of psychiatric counseling, although it is unclear as to how the psychiatrist came to be involved in Leanne's case. Leanne's parents describe her as a socially withdrawn, depressed and distrustful child since the burn injury. She also cries in her sleep. Leanne is one of the few participants from a two parent home, and the only participant to be accompanied by both parents to the interview.

Lizette

Lizette is a nine year old girl who sustained a 48% TBSA flame burn to her face, scalp, back, chest, stomach and both hands when she was five years old. Lizette was burned when petrol was thrown onto a fire in order to facilitate combustion, resulting in an explosion. Lizette has undergone numerous surgical procedures over the last four years and is beginning to tire of the process. Lizette has not had control of her bladder function since the burn injury. Her mother describes Lizette as both attention seeking and socially withdrawn since the burn injury, behavioural changes which she attributes to the social ridicule that Lizette's appearance evokes.

Loyiso

Loyiso is a 12 year old boy who sustained a 28% TBSA flame burn in a paraffin stove explosion when he was two years old. Loyiso burned his face, scalp, chest and both hands. The burns to the scalp have resulted in alopecia, and Loyiso's facial features are grossly distorted. He has undergone many surgical procedures and has been a permanent resident at St Joseph's Home for ten years.

Natalie

Natalie is an 11 year old girl who sustained a 10% TBSA scald to her neck, chest, face and arm when she was two years old. The scald occurred when Natalie pulled a pot of tea off a table. Natalie has an interesting medical history in that she was born with exomphalus minor, a rare condition where the internal organs are outside of the body, requiring protracted hospitalization for bowel derotation and closure.

Ncanisa

Ncanisa is an 11 year old girl who sustained a 20% TBSA scald to her legs and feet when she was a year old. The scald occurred as a result of a primus stove explosion. Ncanisa's legs and feet are badly scarred and she has contractures over her ankles. Ncanisa's hypertrophic and keloid scarring is no doubt compounded by the fact that she did not wear the pressure garments that were made for her. Ncanisa presents a good example of an instance in which larger concerns supercede the burn injury and its subsequent disfigurement: she and her mother live in abject poverty in a squatter camp and much of the content of their disclosures during the interview focused on financial and safety worries. As such, the burn injury appears to be of secondary importance to their basic survival needs.

Neisha

Neisha is an 11 year old girl who sustained a 40% TBSA flame burn when she was five years old. Her face, feet, legs and chest were burned in the fire. The burn injury occurred when a candle fell over and set fire to the room in which Neisha, her younger brother Hassiem (discussed above) and their mother were sleeping. Neisha's mother died in hospital as a result of her burn injuries. Like Hassiem, Neisha lives with her grandmother as the whereabouts of her father are unknown.

Neville

Neville is an 11 year old boy who sustained a 40% TBSA flame burn to his back, buttocks and both arms when he was five years old. The burn injury occurred when petrol was thrown onto a dying fire in order to facilitate combustion. Neville is a

short-tempered child with violent tendencies: he has threatened to stab his mother several times. Neville has become a pyromaniac since the burn injury and truants on a regular basis.

Nina

Nina is a nine year old girl who at age one, sustained a 50% TBSA scald to both legs. The burn arose as a result of parental neglect: her mother (who was allegedly under the influence of alcohol at the time) plunged the infant into a bath of boiling water without checking the temperature. Nina was only taken to hospital some nine hours after the incident and was subsequently removed from her mother's care. Nina is currently in a loving foster home, although she spent six years in an abusive foster care environment. The whereabouts of her biological parents is not known. Nina displays a variety of serious emotional and behavioural disturbances and appears to have significant remedial problems.

Nomawetu

Nomawetu is a 13 year old girl who sustained a 40% TBSA flame burn to her stomach, chest, arms and face when she was 11 years old. The burn occurred as a result of a paraffin stove explosion. Nomawetu is severely disfigured by the burn injury and according to her mother, has subsequently taken to lying and stealing on a regular basis. Nomawetu and her mother live in conditions of dire poverty, so much so that their primary concerns relate to moving from their shack in Nyanga to a safer home, with electricity, rather than taking action to alleviate Nomawetu's objectively hideous disfigurement.

Olivia

Olivia is a 17 year old girl who sustained a 14% TBSA flame burn to her face, scalp and both hands when she was six years old. Olivia's burns were the result of an attempted family murder in which her father doused her, her infant brother, her grandparents and two cousins in petrol before setting them alight. Olivia and her brother survived, although both were severely burned. Her father, grandparents and cousins died in the fire. Olivia's face is grossly disfigured as a result of the burn and she also has alopecia. Several digits have been amputated from both hands. Since

Olivia comes from Worcester, she resided at St Joseph's Home for eight years following the burn injury in order to receive the treatment that she needed. She has been at home with her mother for the past three years.

Rasheeda

Rasheeda is a 20 year old young woman who sustained a 50% TBSA flame burn to her chest, stomach and arms when she was nine years old. Rasheeda was burned when petrol was thrown onto a braai to facilitate combustion. The burn and subsequent disfigurement have had a profound impact on Rasheeda. She is preoccupied with thoughts that she will never marry because of her scars, and that if she does marry, she will not be able to bear children. In terms of the latter, Rasheeda and her family believe (falsely) that she sustained internal burns to her reproductive organs and that her skin is not sufficiently elastic to tolerate a pregnancy. Rasheeda has limited social skills and shrinks from human contact. She is anxious and depressed, so much so that she admits to contemplating suicide on a daily basis.

Richard

Richard is a 12 year old boy who sustained a 40% TBSA scald to his face, back and both arms when he was four years old. Richard sustained the scald when he fell into a tub of boiling water. Richard has a marked fear of fire and is described as an aggressive child. He has stabbed his older brother twice in response to name-calling about his burn scars. Richard has also threatened to kill himself.

Shane

Shane is an eight year old boy who sustained a 24% TBSA scald to his chest, stomach and arms when he was a year old. The scald occurred when Shane pulled a jug of boiling water off a table. Shane did not require skin grafting for his scald. The most remarkable aspect of the interview with Shane's mother is her overwhelming passivity: although Shane reported teasing and bullying at school, and showed a marked self-consciousness regarding his disfigurement, his mother was not aware of any such problems and claimed that Shane's social adjustment is entirely normal.

Shannon

Shannon is an 11 year old boy who was burned in a shack fire at age one. He sustained a serious 35% TBSA burn to his face, hands, feet, legs, stomach and arms, resulting in the amputation of both feet and one hand. Shannon's face is also severely disfigured and he has lost several facial features as a result of his injuries. Shannon is confined to a wheelchair and is awaiting prostheses for his feet. He has undergone countless surgical procedures and has been a resident of St Joseph's Home for ten years.

Sipho

Sipho is an 11 year old boy who sustained a 35 % TBSA flame burn when he was three years old. He was burned in a shack fire of unknown origin and sustained circumferential burns to both hands; and to his face, neck and scalp. Sipho's face is significantly asymmetrical as a result of the burn injury and he has alopecia. He has undergone several dozen corrective procedures and has been a permanent resident of St Joseph's Home for the past eight years.

Taryn

Taryn is ten year old girl who sustained a 35% TBSA scald to her buttocks, chest, stomach, arms and legs at age two years. Taryn sustained her scald when she fell into a basin of boiling water. She is one of the few participants who did not require skin grafting as a result of her burn and her cosmetic disfigurement is minimal. Taryn was born with a congenital bilateral hearing problem, resulting in slow progress at school.

Tracey

Tracey is a 14 year old girl who sustained a 12% TBSA circumferential flame burn to both thighs when she was ten years old. The burn injury occurred when methylated spirits was thrown onto a braai to facilitate combustion. Several people were injured, but Tracey sustained the most serious burn. Interestingly, Tracey's twin sister who was not home at the time of the burn accident, complained of pain in her legs throughout Tracey's hospitalization.

Wayne

Wayne is a nine year old boy who sustained a 30% TBSA scald to his neck, arm, chest and back when he was a year old. The burn injury occurred when Wayne pulled a kettle of boiling water down onto himself. As a result of the boiling water penetrating his left tympanic membrane, Wayne is partially deaf in one ear and suffers from continuous ear infections. His mother describes him as a destructive and aggressive child.

Yolanda

Yolanda, a Tygerberg Hospital recruit, is a 12 year old girl who sustained a 1% TBSA contact burn (hot ash) to her hand at age three years. Yolanda is in the care of her great-aunt as her own mother is described as an alcoholic vagrant who is suffering from mental illness. The whereabouts of her father are unknown. Yolanda's hand appeared badly contracted at the interview and she was not able to straighten her fingers or use her hand at all. By special arrangement with Prof. Rode, Head of the Department of Paediatric Surgery at the Red Cross Children's Hospital, Yolanda was admitted for a contracture release and skin graft immediately after the interview.

Zolani

Zolani is an 11 year old boy who sustained a 35% TBSA flame burn to his face, scalp, arms, chest and hands when he was five years old. The burn injury came about when Zolani's neighbour made a fire in a used paint tin and added turpentine to facilitate combustion, resulting in an explosion. Zolani's face is severely scarred and he is the object of much social ridicule. Zolani started school late as a result of the burn and has subsequently failed two grades at school. His father, whom he did not know, is deceased, and Zolani lives with his mother.

APPENDIX B

ETHICAL DOCUMENTATION

UNIVERSITY OF CAPE TOWN



Research Ethics Committee

Faculty of Medicine

Anzio Road, Observatory, 7925

Queries : Martha Jacobs

Tel : (021) 406-6492 Fax: (021) 406-6390

E-mail : Martha@medicine.uct.ac.za

14 August 2000

REC REF: 191/2000

Ms L Liebowitz
Psychology

Dear Ms Liebowitz

**DETERMINING THE PSYCHOLOGICAL AND SOCIAL SEQUELAE OF
THERMAL INJURY SUFFERED IN CHILDHOOD: TOWARDS A
COMPREHENSIVE REHABILITATION PROGRAMME FOR PAEDIATRIC
BURN SURVIVORS**

Thank you for your application submitted to the Research Ethics Committee on 28 July 2000.

I have pleasure in informing you that the Research Ethics Committee has **formally approved** the above study 11 July 2000.

You may proceed with the trial once the financial agreement/contract and protocol have been processed through the department of Research Development and duly signed by the authorised University of Cape Town signatories.

Included is a list of Research Ethics Committee Members who have formally approved your protocol.

Please quote the above Reference number in all correspondence.

Yours sincerely

PROFESSOR DM DENT
ACTING-CHAIRPERSON

UNIVERSITY OF CAPE TOWN

RESEARCH ETHICS COMMITTEE 1999/2000



Faculty of Medicine
Anzio Road, Observatory, 7925

1. CHAIR: **Professor P I Folb (Male)**
MBChB, MD, FRCP, FCP (SA)
Professor of Pharmacology; Director: World Health Organization
Collaborating Centre for Drug Policy
2. EX-OFFICIO: **Professor N Padayachee (Male)**
MBChB, MMED (COMM HEALTH) DTM&H DPH DOH DHSM FRSH
MIPH
Dean of Health Sciences Faculty
3. EX-OFFICIO: **Professor A A Forder (Male)**
MBChB, Mmed (Microbiology) Pathology
Professor Medical Microbiology &
Deputy Dean of Medicine
4. EX-OFFICIO: **Dr P Mitchell (Male)**
MBChB, FCP (SA)
Chief Medical Superintendent
5. MEMBER: **Professor D Beatty (Male)**
MBChB, MD, FCP (Paed) (SA)
Professor and Head of Department of Paediatrics & Child Health
6. MEMBER: **Professor SR Benatar (Male)**
MBChB, FFA (SA), MRCP (UK), FRCP (London) FACP (Hons)
Professor and Head of Department of Medicine, Director of
UCT Bioethics Centre
7. MEMBER: **Professor DM Dent (Male)**
MBChB, CHM, FRCS (UK), FCS (SA)
Professor of Surgery
8. MEMBER: **Professor R Kirsch (Male)**
MBChB, MD, Dsc (Med), FCP (SA)
Professor of Medicine, Executive Director of MRC/UCT
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9. MEMBER: **Sr L Mtwisha (Female)**
BA, Diploma in Nursing: Theatre Technique
Matron – Groote Schuur Hospital (Theatre) (Female)
10. MEMBER: **Dr AH Robins (Male)**
MBChB, DPM, MD, MRC (Psych)
Senior Lecturer in Department of Pharmacology (Male)

11. MEMBER: **Ms V Stacey (Female)**
Anglican Chaplain - GSH

CONSENT TO PARTICIPATION IN RESEARCH

I, the undersigned _____ (full name)

mother/father/guardian of _____ (child's name)

hereby grant permission to the researcher, Lesley Liebowitz, to use the information disclosed by myself and my child on the terms discussed and for the purposes explained above, provided that this information remains confidential. I understand that the photographs of my child will become the property of the Red Cross Children's Hospital to be used at their discretion and that I cannot make any claim whatsoever on the Hospital or the Cape Provincial Administration as a result of publicity in this connection.

I declare that I understand the nature and purpose of my own and my child's participation in this research and consent to such participation.

Signature: _____

Date: _____

FOR OFFICE USE ONLY

Parent's initials: _____ Parent participant #: _____

Child's initials: _____ Child participant #: _____

Contact telephone number: _____

Comments

APPENDIX C

THE INTERVIEW SCHEDULE

INTERVIEW SCHEDULE

1. DEMOGRAPHIC INFORMATION (CHILD)

- 1.1 Date of birth
- 1.2 Present age
- 1.3 Age at time of burn
- 1.4 Residential area
- 1.5 Home language
- 1.6 Interview language
- 1.7 Racial classification as per medical folder
- 1.8 Family structure – siblings, parents, extended family
- 1.9 Living arrangements
- 1.10 School attendance (if eligible)
- 1.11 Grade/standard at school
- 1.12 Employment status (if eligible)

2. DEMOGRAPHIC INFORMATION (CAREGIVER)

- 2.1 Date of birth
- 2.2 Present age
- 2.3 Home language
- 2.4 Interview language
- 2.5 Race as per medical folder
- 2.6 Educational status
- 2.7 Employment status
- 2.8 Living arrangements
- 2.9 Monthly income
- 2.10 Relationship to child
- 2.11 Marital status
- 2.12 Number of dependents
- 2.13 Medical history

3. MEDICAL HISTORY AND INFORMATION RELATING TO BURN INJURY

- 3.1 Cause of burn injury

- 3.2 Description of events surrounding burn injury
- 3.3 Fatalities or other injuries arising from incident
- 3.4 First aid administered
- 3.5 Length of time since burn injury
- 3.6 Locus of burn
- 3.7 Severity of burn
- 3.8 Skin grafting or other surgery during initial hospitalization
- 3.9 Subsequent hospitalization for further plastic surgery
- 3.10 Post-discharge treatment: clinic attendance, pressure garments and splints
- 3.11 Most recent clinic visit
- 3.12 Use of local doctor or clinic
- 3.13 Other medical history

4. THE BURN INJURY (CHILD)

- 4.1. Can you tell me what happened when you got burned?
- 4.2. How did you feel?
- 4.3. What did you do?
- 4.4. Who helped you?
- 4.5. Do you still think about it?

(CAREGIVER)

- 4.6 Do you remember what happened when the child was burned?
- 4.7 How did you feel?
- 4.8 What did you do?
- 4.9 Who helped you?
- 4.10 Do you still think about it?

5. HOSPITALIZATION EXPERIENCE (CHILD)

- 5.1 Tell me about the experience of being in hospital for your burn
- 5.2 Do you remember the hospital?
- 5.3 What happened to you while you were in hospital?
- 5.4 How did you feel?
- 5.5 Did your parents come and visit you?
- 5.6 Did your friends visit you?

- 5.7 Did you like that?
- 5.8 What did you like the least about the hospital?

(CAREGIVER)

- 5.9 Tell me about the time when your child was in hospital.
- 5.10 How long did she stay for?
- 5.11 How did you feel?
- 5.12 What worried you the most?
- 5.13 Did you visit your child? How often?
- 5.14 Did other members of the family visit your child? How often?
- 5.15 If not, why not?
- 5.16 Did the child's friends visit her in hospital? How often?
- 5.17 If not, why not?
- 5.18 Did the child have any contact with his school friends and teacher while he was in hospital?
- 5.19 How was this arranged?
- 5.20 Did your child have to have operations? What kind?
- 5.21 Did your child have to go to Sarah Fox after the hospital?
- 5.22 For how long?
- 5.23 Did your child go to St Joseph's Home? For how long?

6. RETURNING HOME (CHILD)

- 6.1 Do you remember going home from the hospital?
- 6.2 How did you feel? Were you scared? Why?
- 6.3 Did you have to wear pressure garments and splints?
- 6.4 Did you use them?
- 6.5 Did you have exercises to do?
- 6.6 Did you do them? Why not?
- 6.7 How did your family react when you got home?
- 6.8 How did your friends react when you got home?
- 6.9 Did they come and visit you?
- 6.10 Did they say anything that made you feel sad or happy?

6.11 What did you do those first few weeks that you were at home?

(CAREGIVER)

6.12 Tell me about taking your child home. How did you feel?

6.13 What was worrying you the most?

6.14 How did the rest of the family react?

6.15 How did your friends react?

6.16 How did the child's friends react?

6.17 Did you have splints and pressure garments to take home for him to wear?

6.18 Did you use them? Why not?

6.19 Did you have exercises for him to do?

6.20 Did you do them? Why not?

6.21 What was your child's behaviour like those first few weeks that he was at home?

6.22 Did you have to make new arrangements for your work and your living arrangements to accommodate looking after your child?

6.23 How did this affect you?

6.24 Did you have support from the community during this time?

6.25 How did the child keep up with her schoolwork?

7. RETURNING TO SCHOOL (CHILD)

7.1. Do you remember going back to school?

7.1 Did you miss a lot of work?

7.2 What was it like being back at school?

7.3 Did anybody tease you or bully you?

7.4 Did you get help from your teacher?

(CAREGIVER)

7.5 Tell me about your child going back to school.

7.6 How long after the burn injury did he go back?

7.7 What happened?

7.8 Was he teased or bullied?

7.9 How did he react to this?

- 7.10 Did you get help from the child's teacher or the principal?
- 7.11 Did the teacher ever tell you that anything was wrong with the child?
- 7.12 Did you do anything about the teasing e.g. talking to other parents
- 7.13 Did your child refuse to go to school?

8. DISFIGUREMENT (CHILD)

- 8.1 Tell me about your scars from the burn?
- 8.2 Do they worry you?
- 8.3 Why?
- 8.4 What worries you about them?
- 8.5 Do people say nasty things to you?
- 8.6 Who? Friends, family, strangers?
- 8.7 What sorts of things do they say?
- 8.8 How do you react?
- 8.9 Do you think that the scars are improving?
- 8.10 Have you had plastic surgery for the scars?
- 8.11 Would you like to have more surgery?
- 8.12 Which part of the scars are the worst for you?
- 8.13 Why?
- 8.14 Do the scars prevent you from wearing certain clothes or swimming?
- 8.15 Do they prevent you from taking part in sports?
- 8.16 Are you embarrassed to show other people your scars?
- 8.17 Who are you embarrassed in front of?
- 8.18 Do you mind if someone asks to see your scars?
- 8.19 Do you mind if someone asks you what happened to you?
- 8.20 What do you say?
- 8.21 Do people stare? Who? When?
- 8.22 Do you say anything? What?

(CAREGIVER)

- 8.23 Tell me about the child's scars from the burn.
- 8.24 Do they worry you? In what way?
- 8.25 Do they worry him? In what way?

- 8.26 How do people react to the scars? (Family, friends and strangers)
- 8.27 What sorts of things do they say?
- 8.28 What do you say when this happens? How do you react?
- 8.29 Do you think that the scars are improving?
- 8.30 Do you think that he should have (more) plastic surgery?
- 8.31 Which part of the scars do you think are the worst?
- 8.32 Why?
- 8.33 How do you think your child feels about these scars?
- 8.34 Do the scars prevent him from playing sports or swimming or wearing certain clothes?
- 8.35 Are you embarrassed when people ask what happened? How have you told him to react?
- 8.36 How does he react?
- 8.37 What would you say if someone asked to see his scars or asked what happened?
- 8.38 Do people stare?
- 8.39 Do they say anything in response? How do you react in this sort of situation?
- 8.40 Have you taught your child to handle these situations in any specific way?

9. PHYSICAL DISABILITY (CHILD)

- 9.1 How has your burn injury affected what you can and cannot do in terms of sport or hobbies or dressing yourself or going out?
- 9.2 Can you look after yourself or do you need to be looked after?

(CAREGIVER)

- 9.3 Has the burn injury affected the kind of activities that your child can participate in?
- 9.4 Does he need to be looked after all the time?

10. BEHAVIOURAL AND EMOTIONAL PROBLEMS (CHILD)

- 10.1 Have you had any counseling or help about how to deal with your scars and burn injury?
- 10.2 From whom?
- 10.3 When?

- 10.4 What were you told?
- 10.5 Did it help?
- 10.6 What sorts of difficulties do you have?
- 10.7 Examples, frequency, severity of problem, approximation of onset, possible precipitators
- 10.8 How do you cope/what do you do when this happens?
- 10.9 What makes it better?
- 10.10 Who do you talk to now if something is bothering you?

10.11 SLEEPING BEHAVIOUR

- Do you sleep through the night?
- Do you have nightmares?
- What are they about?
- What do you do?
- Do you sleepwalk?
- Do you take naps during the day?
- Do you have difficulty falling asleep at night?

10.12 BLADDER AND BOWEL CONTROL

- DO YOU WET YOUR BED? AND DURING THE DAY?
- DO YOU SOIL YOUR PANTS? AND DURING THE DAY?

10.13 EATING BEHAVIOUR

- Do you eat well? Have you got a good appetite?
- Have you put on weight? Or lost weight?
- Do you eat a lot of junk food?

10.14 NERVOUS BEHAVIOUR

- Do you bite your nails?

- Do you stutter or stammer?
- Do you fidget?
- What is your concentration like?
- Are you restless or overactive? Do you have problems sitting still?
- Do you suck your thumb?

10.15 SOCIAL BEHAVIOUR - PEERS

- Tell me about your friends.
- Do you have friends at school?
- In the neighbourhood?
- Do your peers tease you?
- Do your peers bully you?
- Do you think that you are lonely? Why?
- Do you bully other children? When? Why? Which children?
- Do you play sports at school?
- Do you have hobbies?
- Do you belong to any organizations?
- Who is your best friend?
- What do you do together?

10.16 SOCIAL BEHAVIOUR - SIBLINGS

- How do you get along with your siblings?
- Do you fight? Why?
- How are these issues resolved?

10.17 SOCIAL BEHAVIOUR – TEACHERS

- Do you get on with your teachers?
- Are there problems at school?
- What? How do you deal with these problems?

10.18 SOCIAL BEHAVIOUR- PARENTS

- How do you get along with your parents?
- Are you obedient or defiant?
- Are you close to them?
- Would you tell them if you had a problem?
- Who would you tell?
- What are the problems?

10.19 SOCIAL BEHAVIOUR – OTHER

- Are there any other adults that you are close to?
- Would you confide in them?

10.20 EMOTIONAL INDICATORS

- Are you a happy child?
- Are you often miserable?
- What makes you miserable/happy?
- How do you show it?
- Do you think that people are against you?
- Do you have self-confidence?
- Do you get worried easily?
- What worries you?
- Do you have temper tantrums?
- Are you fussy about having clean hands, or having anything in a particular order?
- What are you scared of? Dogs? Night time? Changing in front of others? Crowds?
- What do you do in these situations?
- Do you have a problem meeting new people?
- Are you afraid to be left alone in the house?
- Are you destructive? What do you destroy?
- Do you tell lies?
- Do you steal?

- Do you drink?
- Do you take drugs?
- Do you smoke cigarettes?
- Do you bunk school?
- Have you ever run away from home?
- Do you ever get into fights?
- Do you ever talk about killing yourself or dying?
- Have you ever tried to kill yourself?
- Is there any physical or sexual abuse in the family?
- Have you ever been in another accident or witnessed one?
- Or a crime?
- Do you have somatic complaints like headaches or stomach aches?
- Do you express fears that something terrible will happen to you or the people that you love?
- Do you hear voices or see things that no one else can hear or see?
- Who would you go to if you had a problem?

10.21 REPEAT AND REPHRASE ALL QUESTIONS FROM 10.1 TO 10.20 FOR CAREGIVER

- Add in questions about caregiver's reactions to each of the emotional or behavioural problems with which the child presents

11. SELF PERCEPTION (CHILD)

- 11.1 How do you feel about yourself?
- 11.2 What do you like about yourself?
- 11.3 What do you not like about yourself?
- 11.4 What do you wish you could change?
- 11.5 If you had three wishes what would they be?
- 11.6 What do you wish for your future?
- 11.7 Do you have any concerns about your future?
- 11.8 What career would you like to follow one day? Why?

12. SEXUAL AND ROMANTIC RELATIONSHIPS (CHILD – IF APPROPRIATE)

- 12.1 Do you have a boyfriend or girlfriend?
- 12.2 What do you do together?
- 12.3 How did you meet?
- 12.4 Are there problems in your relationship? What are they?
- 12.5 Do your problems have to do with your scars?
- 12.6 Do you think that you will marry some day?
- 12.7 Do you want to have children?

(CAREGIVER)

12.8 REPEAT AND REPHRASE ALL QUESTIONS FROM 11.1 TO 11.7 FOR CAREGIVER AND ENCOURAGE DISCUSSION AROUND CHILD'S FEELINGS ABOUT HIS/HER BODY

13. SOCIAL SUPPORT (CHILD AND CAREGIVER)

- 13.1 Who does the child talk to if he has a problem?
- 13.2 Who does the caregiver talk to if she has a problem?
- 13.3 What is the marital relationship like?
- 13.4 Is there any extended social support network?
- 13.5 Is there any community support?
- 13.6 Is the family religious? Do they get support from the church?
- 13.7 Does the family participate in recreational activities?
- 13.8 Who would the family turn to if they needed assistance?

14. THE FUTURE (CHILD AND CAREGIVER)

- 14.1 What would have made this ordeal easier for you?
- 14.2 What do you need to help you now?
- 14.3 What advice would you give to other children who have been burned?
- 14.4 What advice would you give to the parents of other children who have been burned?

14.5 What sort of future do you think your child has?

14.6 What is your biggest concern about the future?

15. ASK CHILD AND CAREGIVER FOR QUERIES AND CLARIFICATION