

SOCIO-ECONOMIC AND CLINICAL FACTORS PREDICTIVE OF PAEDIATRIC QUALITY OF LIFE POST BURN INJURY

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ABSTRACT

Trauma is the leading cause of death in children. Burns represent the second most common cause of accidental death in children under the age of five. Burns are amongst the most traumatic injuries and may impose significant psychological, educational, social and future occupational impairments to the young child.

Quality of life post discharge from a South African hospital is poorly researched. It is also not known whether poor socio-economic factors contribute to the high incidence of children with burn injuries who are admitted to the Paediatric Burns Unit. This cross-sectional study aims to determine the socio-economic and clinical factors which predict quality of life in children with burn injuries in a burns unit in South Africa.

The Paediatric Quality of Life Inventory (PedsQL) and the Household Economic and Social Status Index (HESSI) questionnaires were administered to children and their caregivers one week post discharge and three months post discharge from the Johnson and Johnson Paediatric Burns Unit, Chris Hani Baragwanath Hospital, Soweto.

The findings of this study show that children three month post discharge from a burn injury have a minimally lower score in quality of life than the expected normal score. The improvement in the PedsQL overall scores suggests that the quality of life for children is good despite being burnt. The severity of the burn (partial thickness and full thickness) was found to be a significant clinical predictor of quality of life ($p=0.00$). The poor socio-economic status was clearly evident in demographic data of the subjects. A marginally significant socio-economic predictor of quality of life was family problems reported by some of the mothers ($p=0.07$). To some extent this highlights the increased risk of burn injury where there are poor socio-economic circumstances.

The results from this study are particularly important in identifying areas for further research that would be beneficial to developing countries and in particular South Africa. There has been limited research done on paediatric burn injuries locally and so there is a large gap in the literature on paediatric burn injuries in South Africa. Furthermore, the results from this study will contribute to the development of a more comprehensive rehabilitation and management program for children suffering burn injuries in South Africa.

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Johnson and Johnson for their support in the burns unit and with this project.

DECLARATION

I declare that this research report is my own unaided work, except to the extent indicated in the reference citation and acknowledgements. It is being submitted in partial fulfilment of the requirements of the degree of Master of Science (Physiotherapy) at the University of the Witwatersrand. It has not been submitted before for any other degree or examination in any other University.

Merryn Weedon

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LIST OF ABBREVIATIONS

ADL	-	Activities of Daily Living
ANOVA	-	One Way Analysis of Variance
HESSI	-	Household Economic and Social Status Questionnaire
HRQOL	-	Health Related Quality of Life
MODS	-	Multiple Organ Dysfunction Syndrome
PedsQL	-	Pediatric Quality of Life Inventory
QLQ	-	Quality of Life Questionnaire
SF-36	-	Short Form 36
WHO	-	World Health Organisation

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Chapter 1: INTRODUCTION

Trauma is the leading cause of death in children (Lakhoo, 1995). Burns represent the second most common cause of accidental death in children under the age of five (Lakhoo, 1995). Burns are amongst the most traumatic injuries and may impose significant psychological, educational, social and future occupational impairments to the young child (van Niekerk, 2007).

Burns occur most frequently in children aged one to five years old. Young adults and children under the age of five years have the highest risk of death from burn injury (Morrow, 1996). Hot liquid burns (hot water, tea and oil) are the most common and regularly occur in the home. Flame injury normally results in a larger body surface area being burnt (Leong, 1995). In South Africa burns from fire, paraffin stove explosion and torched homes are common with the increasing urban informal settlement (Lakhoo, 1995). Toddlers and infants have been associated with increased number of burns due to their curiosity of the environment and an increased yet still evolving and unstable ability to explore their environment (Van Niekerk, Rode and Laflamme, 2004). Boys have also been associated with an increased risk of burn injury due to their mischievous nature and greater activity levels compared to those of girls (van Niekerk, 2007; Kai-Yang, Zhao-Fan, Luo-Man, Yi-Tao, Tao, Wei, Bing, Jie, Yu and Yu, 2008). However, it has been shown that older girls have a higher risk due to their domestic activities (Van Niekerk, Rode and Laflamme, 2004; Piazza-Waggoner, Dotson, Adams, Joseph, Goldfarb and Slater, 2005). During the winter season it has been reported that there is a higher incidence rate. This is to be expected as families are exposed to the cold weather and attempt to keep warm by lighting fires or using heaters (Van Niekerk, Rode and Laflamme, 2004).

Statistics taken from the Johnson and Johnson Paediatric Burns Unit Admissions Register, Chris Hani Baragwanath Hospital (Soweto, Johannesburg) illustrate the highest number of admissions to the unit was in the months May to August in 2006 and 2007

(Appendix Ia and Ib). Furthermore the most common cause of burn injury was hot water burns followed by open flame burns in 2006 and 2007 (Appendix Ic and Id).

Results from a study done in Karachi, India, showed that socio-economic factors such as overcrowding in poor housing conditions, lack of proper medical facilities and ignorance were found to be the most important cause of burns (Kildal, Willebrand, Anderson, Gerdin and Ekselius, 2004). In South Africa, the African group has been reported to have lower income levels, literacy rates and overall health status and higher levels of overcrowding in housing. This results in a lower educational level of mothers, lower socio-economic status of the families, and psycho-stress in the families. These have all been linked to an increased risk of paediatric burn injuries (Van Niekerk, Rode and Laflamme, 2004).

In South Africa admission management for a child includes fluid management, pain relief, wound care, prevention of infection, surgical management, nutritional support, prevention of complications, rehabilitation and psychological support (Lakhoo, 1995). The depth (superficial, partial or full-thickness) and site of the injury affects the prognosis. Other medical conditions, associated injuries and the very young ages of the children may exacerbate the burn injury (Leong, 1995).

It is important to implement a holistic and comprehensive management by a multi-disciplinary team including doctors, nursing staff, social workers, speech therapists and audiologists, dietary, occupational and physiotherapy throughout rehabilitation from admission to scar maturation. Positioning is an important aspect of wound care (Lakhoo, 1995) and is currently undertaken by the nursing staff, occupational and physiotherapists in the Chris Hani Baragwanath Hospital Paediatric Burns Unit. Once the patient is medically stable occupational and physiotherapists are involved in the daily active rehabilitation of the patient. Other multi-disciplinary team members involved in the unit include daily input from paediatric surgeons and dietitians. Input from social workers, audiologists and speech and language therapists are on a referral basis only when required.

The fear of permanent disability and the family's guilt may hinder the healing process. Support is fundamental in preserving the child's self-esteem and returning him/her to society as a functional person (Leong, 1995). Adult survivors may experience acute psychological distress and this may be similar in older children post burn injury. This may indicate a need for a mental health professional to provide assessment and necessary intervention in a specialised burns unit (Fauerbach, Lezotte, Hills, Crones, Kowalske, de Lateur, Goodwin, Blakeney, Herndon, Wiechman, Engrav and Patterson, 2005). Children with severe burn injuries over 40% body surface area often experience chronic disabilities and have a high potential of developing diseases related to poor quality life style (Cucuzzo, Ferrando and Herndon, 2001). However, it has also been found that children who suffered severe burns did not necessarily experience a different quality of life to those who had not been burnt (Sheridan, Hinson, Liang, Nackel, Schoenfeld and Ryan, 2000). It has been suggested that initially children with light to moderate burns had a reduced quality of life one month post burn, however these children showed improvements after twelve months post burn injury. Furthermore, the majority of children with burn injuries regained functionality or regained function to the level prior to the injury although some persisted with long term problems such as pain, scars and cognitive problems (Blakeney, Robert and Meyer, 1998). This research supports the motivation for a mental health care professional to be involved in the holistic treatment of children with burns and to provide support and guidance for burn survivors (Meyer, Blakeney, Russell, Thomas, Robert, Berniger and Holzer, 2004).

PROBLEM

There has been limited documented research in South Africa on quality of life in paediatric burn survivors and it is unknown what the quality of life is post hospitalisation for children with burn injuries. Literature shows variable quality of life for children post burn injury in First World Countries but this could be considerably different in South Africa due to the varying socio-economic statuses. As very little is done in the way of psychological and social support intervention it is not known to what extent patients would benefit from this additional treatment. Clinical factors including cause, percentage

and severity of burn as well as socio-economic factors may have an influence on quality of life outcome. It is also uncertain why the Paediatric Burns Unit has the current numbers of injuries.

QUESTION STATEMENT:

What are the socio-economic and clinical factors which predict quality of life in children with burn injuries?

AIM OF THE STUDY:

The main aim of this study was to determine the socio-economic and clinical factors which predict quality of life in children with burn injuries.

STUDY OBJECTIVES:

- i. To determine the quality of life in children post burn injury.
- ii. To determine the socio-economic factors which predict quality of life.
- iii. To determine the clinical factors which predict quality of life.

SIGNIFICANCE OF STUDY

Currently there is limited evidence in South Africa as to whether socio-economic and clinical factors predict quality of life in children post burn injury. It is also not known whether poor socio-economic factors contribute to the high incidence of children with burn injuries who are admitted to the Johnson & Johnson Paediatric Burns Unit.

The Burns Unit at Chris Hani Baragwanath Hospital represents a typical burns unit found in tertiary hospitals in South Africa, thus the results will have an impact not only on the management and intervention provided at our hospital, but also on that provided by physiotherapists nationwide. The results from this study will contribute to the development of a more comprehensive rehabilitation and management program for children suffering burn injuries.

Chapter 2: LITERATURE REVIEW

This literature review discusses burn injury, childhood burns, epidemiology of burns, acute management, rehabilitation as well as long-term outcomes of burn injury. Socio-economic factors that affect burn injury will also be discussed. The literature was obtained through comprehensive searches on major data bases (PubMed & Medline). Keywords used in the searches were: Burns, Childhood Burns, Socio-economic Factors and Burns, Burn Management, Burn Rehabilitation, Psychosocial Impairments. A hand search was conducted at the Health Sciences Library of the University of the Witwatersrand.

Burn injuries are a serious threat to young children worldwide. Paediatric burns warrant special attention as they can have long term sequelae affecting physical function, personality, behaviour and general development.

2.1 Burn Injury in Children versus Adults

The burn wound is the same, whether it occurs in an adult or a child, but the management of a paediatric burn differs significantly from that of an adult burn (Reid, 1996). The most obvious differences between adults and children are in size and body proportion. Infants have a larger cranial surface area with less area in the extremities than do adults (Rutan and Benjamin, 1996). There are also physiological differences between children and adults which must be considered when treating the paediatric patient, particularly in fluid resuscitation. Paediatric patients with burns should be resuscitated using formula's based on body surface area and not weight-based as routinely practised with adults with burns injuries (Rutan and Benjamin, 1996).

As a result of skin varying in thickness in different parts of the body, application of the same intensity of heat for given periods of time results in different burn depth on different areas of the body. Therefore, in the young child where dermal papillae and appendages have yet to fully develop, deeper burns result from heat

of the same intensity that produces a moderate partial thickness burn in the adult (Campbell, 1996).

2.2 Epidemiology

2.2.1 *Gender and Distribution of Age*

Burns occur most frequently in children aged one to five years old and young adults. Children under the age of five years have the highest risk of death from burn injury (Iregbulem and Nnabuko, 1993; Morrow, 1996); furthermore infants under the age of one year old are at the most risk of burn injuries (Nguyen, Tobin, Dickson and Potokar, 2008). A study in 2008 in China concluded that children had a higher prevalence of burn accidents in comparison with adults. Moreover children aged three years and less (toddlers and infants) had a higher prevalence of burn accidents in comparison with those aged over three years (Kai-Yang et al, 2008). An explanation for this may include negligence of younger children and the immature, still-developing infants' skin is more vulnerable and so this age group of children should be more carefully supervised to prevent burn injuries (Xiang et al in Kai-Yang et al, 2008).

Common causes of burn injury change as a child progresses through the normal stages of development (McLoughlin and McGuire, 1990). Infants can be scalded while being bathed by an unfamiliar caregiver, toddlers are characterised by curiosity of their environment and an increased yet still evolving and unstable ability to explore their environment (Van Niekerk, Rode and Laflamme, 2004). These infants are at risk from spilled hot foods and drinks, hot water, household electrical current, caustic chemicals and hot surfaces like irons and wood-burning stoves (McLoughlin et al, 1990). The number of burn injuries begin to increase again when adolescence is reached (Forjuoh, 2006) with the increased exposure and involvement with heating appliances and flammable substances (Van Niekerk, Rode and Laflamme, 2004). Older children are exposed to a greater range of high-risk activities such as cooking, an indication of greater mobility and

social independence. Activities which are common for children in low-income settings, which increase their risk of burn injuries, are the gathering of firewood and the lighting of fires for morning and evening meals (van Niekerk, 2007).

Boys are hospitalised due to burn injuries more frequently than girls as a result of their mischievous nature and greater activity levels compared to those of girls (Van Niekerk, Rode and Laflamme, 2004; van Niekerk, 2007; Kai-Yang et al, 2008). Burd and Yuen (2005) stated that both sexes are affected by flame burns however boys are more at risk of burn injury. However it has been documented that after the age of four years, girls have a higher risk because of their involvement in domestic activities near open flames and because of clothing styles (Kalayi and Muhammad, 1994; Delgado, Ramirez-Cardich, Gilman, Lavarello, Dahodwala, Bazan, Rodriguez, Cama, Tovar and Lescano, 2002; Van Niekerk, Rode and Laflamme, 2004; Piazza-Waggoner et al, 2005). Nonetheless boys up to the age of four years old have regularly been associated with an excess risk of burn injuries compared to girls due to their own behaviour, rather from an accident (Van Niekerk, Rode and Laflamme, 2004; Piazza-Waggoner et al, 2005; van Niekerk, 2007; Kai-Yang et al, 2008).

2.2.2 *Causes of Burns*

Hot liquid scalding burns (hot water, tea, porridge, soup and oil) are the most common comprising 59% to 92% of all cases, followed by flame, electrical and chemical burns respectively (Kai-Yang et al, 2008). Scalds in younger children typically occur in the home and are caused by saucepans, kettles, taps, stoves, hot beverages, irons and heaters (Banco, Lapidus, Zavoski and Braddock, 1994). Firecracker injuries may occur when children are playing unsupervised and as a result may get burned easily. Common firework injuries are to the hands and eyes, sparklers were responsible for most of the burn injuries (Fogarty & Gordon, 1999).

Fire disasters occur every day in South Africa (City of Johannesburg Emergency Management Services, Fire Safety and Emergency Planning Guideline) resulting in larger body surface area flame injuries (Leong, 1995).

Child abuse is a well recognised cause of injury in children up to the age of four years (Campbell, Van Der Linden and Palisano, 1996). Furthermore neglect is much more common than abuse and is directly related to the education and awareness of the caregiver (Golden, Samuels and Southall, 2003). A systematic review of the features that indicate intentional scalds in children showed hot tap water burns affecting the extremities, buttocks and/or perineum were the most common immersion pattern of injury (Maguire, Moynihan, Mann, Potokar and Kemp, 2008). Chester, Jose, Aldlyami and Moiemmen (2006) researched non-accidental burns in children, “Are we neglecting neglect?” Their retrospective study showed parental drug abuse, single-parent families, delay to presentation and a lack of first aid were statistically more prevalent in the ‘neglect’ group than in the ‘accidental group’. Children in the ‘neglect’ group were also statistically more likely to have deeper burns and require skin grafting. This study showed that burning by neglect is far more prevalent than abuse.

2.2.3 *Severity of Burn*

Burn depth depends upon the amount of heat transmitted to the skin. This depends on two elements: the temperature of the flame, hot liquid or solid and the duration of the exposure (Latarjet, 1995). Burns are classified by three degrees of burn: superficial, partial thickness (moderate) or full (severe) thickness according to the depth of tissue damage. The deeper the burn the more severe the burn is, superficial burns heal spontaneously if correctly treated, while deep burns require grafting (Latarjet, 1995). A second degree burn is where the epidermis is partially burnt through and blistered and deeper burns may extend into the fascia, muscle or bone (Campbell, 1996). Additionally, all burns involving the special areas such as the face, ears, eyes, hands, feet, perineum, all inhalation injuries, circumferential burns, electrical injuries, neo-natal burns and burns in patients

with pre-existing disease are considered to be moderate to severe injuries (Campbell, 1996). Post burn injury there may be different burn depths on different areas of the body which results from skin varying in thickness in different parts of the body (Campbell, 1996).

Patients with superficial and partial thickness burns with less than five percent body surface area may be treated as outpatients (Leong, 1995). Moderately severe uncomplicated burns may be treated in a community hospital by an experienced surgeon or physician. Burns that should be referred to a burn unit include larger second-degree burns (greater than 25% in adults or 20% in children). All third-degree burns greater than 10%, burns of special areas and burns with associated injuries, including inhalation or electrical injuries, fracture or other trauma should also be referred to a burn unit (Campbell, 1996).

Kai-yang et al (2008) reports that the highest proportion of burns were of moderate severity and the lowest proportion were of critical severity. Godwin, Hudson and Bloch (1996) showed the average area of the body surface burned by shack fires in adults was 31% and two-thirds of these patients had third degree burns. Sixty-one percent of these patients also sustained smoke inhalation injury and 40% of them died as a result of their injuries. These statistics highlight the severity of shack fire burns in adults yet equally probable in paediatrics.

2.2.4 *Anatomical Sites of Burns*

The larger the damaged area, the more severe the burn is, taking into account burn depth. The extent of burn injury can be estimated in several ways. One approach is referred to as the 'rule of nines', which divides the body into areas, each representing nine percent or a multiple of nine percent of body surface area. This method is particularly unreliable in children younger than 15 years of age because it underestimates burned areas of the head and neck and overestimates areas of the legs (Solem, 1984 in Campbell et al, 1996). Another method, the Berkow chart is modelled after Lund and Browder's work (1974), which recognises that the

proportion of body surface covering specific body parts changes with age. For example, the head and neck of an infant constitute 20% of the body surface area compared with nine percent in the adult (Campbell et al, 1996).

Burns involving muscle, tendon or bone are most common on digits, hands, feet and over bony prominences such as the iliac crest, patella, anterior tibia and cranium as these areas have only a thin covering of subcutaneous tissue (Solem, 1984 in Campbell et al, 1996).

Certain burn patterns are indicative of possible abuse, such as burns of the buttocks, feet and perineum when the backs of knees and anterior hip areas are not burned (Doane, 1989 in Campbell 1996). This typically occurs when a child is placed in a bath of hot water and the child flexes into a protective position by curling up the hips and knees.

It appears that the extremities have the highest proportion of burns in hospitalised patients (Jia et al, 2002 in Kai-Yang et al, 2008) however there is no consensus in the literature whether the upper limbs or the lower limbs specifically are more affected by burn injury. The head and neck are also common areas of burn and require considerable care and vigilance by the rehabilitation team to prevent potential contractures that may occur (Serghiou, Holmes and McCauley, 2004). Devastating burns to the head and neck have a large impact in patient's functional recovery as well as cosmetic and psychological implications. The basic abilities to see, hear, breathe and communicate verbally or nonverbally may become affected as a direct result of the burn or the scarring that occurs as the burn wounds heal (Serghiou et al, 2004). Facial burn scars also can become a challenge while performing the activities of daily living. In addition to the functional limitations, the patient's self-image may be altered, leading to considerable psychological problems with self-esteem and self-confidence (Serghiou et al, 2004).

2.2.5 *Type of Residential Area and Place of Injury*

Burn injuries that occur in the home account for over 80% of all childhood burn injuries in developed countries and over 90% of all childhood burn injuries in developing countries (Lari, 2002). Electrical appliances, space heaters, furnaces, fireplaces, kitchen stoves and hot plates, cigarettes, matches and lighters, faulty or outdated wiring and candles are all examples of potential sources of fire in the home. The ignitable fuels in homes include mattresses, furniture, flammable liquids, propane, natural gas, drapes and carpets (McLoughlin & McGuire, 1990).

In South Africa burns from fire, paraffin stove explosions and torched homes are common with the increasing urban informal settlement (Lakhoo, 1995). Burn injuries that occur in informal dwellings are often severe. These structures are commonly referred to as 'shacks' and have occurred as a consequence of urban migration and are common in major cities of South Africa (Godwin et al, 1996). These structures are built in informal settlements without proper town-planning, with cramped living quarters; they are made of highly combustible and toxic materials such as painted wood or plastics and are assembled close to one another (Peck, Kruger, van der Merwe, Godakumbura and Ahuja, 2008).

In a rural area of South Africa, the average interval from the time of burn to arrival in the hospital was estimated to be 42 hours (www.who.int). This results in delay of treatment for the burn wounds, possibly increases the risk of secondary complications and may have a negative effect on prognosis. No literature was found on epidemiology of burn injury in rural areas in South Africa, however in a study carried out in China, children from the rural areas accounted 1.6 to 12.94 times more than hospitalisations from the urban areas. Reasons for this include there are more people living in the countryside in China as well as urban families comply with the one-child policy and so they are more likely to be more cautious (Kai-Yang et al, 2008). Studies on burn management and epidemiology from the

rural areas in South Africa would be beneficial and interesting to compare with local studies done in urban areas.

Kai-Yang et al (2008) comments that the majority of burn injuries occur indoors (1.62 to 17 times the rate of injuries that occur outdoors) and that this is likely due to younger children living and playing mainly indoors. Other studies, particularly those reported by Forjuoh, Guyer and Smith (1995), Fernandez-Morales, Galvez-Alcaraz, Fernandez-Crehuet-Navajas, Gomez-Grazia and Salinas-Martinez (1997), and Panjeshahin, Lari, Talei, Shamsnia and Alaghebandan (2001) have showed that indoor burns occurred mainly in the kitchen and bathroom. Van Niekerk, Seedat, Menckel & Laflamme (2007) comment how caregiver's testimonies emphasise the involvement of necessary communal tasks, including chores, child care, unexpected events, crises and work and this may decrease the caregiver's ability to supervise and protect the child in hazardous home environments.

Kai-Yang et al (2008) found that most of the burn injuries occurred in peak hours between 12:00 to 13:00 and 17:00 to 20:00 and thought this had to do with mealtimes. Forjuoh et al (1995) found two peak times for burn injury, firstly the late morning period after breakfast when children had been left at home. The second peak time for burn injury was around the evening meal time. Van Niekerk (2007) comments on Pedan's (1997) findings in a study in Cape Town, South Africa that sleep times and just after children returned home from school were peak times for scalding injuries to occur.

2.2.6 Seasonal Variation in Burn Injury

There is a lack of consensus in the literature which season has higher incidence rates of burn injury. This may be due to the varying causes of burn injury in the different countries. Carroll, Gough, Eadie, McHugh, Edwards and Lawlor (1995) in Ireland and Delgado et al (2002) in Peru report that burns occur most frequently in summertime and school holidays whereas Chien, Pai, Lin and Chen

(2003) in Taiwan and Dedovic, Brychta, Koupilova and Suchanek (1996) in Czech Republic found that spring is the most common season. Yet Kai-Yang et al (2008) in China could not find any patterns in the distribution of seasons in their analysis of data.

In the limited evidence from South Africa, Van Niekerk, Rode and Laflamme (2004) found a significantly higher incidence rate of burn injury during the winter season in this developing country. This is to be expected as families are exposed to the cold weather and attempt to keep warm (Van Niekerk, Rode and Laflamme, 2004). Similarly, van Niekerk (2007) found that burn injury incidence was highest in the winter but only significantly greater than the rate in summer in South Africa. An explanation for these seasonal differences in the different countries is not known.

2.2.7 Trends in Different Countries

According to the World Health Organisation's report in 2007, fire-related burns were responsible for nearly 322 000 deaths in 2002 in the world, as well as fire-related burns are one of the 15 leading causes of death and burden of disease among children and young adults, ages two to 25 globally.

The World Health Organisation has published the following statistics about burn injuries in paediatrics and socio-economic related burn injuries:

- Africa: high rates of fire-related deaths in children
- USA: Burns rank fourth as a cause of unintentional child injury
- In France, childhood burns account for between three and eight percent of all injuries in children and are the second cause of childhood deaths after drowning.
- Women in low- and middle-income regions of the Eastern Mediterranean have high rates of burn injury
- House fires are the third leading cause of unintentional injury death in aboriginal communities in Greenland and North America (www.who.int)

In addition, a global assessment of hospitalised paediatric patients with burns conducted in 2005 (Burd and Yuen) indicates that the highest incidence of hospitalised paediatric patients with burns is in Africa, the lowest number being in America. Furthermore, Africa showed the highest rate of death from fire-related burns in children aged newborn to four years of age, of both sexes, with boys more at risk.

2.2.8 *Mortality and Causes of Death*

In South Africa, burns are the third most common external cause of death in children younger than 18 years (Van Niekerk, Rode and Laflamme, 2004). However since 1980, the number of children who survive massive burns has increased significantly (Wolf, Rose, Desai, Mileski, Barrow and Herndon, 1997). This is due to the development of comprehensive burn centres with the associated advances in treatment as well as advances in general medical management of burn wounds (Esselman, 2007).

Causes of death may include infection, shock and multiple organ dysfunction syndrome (MODS) (Kai-Yang et al, 2008). Predictors of mortality consist of pre-morbid health status, inhalation injury, larger percentage burns for younger infants as well as deeper burns (Kai-Yang et al, 2008). A study done by Morrow, Smith, Cairns, Howell, Nakayama and Peterson (1996) showed that increased burn size leads to increased risk of mortality among children. A logistic regression analysis also found that children aged newborn to four years of age had a higher risk of death independent of burn size (Morrow et al, 1996). Possible reasons for the higher paediatric burn mortality rate include an immature immune system and increased fluid requirements, which place children at a higher risk for sepsis and hypovolemic shock after burn injury (McLoughlin and McGuire, 1990).

2.3 Socio-Economic Factors Affecting Burn Injury

Some evidence has linked a number of familial factors to burn injuries amongst children. It has been documented globally that poor socio-economic circumstances increase the risk of paediatric burn injuries (Cubbins, LeClere and Smith, 2000; Van Niekerk, Reimers and Laflamme, 2006; Forjough, 2006; Edelman, 2007; van Niekerk, 2007; Peck et al, 2008). The World Health Organisation (WHO) states that over 90% of fatal fire-related burns occur in low- and middle-income countries. Over 98% of deaths from fire and burns occur in developing nations, which are least able to provide the resources for care or the community support for rehabilitation (Peck et al, 2008).

International and local studies have linked a number of factors to the occurrence of burns amongst children (Werneck and Reichenheim, 1997; Delgado et al, 2002; Van Niekerk, Rode and Laflamme, 2004, van Niekerk, 2007). These include family education, poor living conditions and overcrowding. Environmental conditions do contribute to the occurrence of injuries, such as the use of various fuels for heating and cooking, and various heating and cooking appliances (van Niekerk, 2007). Cultural and religious traditions may also increase the risk of injury, such as the long flowing, highly flammable cotton robes commonly worn by African children. Clothing fires were the cause of 25% of all flame burns in Zaire, Africa (Kalayi & Muhammad, 1994). Results from a study done in Karachi, India, showed that socio-economic factors such as overcrowding in poor housing conditions, lack of proper medical facilities and ignorance were found to be the most important cause of burns (Kildal et al, 2004). Alcohol consumption and cigarette smoking amongst parents or other adults is also thought to be an injury risk (Boukind, Chafiki, Terrab, Alibou, Bahechar and Zerouali, 1995; Werneck and Reichenheim, 1997).

In South Africa, the African population has been reported to have lower income levels, literacy rates and overall health status and higher levels of overcrowding in housing (Barbarin and Richter, 1999; Van Niekerk, Rode and Laflamme, 2004).

This results in a lower educational level of mothers, unemployment, lower socio-economic status of the families, decreased parental alertness to burns and psycho-stress in the families. These have all been linked to an increased risk of paediatric burn injuries (Werneck and Reichenheim, 1997; Pomerantz, Denise Dowd and Buncher, 2001; Van Niekerk, Rode, Laflamme, 2004; Edelman, 2007). Living in areas characterised by overcrowding and poverty, as well as households headed by females and children not being the son or daughter of the household head are also significant risk factors for burn injury (Cubbins et al, 2000; Delgado et al, 2002; Van Niekerk, Reimers and Laflamme, 2006). The lack of childcare services in the poorer townships also results in children being left alone or with an aged relative caring for a number of children and therefore increases the risk on injury (Van Niekerk, Reimers and Laflamme, 2006; Frenkel, 2008).

A significant number of South African families live in single room shacks, traditional dwellings and mud huts, which have no electricity and therefore have to use alternative means for lighting and cooking such as gas stoves, primus paraffin stoves as well as fire bolas. Poverty affects the choice, quality and condition of appliances as well as the fuel-type used (Peck et al, 2008). The cramped living spaces suggest that children are much more likely to be present when adults are cooking and heating water. The dangers of storing flammable substances and primus paraffin stoves have been recognized (Hudson, Rode and Bloch, 1994; Forjuoh, 2006). These stoves and flammable substances are prone to exploding or falling over and causing fires, and such accidental fires have been known to occur among people of poor social circumstances (Hudson, Rode and Bloch, 1994; Gupta, Bansal, Gupta and Goil, 1996; Forjuoh, 2006; Frenkel, 2008). The occurrence of burn injury in children is highly influenced by aspects of the local environment, such as close proximity of the shacks to one another leading to fires spreading rapidly, causing extensive damage and injury (Godwin et al, 1996; Van Niekerk, 2007).

In South Africa, stressful experiences such as household poverty and community violence may affect psychological functioning and development (Barbarin and Richter, 1999). Duncan, Brooks-Gunn and Klebanov (1994) in Barbarin and Richter (1999) reported that there is a strong link between family welfare and child development. A study done in the Johannesburg-Soweto area documented that children from moderately safe communities achieved better outcomes than those from very safe or very unsafe communities (Barbarin and Richter, 1999).

The Household Economic and Social Status Index (HESSI) is a developed self report measure of material resources including food, assets and housing as well as capital resources such as occupation, education of caregivers and marital status. It was developed in South Africa and has been used extensively in research conducted in Soweto (Barbarin and Richter, 1999). The questionnaire gives an indication of the socio-economic status of a population (Barbarin and Richter, 1999).

2.4 Medical Management of a Child with Burn Injury

When a child is admitted to the appropriate facility, an estimate of the depth and surface area of the burn and the child's overall condition is first made (Campbell, 1996). Mortality due to burn injuries has declined significantly because of the development of comprehensive burn centres with the associated advances in treatment, including improvements in the resuscitation of patients with severe burns, topical antimicrobial agents, newer antibiotics, early excision and grafting and more recently, the use of artificial substitutes for skin grafting (Esselman, 2007). The principal aims of burn wound care are to allow survival of any remaining viable tissue, to prevent infection and to promote wound healing (Leong, 1995). However equally important is addressing the social and psychological outcomes (Campbell et al, 1996).

In South Africa, management of children in hospital includes fluid management, pain relief, wound care, surgical management, prevention of infection, nutritional

support, prevention of complications, rehabilitation and psychological support (Lakhoo, 1995). The depth (superficial, partial or full thickness) and site of the injury affects the prognosis. Inhalation injury, associated injuries, other medical conditions, and the very young ages of the children may exacerbate the burn injury and lead to a poorer prognosis (Leong, 1995; Esselman, 2007).

2.5 Pain Management

Pain management is an important part of a comprehensive treatment program after burn injuries and needs to be managed adequately for optimal patient outcome and rapport with the treatment team (Esselman, 2007). In addition to the constant pain caused by the burn injury itself, the treatment of burns with daily debridement of necrotic tissue results in intermittent severe procedural pain (Esselman, Thombs, Magyar-Russell and Fauerbach, 2006). However, pharmacological analgesia is not a priority in full thickness burns because the sensory nerve endings have been destroyed and the wound itself is painless, unlike superficial or partial thickness burns (Leong, 1995). Sedation should be kept to a minimum to avoid cardio-respiratory depression (Leong, 1995). Although the use of anxiolytic and sedating medications may be necessary to ensure proper management of pain, these medications should be monitored carefully to ensure that children are not too heavily sedated to participate in their active recovery (Serghiou, Rose, Pidcock, Esselman, Engrav, Kowalske and Lezotte, 2008).

2.6 Wound Healing

Healing requires absence of infection, proper oxygen supply, proper nutritive supply as well as protection from further trauma as the epidermis is fragile (Latarjet, 1995). Regeneration of epithelial elements in partial-thickness injury comes from the epithelial cells lining every hair follicle and sweat gland (Campbell, 1996). Healing of partial-thickness burns usually takes 14 days, but if the burn is sufficiently deep these burns may take 21 days for complete healing (Campbell, 1996). As the epithelium grows, the normal pigmentation gradually

and progressively returns. As the regenerated epithelium forms the keratin layer, the function of the skin in maintaining and conserving core body temperature is restored (Campbell, 1996). With full thickness burns the dermis and epidermis have been destroyed and the skin can only be restored by skin grafting (Lakhoo, 1995). Wound healing may be delayed due to anaemia and malnutrition and results in failure of skin grafts (www.who.int).

2.7 Acute Holistic Rehabilitation

It is important to implement holistic and comprehensive management by a multi-disciplinary team including doctors, nursing staff, social workers, speech therapists and audiologists, dieticians, occupational therapy and physiotherapy throughout rehabilitation from admission to scar maturation. Burn injuries result in significant physical and psychological complications that require comprehensive rehabilitation treatment and coordination with the acute care burn team (Esselman, 2007). Disability is limited by exercise, elevation, splinting, early closure of wounds and pressure garments. Two major goals of burn care are survival and limitation of physical and emotional disability with optimal function (Lakhoo, 1995).

Positioning is an important aspect of wound care which is undertaken by nursing staff and physiotherapists. The main treatment goals for physiotherapy include respiratory management, oedema management, mobility, function, exercise tolerance and for occupational therapy include splinting, oedema management and scar management (Simons, King and Edgar, 2003). Active and passive range of motion exercises are needed to facilitate function (Serghiou et al, 2008).

There is an increasingly recognised role that culture plays in determining how a burn injury, its causes and the recovery process are perceived by patients and families. Cultural aspects can impact interactions between patients and families and the burn team as well as medical decision making. Culture also influences coping patterns of patients and families (Thombs and Fauerbach, 2005). This

factor should be taken into consideration when dealing with patients and families with different cultures and beliefs.

2. 8 Long Term Rehabilitation

Total rehabilitation or ‘optimal outcome’ is achieved when a patient with burns returns to his or her pre-injury level of function, which includes physical, social, emotional, mental and spiritual well-being. In order to achieve this, rehabilitation therapists should be moving towards setting function-based outcomes with patients. The use of function-based outcomes to drive a ‘critical pathway’ (best path to achieve the optimal outcome) can enhance all components of a patient rehabilitation program including assessment, treatment, education, patient satisfaction, cost containment and research (Staley and Richard, 1996).

Severe burns result in persistent and extensive skeletal muscle catabolism and weakness, which is worsened by prolonged physical inactivity (Hart, Wolf, Chinkes, Gore, Mical, Beauford, Obeng, Lal, Gold, Wolfe and Herndon, 2000). The current standard of care consists of rehabilitation exercises of occupational therapy and physiotherapy which can be done in a hospital setting or in a patient’s home. There are problems with compliance because these exercises are often done without professional supervision and often lack structure (Hart et al, 2000). Muscle catabolism and weakness often persist despite physiotherapy (Suman and Herndon, 2007). The physical weakness linked with severe burns is often complicated by cardiac and systemic shock, hyper metabolism, respiratory injury, sepsis, post burn seizures, compromised bone formation, major surgeries, malnourishment, disturbed growth patterns and psychosocial issues (Blakeney, Meyer, Moore, Murphy, Broemeling, Robson and Herndon, 1993; Wolf et al, 1997; Hart et al, 2000). Furthermore decreased endurance and muscle strength are major obstacles to a burn survivor’s return to school and performance of activities of daily living (ADL’s). It has been demonstrated recently that children with more than 40% total body surface area burns which were assessed six months post burn

injury showed a loss of skeletal muscle resulting in a decrease in muscle function (Alloju, Herndon, McEntire and Suman, 2008).

Suman and Herndon in Galveston, Texas (2007) investigated whether the benefits of exercise by children with burn injuries are maintained three months after the exercise program was completed. From this randomised controlled study, Suman and Herndon demonstrated the benefits of a 12-week supervised and structured in-hospital exercise program relative to a home exercise program. Additionally, there were improvements in lean body mass and muscle strength relative to a no-exercise control as well as a continued improvement in these benefits three months after the structured and supervised exercise program is stopped. However, a limitation of this study is that the number of subjects in both groups was small and the possibility of a type II error in the study cannot be ruled out. Yet Suman and Herndon's (2007) results are important in the development of a more comprehensive physiotherapy program for children with burns post discharge and highlight that children may benefit from an in-hospital exercise program once their wounds are fully healed.

Rehabilitation for patients with severe burn injuries includes treatment of contractures, heterotopic ossification, hypertrophic scarring, weakness due to loss of muscle mass, amputations, neuropathies and returning to school/work (Esselman et al, 2006; Esselman, 2007). The prevention and treatment of hypertrophic scarring is one of the most important issues in burn rehabilitation (Esselman et al, 2006). In children, the scars cannot expand to keep pace with the growth of the child and this may lead to contractures (www.who.int/surgery - WHO Surgical Care at the District Hospital, 2003).

However, not so well known challenges may include sleep difficulty, pruritus (itching) (Casaer, Kums, Wouters, Van den kerckhove and Van den Berghe, 2008), and the impact of societal reactions to burn-related cosmetic disfigurement. Other challenges may include sensitivity to temperature extremes as full thickness

burns damage the dermal appendages including the sweat glands resulting in problems with thermoregulation.

2.9 Long Term Outcomes

The two major goals of burn care are survival and limitation of physical and emotional disability with optimal function. The ultimate treatment aim for the patient is to return back into the community as a functional person (Lakhoo, 1995).

2.9.1 Long-Term Complications Post Burn Injury

Burn injuries result in significant rehabilitation challenges due to the long-term physical complications and psychological issues (Esselman et al, 2006). However, the majority of children with burn injuries regained function to the level prior to the burn injury although some persisted with long term problems such as scars, pain and cognitive problems (Blakeney et al, 1998).

Joint contractures remain the most frequent musculoskeletal complication in children (McCauley, Robson, Herndon, Evans and Blakeney, 1996). Individuals with severe burn injuries are at risk for developing hypertrophic scarring, which is characterised by red, raised and rigid scar tissue and results in contractures and deformities when the scar tissue crosses joints in the body (Esselman, 2007). Hypertrophic scarring results in physical and psychological impairments after burn injuries and custom made pressure garments by occupational therapists are the most effective and comfortable treatment for hypertrophic scars (Macintyre, 2007).

Other musculoskeletal complications include exposed tendons and joints and heterotopic bone formation. The most common site of heterotrophic ossification is the elbow joint however this ossification is rare in children but may be evident in the adolescent population (Campbell, 1996). Amputations after burn injuries are complicated by the associated fragile skin and contractures that make prosthetic

fitting challenging. Major amputations are common in high-voltage electrical injuries but thermal injuries can often result in finger amputations (Esselman, 2007). Neuropathy after burn injury is often not recognised but can affect strength and function (Esselman, 2007). Children who survive inhalational injury have a high risk of cardiopulmonary complications later in life and may suffer from chronic pulmonary disease as well as decreased exercise tolerance (McCauley et al, 1996). Psychological impairments post burn injury may include social withdrawal, sleep disturbances as well as body-image issues (Esselman et al, 2006).

Research conducted at John Hopkins University School of Medicine found the cause of burn, percentage of burn and body areas affected the prognosis and long term outcome of burn survivors. In adults, greater in-hospital psychological distress was associated with decreased rate of recovery of both physical and psychosocial health and function at six months and one year post injury. Similarly, larger burn size was associated with more physical but not psychosocial impairment (Fauerbach, Lezotte, Hills, Cromes, Kowalske, de Lateur, Goodwin, Blakeney, Herndon, Wiechman, Engrav and Patterson, 2005).

2.9.2 Psychosocial Challenges Post Burn-Injury

The fear of permanent disability and the family's guilt may hinder the healing process. Support is fundamental in preserving the child's self-esteem and returning him/her to society as a functional person (Leong, 1995). Acute psychological distress as well as its association with poor recovery may indicate need for a mental health professional to provide assessment and necessary intervention in a specialised burns unit (Fauerbach et al, 2005).

A study undertaken in Washington USA reported a positive effect of social workers, psychologists and spiritual care staff on patients, and their relatives, who

suffered severe burn injuries. This effect had a positive influence on their survival and length of hospital stay (Muangman, Sullivan Wiechman, Bauer, Honari, Hemibach, Engrav and Gibran, 2005). Depending on the severity of the burn injury, some burn survivors may experience identifiable psychopathology (Rosenberg et al, 2007). Some children require psychosocial rehabilitation such as learning to cope with the social response to residual disfigurement (Rosenberg, Blakeney, Thomas, Holzer, Robert and Meyer, 2007). Social skill interventions have been found to be effective for children with facial disfigurement who face social challenges similar to burn survivors (Pruzinsky, 2005). Frenkel (2008) states that where the burden of burns is the highest, psychological services may be the scarcest. As a result, Frenkel has set up a successful weekly support group at the Red Cross Hospital Western Cape, South Africa, for parents with children with burn injuries (Frenkel, 2008).

Burn survivors in Texas, USA were interviewed at two years post burn injury (>30% body surface area) and results showed that majority of the survivors did not have major psychological problems. Significantly, young girl survivors expressed anger and adolescent females were withdrawn and attempted to hide (Meyer et al, 2004).

2.9.3. *Quality of Life*

As the burn survivor progresses into the rehabilitation phase, quality of life becomes one of the most important aspects of recovery (Baker, Rosenberg, Mossberg, Holzer, Blakeney, Robert, Thomas and Meyer, 2008). The expected psychosocial outcome and quality of life of paediatric burn injuries has improved within the last 15 years (Blakeney et al, 1998).

There appears to be no agreement in the literature what the quality of life is post burn injury. In Norway a study suggested that initially children with superficial to moderate burns had a reduced quality of life one month post burn, however, showed improvements after twelve months (Vollrath and Landolt, 2005). A factor

which predicted the quality of life was the child's personality (Vollrath and Landolt, 2005). It has been documented that patients use different coping strategies to manage their burn injuries and these strategies are not related to the severity of burns but rather seem to be affected by personality traits (Kildal et al, 2004).

Overall quality of life for young adult burn survivors has been shown to be lower compared to the population with no burn injuries in Galveston, Texas (Baker et al, 2008). This was illustrated using the Quality of Life Questionnaire (QLQ). However scores with the Short-Form (SF)-36 were similar between young burn survivors and non-burn subjects. This is an indication that the SF-36 is considered a general health quality of life questionnaire and identifies perceived health issues whereas the QLQ assesses people's specific behaviours to determine quality of life (Baker et al, 2008). Similarly, a study conducted in New York, USA investigated the long-term quality of life of 60 patients who had survived massive burns (>70% total body surface area) as children with the SF-36. Results revealed that the majority of the SF-36 scores were similar to the non-burn population, but 15-20% of the patients had scores that suggested serious physical limitations. Therefore patients who were younger than 18 years of age when they were injured did not necessarily experience a different quality of life to those who had not been burnt (Sheridan et al, 2000). Furthermore, comprehensive burn care that included experienced multi-disciplinary aftercare, early integration with preburn activities and a supportive family environment was associated with a better recovery (Sheridan et al, 2000).

On the other hand, Cucuzzo et al (2001) comments that children with severe burn injuries (over 40% body surface area) often experience chronic disabilities and have a high potential of developing diseases related to poor quality life style. However no studies were found with these similar findings in the literature.

It appears from the literature that overall quality of life of burn survivors is similar to the non-burn population although burn survivors do have an increased risk of long-term complications post burn injury and this may decrease their quality of life.

Another factor impacting on a burn survivor's quality of life is relationships with caregivers and family post burn injury. Mothers of children with burn injuries suffer high levels of stress which consequently impacts on the parent child relationship (Meyer et al, 2004). Furthermore, there is an association with increased self-esteem and life satisfaction with family support in adolescent patients (Davidson, Bowden and Feller, 1981).

2.10 Assessment of Quality of Life

Health related quality of life (HRQOL) has been increasingly recognised as an essential health outcome measure in clinical trials and health services research and evaluation. Quality of life includes functional capacity, role performance, perceived well-being and life satisfaction as well as impairments (Wenger, Mattson, Furberg and Ellinson, 1984 in Fauerbach et al, 2005). Quality of life challenges post burn injury may include post trauma distress, depression as well as body image dissatisfaction (Fauerbach et al, 2005).

The Paediatric Quality of Life (PedsQL) 4.0 Generic Core Scales includes child self-report for ages five to eighteen and parent proxy-report for ages two to eighteen. The questionnaire includes physical, emotional, cognitive and social health sections as per the World Health Organization guidelines (Varni, Limbers and Burwinkle, 2007). In certain circumstances where the child may be too young or ill to answer questions, a parent proxy may be used. Various studies have proven the PedsQL a valid and reliable HRQOL measuring tool (Varni, Seid and Rode, 1999; Varni, Seid and Kurtin, 2001; Varni, Burwinkle, Seid and Skarr, 2003; Varni et al, 2007).

Varni, Seid and Kurtin (2001) researched the reliability and validity of the PedsQL in healthy and patient populations and concluded an internal consistency reliability for the total scale score ($\alpha = 0.88$ child, 0.90 parent report), physical health summary score ($\alpha = 0.80$ child, 0.88 parent report) and psychosocial health summary score ($\alpha = 0.83$ child, 0.86 parent report). Validity was demonstrated using the known-groups method, correlations with indicators of morbidity and illness burden and factor analysis (Varni et al, 2001). Results from the study by Varni et al (2007) showed that children as young as five years old can reliably and validly report their quality of life when given the chance with an age appropriate instrument. In the same way Varni et al (2007) demonstrated that parent-proxy for the age group two to sixteen years old was valid and reliable. In addition Varni et al (2007) stated that parent proxy-report should only be used if the child is too young, ill or otherwise unable to self-report.

No studies were found in the literature using the PedsQL to determine quality of life in paediatric burn survivors.

2.11 Burn Prevention

Prevention is an important aspect of burn management. Prevention of the burn injury is better than treating the child with burn injuries with its associated consequences (Leong, 1995). Burns are not random events and therefore are largely preventable injuries. However burns prevention is not quick, cheap and easy and requires long-term plans to get public support for safer product designs and for regulations, which are necessary for effective burn prevention (McLoughlin, 1995).

There appears to be no consensus in the literature as to whether prevention programmes have decreased rates of burn injury in paediatrics. A systematic review “Community-based interventions for the prevention of burns and scalds in children” (Turner, Spinks, McClure and Nixon, 2007) showed that only three studies in the searched literature met the inclusion criteria and only one of these

three studies showed a significant decrease in paediatric burn and scald injury in the intervention community compared with the control community. The community-based approach is characterised by a shared ownership of the injury problem and its solution between experts and community members, and joint responsibility for determining appropriate interventions (Moller, 1991 in Turner et al, 2007). However more high-quality research studies are required in this area to support the use of the community approach.

In contrast, prevention programs in the USA and Norway have been successful in decreasing the burn injury rate (Erdmann, Feidman, Rivara, Heimbach and Wall, 1991; Ytterstad and Soggard, 1995). Furthermore, prevention programs have decreased incidence of electrical burns in Denmark, firework burns in India as well as residential fires from cigarettes in the United States of America. (McLoughlin, 1995). Various changes have been made globally such as smoke alarms in homes, education of children and families and regulation of hot water temperatures taps. These changes have resulted in a decreased incidence of burn injuries (Turner et al, 2007). Individuals need to prevent death and injuries caused by house fires by modifying ignition sources (cigarettes and lighters), giving early warning for occupants to evacuate the area from smoke and potential fire (smoke detectors) and extinguishing the flames (sprinkler systems) (McLoughlin et al, 1990).

These changes have had limited application in South Africa due to limited availability of resources (Turner et al, 2007). Furthermore, little research has been done in low and middle income countries in particular South Africa on prevention strategies and their effectiveness (van Niekerk, 2007). The physical aspects of the home environment need to be addressed, these include spatial layout, storage and working facilities, supervision and chore management as well as heating appliances that integrate safety technology (van Niekerk, 2007). Further studies particularly in South Africa are required to establish if prevention programmes are being effective in decreasing the rate of paediatric patients with burn injuries.

2.12 Conclusion of Literature Review

After an in-depth literature search of burn injury, it is evident that a need exists for more local African studies to be conducted, particularly with regards to quality of life and the factors predicting quality life in paediatric patients with burn injuries post discharge in a South African setting.

Chapter 3: METHODS

In this chapter, the methodology used in this research report will be presented. Demographic information will be presented first, followed by information on the assessment tools used.

3.1 Location

The study was conducted at the Johnson and Johnson Paediatric Burns Unit at Chris Hani Baragwanath Hospital in Soweto, Gauteng, South Africa. This is the largest African township in the Gauteng province of South Africa and has a population of 1.5 million people (www.soweto.co.za/html/facts.htm). Children who are discharged from the paediatric burns unit attend the out-patient clinic weekly until their wounds have fully healed. Patients attending this clinic are from similar socio-economic and cultural backgrounds.

3.2 Ethical Clearance

Prior to commencement of data collection, ethical clearance was obtained from the Committee for Research on Human Subjects of the University of the Witwatersrand (Clearance number: M07-10-25) (Appendix II). Permission was also obtained from the Senior Clinical Executive of Chris Hani Baragwanath Hospital.

3.3 Sample Selection

The data for 70 consecutive children (boys and girls) post burn injury between two to twelve years of age were analysed. Informed consent and assent (for children older than eight years of age) had been obtained from the caregivers and children prior to assessment (Appendix III and IV)

3.4 Inclusion Criteria

- Boys and girls between the ages of two and twelve year's old post discharge from the paediatric burns unit
- Children deemed fit for participation by the doctor at the clinic
- Children attending the out patient clinic for follow up post discharge

3.5 Exclusion criteria

- Previous and current medical problems that may impair aspects of joint range
- Refusal to participate and withdrawal at any time

3.6 The Study Population

The data from 70 consecutive children post burn injury fitting the inclusion criteria, who had been assessed using the PedsQL as well as the HESSI were analysed. The children came from Soweto and surrounding areas, and thus had similar socio-economic and educational backgrounds.

3.7 Assessment Tool

The PedsQL was the assessment tool of choice, as it has been proven a valid and reliable health related quality of life tool (Varni et al, 1999; Varni et al, 2001; Varni et al, 2003; Varni et al, 2007). Permission was obtained from the Mapi Research Institute in France to use the PedsQL in this study.

The HESSI is a developed self report measure of material resources including food, housing, assets as well as capital resources such as occupation, marital status and education. This was used to obtain the child's socio-economic and family background information.

3.8 Procedure

Consecutive children between the ages of two and twelve years old age and their caregivers, attending the Johnson and Johnson paediatric out-patient clinic for their initial follow-up visit one week post discharge were approached and asked to

participate in this study. Verbal permission was gained from the caregivers and children (if old enough) to access information in the child's hospital file. The child's burn history was obtained from the hospital file to ascertain whether the child fitted the inclusion criteria of the study. Caregivers were approached before the clinic started so they would not lose their place in the queue. This ensured that the child had not yet been traumatised from wound exposure, washing and dressing.

An English information sheet for the caregiver and the child (if old enough) were given as well as a verbal explanation to the child, which explained the study and requested participation (Appendix V and VI). A trained physiotherapy assistant was available for translation if required. Caregivers and children were given at least 30 minutes to read the information sheet before enrolling in the study, and were given the opportunity to ask questions.

Once written informed consent had been obtained, the child and caregiver were seated in the physiotherapy and occupational therapy gym. The HESSI questionnaire (Appendix VII) was administered first, followed by the PedsQL (Appendix VIII) (correct PedsQL for the age of the child). The questionnaires were administered either by the physiotherapist or the physiotherapy assistant, who were both familiar with the questionnaires. The child and caregiver were given a three month follow up date.

At the three month follow up appointment the PedsQL was administered for the second time. The questionnaires were administered before the clinic started as after washing and dressing change the child was in pain and may have affected the results.

Quality of life scores were calculated as per the manual sent by Mapi Research Institute. Items were reverse-scored and linearly transformed to a 0-100 scale (0=100, 1=75, 2=50, 3=25, 4=0), so that the higher scores indicated a better HRQOL. A normal expected quality of life score is 200 (sum of physical health summary score and psychosocial health summary score). Scale scores were computed as the

sum of the items divided by the number of items answered (this accounts for missing data). If more than 50% of the items in the scale were missing, the scale score was not completed. The physical health summary score (15 items) is the same as the physical functioning scale and expected normal score is 100. To create the psychosocial health summary score (15 items), the mean was computed as the sum of the items divided by the number of items answered in the emotional, social and school functioning scales and expected normal score is 100.

3.9 Statistical Analysis

All the data collected were analysed by the Medical Research Council of South Africa. After a univariate analysis of outcome verses clinical and socio-economic factors, not more than six to eight factors were anticipated to enter a multivariate analysis. By convention 10-15 subjects were required per clinical and socio-economic factor and a sample size of 80 was envisaged. However, due to unforeseen circumstances, it was only possible to include 70 subjects into the study.

Data was analysed from the questionnaires. Descriptive statistics included means, standard deviations, frequencies and percentages, cross tables and graphs.

A one-way analysis of variance (ANOVA) was employed to compare the categories of socio-economic factors with respect to quality of life. In the case where there were more than two categories specific differences were determined from pair-wise at the Bonferroni adjusted level of significance. ANOVA for ranks were done in cases where the assumption of ANOVA were not met. Severity levels were also compared with respect to hospital stay in ANOVA. The association between clinical and quality of life was assessed using correlations and multiple linear regression analysis. Pre and post-scores were compared using Student's paired t-test and the affect of individual items making up the scores were tested for using McNemar's test for symmetry. Testing was done at the 0.05 level of significance.

Chapter 4: Results

In chapter 4 the results of this study will be presented. The data from 70 subjects were analysed. All children assessed were African, and most were brought to the clinic by their mothers or grandmothers.

4.1 Age

The children were divided into the following groups: 2 – 4 years old (young children), 5 – 7 years old (pre-school children) and 8 – 12 years old (older children). The mean age of the total sample was 4.11 (± 2.37) years of age.

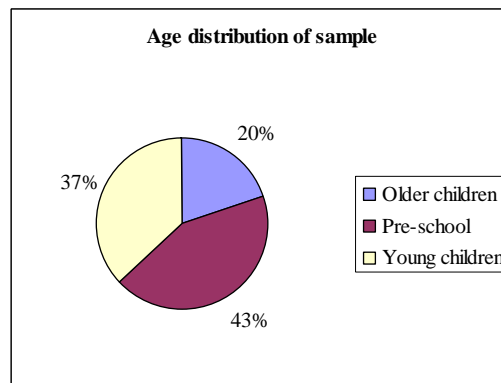


Figure 4.1: Age distribution of the sample

The sample was further divided according to whether or not the child was attending crèche or school.

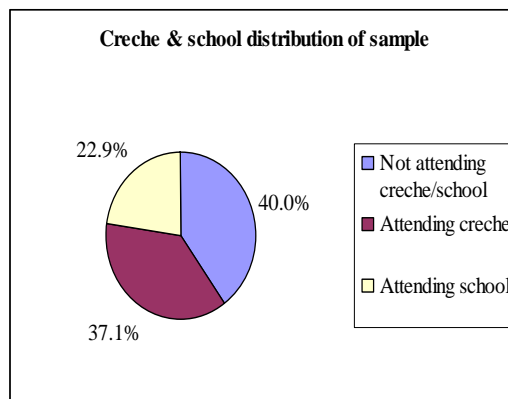


Figure 4.2: Crèche & school distribution of the sample

As can be noted in figure 4.2, nearly half the children were being cared for at home and were not attending crèche or school.

4.2 **Socio-Economic Background**

The HESSI questionnaire was used to obtain information on the children's socio-economic background (Appendix VII). The areas that were investigated were: mother has support from a partner and family, level of mother and partner education, number of occupants living in the house, the type of housing including a kitchen, bathroom and the number of bedrooms for sleeping, facilities and accessories used in the household, how often children go hungry and finally the safety of the area in which the house is located.

4.2.1 **Mother's Support From Partner And Family**

Just over 64% of mothers were currently living with a partner (husband/boyfriend) and 70% of mothers reported that their family was there for them when they needed help. However, 10% of mother's reported that their family had a lot of problems.

4.2.2 **Education Levels**

Most of the mothers and partners completed secondary education (Standard 5 - Matric). From the sample, 22.9% of mothers attained standard five to seven, 38.6% attained standard eight to nine and only 20% of mothers attained a matric education. It is important to note that five percent of the mothers have an education level of less than standard three.

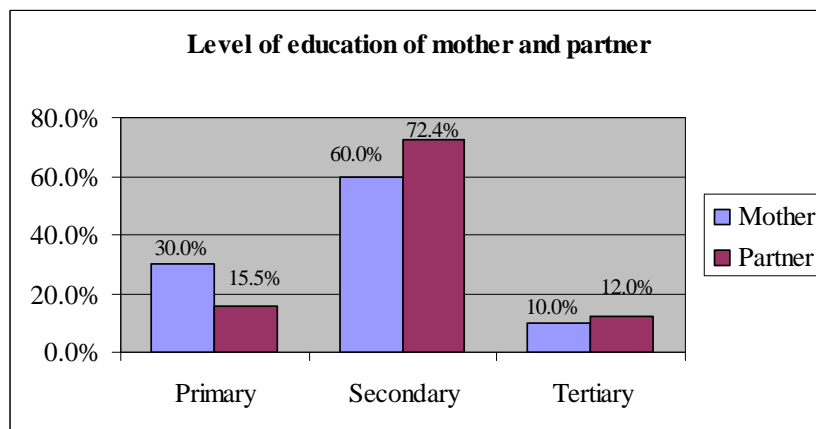


Figure 4.3: Level of education of mother and partner

4.2.3 Type of Housing

It can be seen from figure 4.4 below that a large proportion of families reside in shacks with no separate rooms just for sleeping.

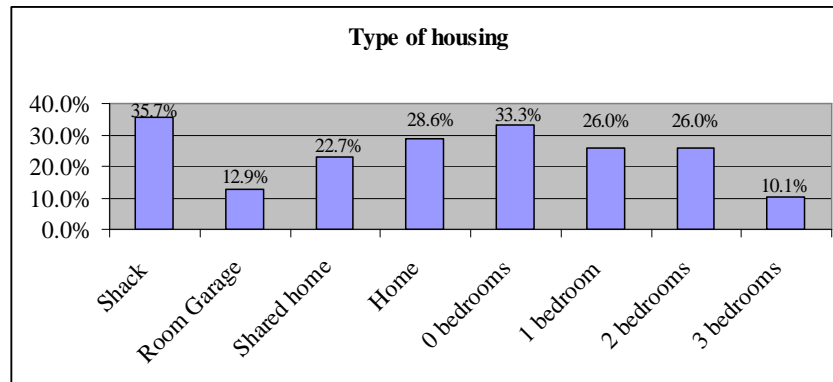


Figure 4.4: Types of housing

4.2.4 Number of Occupants Living in the Household

Ten percent of the sample had between eight to ten people living in the household, the maximum number of people in one household was 12 and 50% of the sample live in households with more than five occupants.

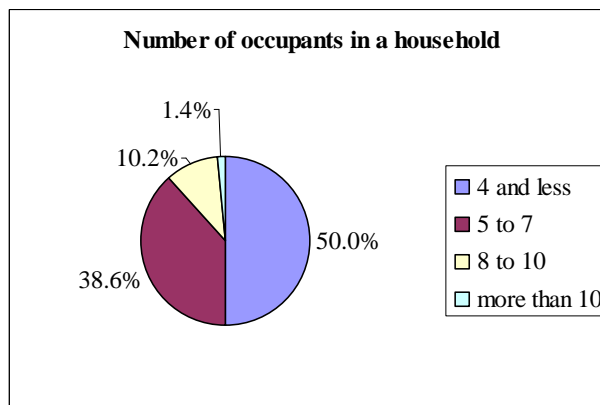


Figure 4.5: Number of occupants in a household

4.2.5 Facilities and Accessories Used In the Household

It can be seen from figure 4.6 that separate bathrooms are not common in the sample, with most families using an outside flush toilet. However 81.4% of the sample has a television and 67.1% a fridge in the household and so these accessories are frequent in the sample.

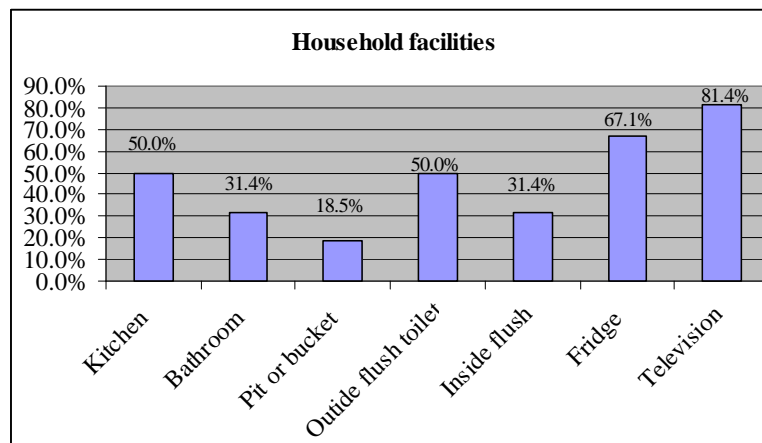


Figure 4.6: Household facilities

4.2.6 Children Gone Hungry

The caregivers were asked how often their children have gone hungry as a result of having no food. This is an indication of their socio-economic position. Although 68.6% caregivers replied never, 14.3% of caregivers stated that their children had often gone hungry and 1.4% replied that their children went hungry all the time.

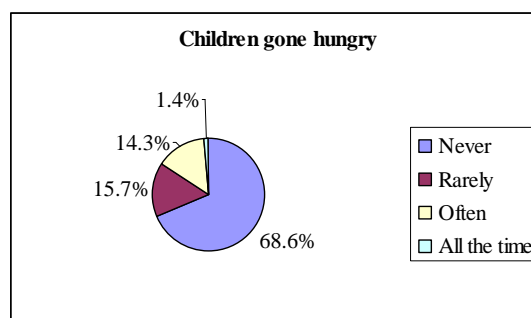


Figure 4.7: Children gone hungry

4.2.7 Safety of Child

The majority of caregivers reported that they live in a safe area however 17, 1% reported that their residential area was dangerous and a further 50% reported that they worry all the time when their child is playing outside the home.

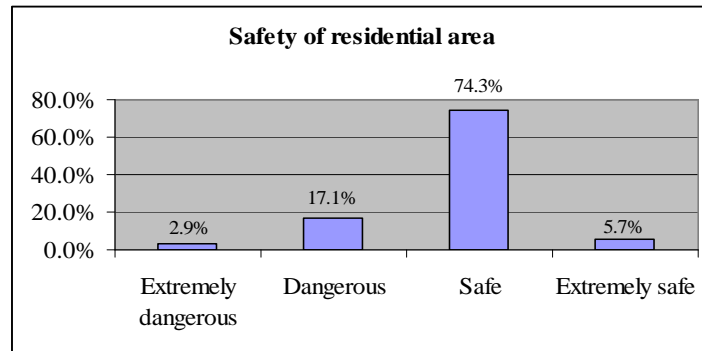


Figure 4.8: Safety of residential area

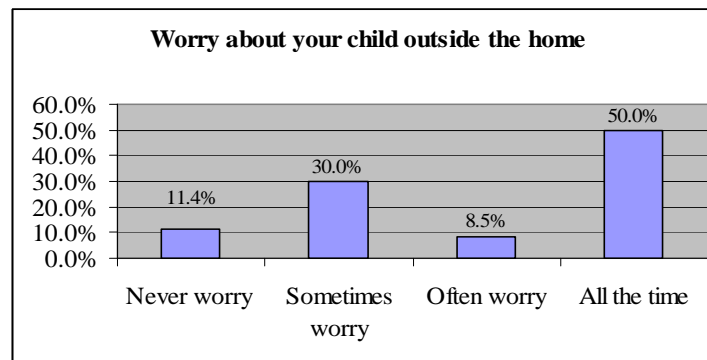


Figure 4.9: Worry about your child outside the home

4.3 Characteristics of Burn Injuries of the Sample

The data of the characteristics of the burn injuries are shown in table 4.1. The cause of burn was either flame burn, hot water or hot oil burn whereas the areas of burn, thickness of burns as well as the treatment received may have included more than one of the options below.

Table 4.1: Characteristics of burn injuries of sample

Cause of burn:	% (n=70)
Flame	31.4
Hot water	64.3
Hot oil	4.3
Area of burn:	
Face	27.1
Head	4.3
Neck	14.3
Upper limb	60.0
Chest	10.0
Trunk	40.0
Perineum	2.9
Buttocks	14.3
Lower limbs	51.4
Thickness of burns:	
Superficial thickness	75.7
Partial thickness	81.4
Full thickness	7.1
Treatment received:	
Superficial skin graft (SSG)	21.0
Sloughectomy	14.0
Occurrence of burn injuries in age groups:	
Younger children	37.1
Pre-school	42.9
Older children	20.0
Occurrence of flame burn injuries:	
Younger children	15.4
Pre-school children	36.7
Older children	50.0
Occurrence of hot water burn injuries	
Younger children	76.9
Pre-school children	63.3
Older children	42.9

Areas of the body affected by burn injury:	
Upper limb	
- Younger children	73.0
- Pre-school children	56.7
- Older children	42.9
Chest	
- Younger children	19.2
- Pre-school children	3.30
- Older children	7.10
Trunk	
- Younger children	42.3
- Pre-school children	40.0
- Older children	35.7
Lower limbs	
- Younger children	42.3
- Pre-school children	60.0
- Older children	50.0
Children attending neither crèche or school:	
Superficial thickness	82.1
Partial thickness	85.7
Full thickness	3.60

It can be seen from the table above that hot water burns were the most common cause of burn injury and limbs most frequently affected. Pre-school children had the most common occurrence of burn injury followed by younger children. Pre-school and older children have the highest occurrence of flame injuries and younger children have the highest occurrence of hot water burns. Younger children had higher number of upper limbs and chest area burns whereas pre-school children had higher number of lower limbs area burns. Children not attending crèche/school had the highest number of superficial and partial thickness burns.

The mean body surface area burn of the sample was 11% (± 10.1) and the mean length of hospital stay was 22 days (± 20.5) for the sample.

In this sample, there were no inhalation burns, chemical or electrical and no children underwent an escharotomy in their management of their burns.

4.4 Quality of Life

The mean quality of life scores one week post discharge from the burns unit were 152.63 (± 20.41) and 180.87 (± 31.31) three months post discharge. The expected 'normal' score for the physical and psychosocial sections is 100 each which totals to a score of 200. A score of 200 is expected for a 'normal' quality of life in children using the PedsQL.

4.4.1 Changes in Quality of Life

Only 41 children returned for the three month follow up visit. The table below shows the quality of life scores at their initial assessment and the three month follow up assessment.

Table 4.2 Quality of life scores of children at initial assessment one week post discharge and three month follow up assessment (n=70)

Variable	Mean	Standard Deviation
Physical initial	73.25	20.41
Physical follow up	92.61	19.17
<i>Difference</i>	<i>-19.09</i>	<i>24.88</i>
Psychosocial initial	79.11	15.07
Psychosocial follow up	88.26	14.93
<i>Difference</i>	<i>-9.15</i>	<i>18.70</i>
Quality of life initial	152.63	30.23
Quality of life follow up	180.87	31.31
<i>Difference</i>	<i>-28.24</i>	<i>40.53</i>

It is evident from the table above that the quality of life scores improved from the initial visit to the follow up visit and scores were 10% short of expected 'normal' quality of life three months post discharge. The largest improvement in scores was in the physical section 19.09 (± 24.88). The psychosocial section did improve 9.15 (± 18.70) but not to the extent of the physical section ($p=0.00$).

4.4.2 Physical and Psychosocial Health Summary Scores

The physical and psychosocial health summary scores were found to be moderately positively correlated ($r = 0.5013$) when the hospital stay was less than 51 days. There were five children who stayed more than 51 days and were seen as outliers in the analysis. Thus these five children were not included in the statistical analyses.

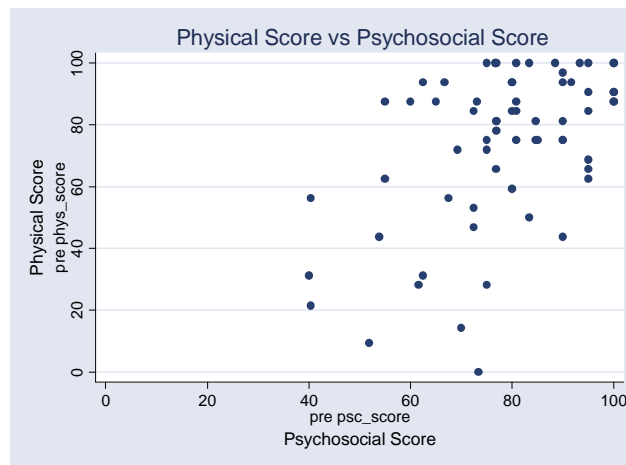


Figure 4.10 Physical quality of life scores versus psychosocial quality of life scores

4.4.3 Components of the Total Physical and Psychosocial Health Summary Scores

Certain components were found to contribute more than others to the total physical and psychosocial scores as seen in table 4.3 below. This data was collected one week post discharge and at three months post discharge.

Table 4.3 Components of the Physical and Psychosocial Health Summary Scores of Quality of Life

<i>Construct</i>	<i>Item</i>	<i>P-value</i>
Physical	1. Walking	0.17
	2. Running	0.10
	3. Participating in active play or exercise	0.38
	4. Lifting something heavy	0.24
	5. Bathing	0.01
	6. Helping to pick up own toys	0.01
	7. Having hurt or aches	0.00
	8. Low energy level	0.04
Psychosocial – Emotional	1. Feeling afraid or scared	0.10
	2. Feeling sad or blue	0.27
	3. Feeling angry	0.29
	4. Trouble sleeping	0.41
	5. Worrying	0.05
Psychosocial – Social	1. Playing with other children	0.20
	2. Other kids not wanting to play with child	0.22
	3. Getting tease by other children	0.37
	4. Not able to do things that other children his or her age can do	0.55
	5. Keeping up when playing with other children	0.38
Psychosocial – School	1. Doing the same activities as peers	0.14
	2. Missing school/crèche because not feeling well	0.46
	3. Missing school/crèche to go to the doctor or hospital	0.14

It can be seen that bathing, helping to pick up own toys, pain and energy levels in the physical section and an emotional component (worrying) in the psychosocial section caused a significant shift within the total score. An example of this is if the child's pain levels decreased and energy levels improved, the child's quality of life would improve. These components contributed most significantly to the quality of life scores one week post discharge and three months post discharge.

The physical and psychosocial health summary scores were found to be well correlated with quality of life (physical $r= 0.93$; $p=0.00$; psychosocial $r = 0.78$; $p= 0.00$).

4.5 Clinical Factors – Length of Hospital Stay

4.5.1 Length of Hospital Stay for the Different Age Groups

A log rank test showed the different age groups do not differ significantly with respect to length of stay ($p= 0.489$)

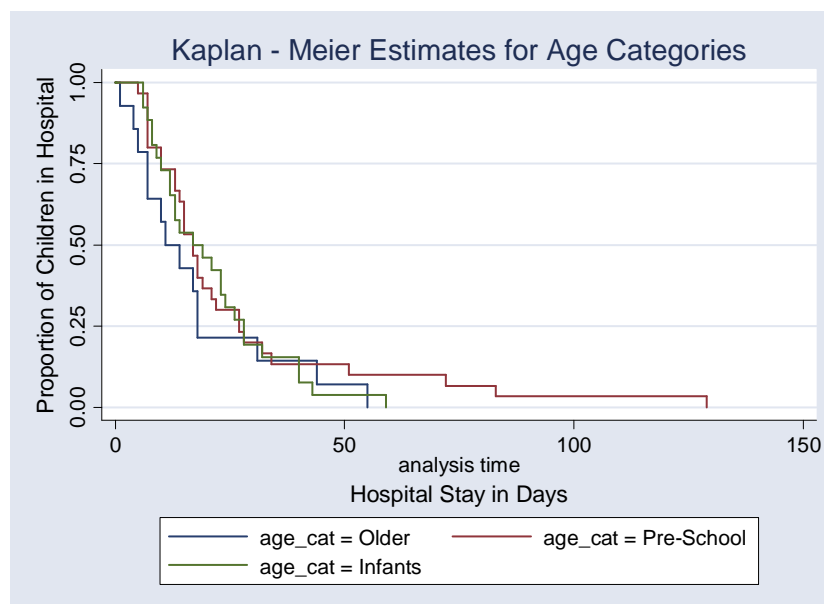


Figure 4.11 Length of hospital stay for the three different age groups

4.5.2 Length of Hospital Stay With Regards To Percentage Burn

It is noted that five children stayed more than 51 days and were seen as outliers. These five ‘outliers’ were omitted from statistical analyses.

There was a poor correlation between length of hospital stay and burn percentage ($r=0.3470$; $p=0.05$).

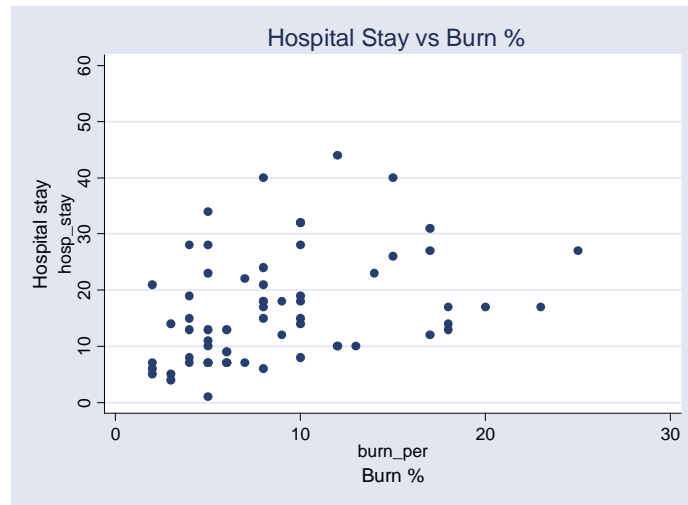


Figure 4.12 Length of hospital stay versus burn percentage

4.5.3 Length of Hospital Stay with Regards to the Severity of the Burn

The length of stay of children with superficial and partial thickness burns do not differ from each other but both have a significantly shorter length of hospital stay than children with full thickness burns ($p=0.009$).

Table 4.4 Comparison of hospital stay of children with different severity burns

Severity category	No of days in hospital	Mean (hosp stay)	SD (hosp stay)
Superficial thickness	12	12.50	7.89
Partial thickness	53	20.38	14.48
Full thickness	4	46.00	29.10

It must be noted that there was an influential observation by one subject who stayed in hospital for more than 100 days and as a result this 'outlier' was omitted from statistical analyses. Therefore subjects with hospital stay of less than 100 days were used for statistical purposes.

4.6 Clinical Factors – Quality of Life

The mean quality of life scores of children with different types of burn injury is illustrated in Table 4.5.

Table 4.5 Comparison of types of burn injuries and mean quality of life scores

Type of burn	Mean Quality of Life Score
Flame burn injury (n=22)	162.41
Hot water burn injury (n=45)	147.04
Hot oil burn injury (n=3)	140.02

It is noted that children sustaining hot water burns scored lower quality of life scores than children sustaining flame burns. This may due to the increased frequency of children sustaining hot water burn injury as well as the common causes of hot water burn injury is spillage of hot liquids and so affects a larger body percentage.

A regression analysis was done further to determine which clinical factors were found to be predictive of quality of life. The results are shown in the table below:

Table 4.6 Regression analysis of clinical factors predictive of quality of life

<u>Clinical Factor</u>	<u>P value</u>
Severity of burn (partial and full thickness)	0.00
Cause of burn (hot water and flame)	0.10
Length of hospital stay	0.68
Age categories	0.73

It can be seen from the table above that the severity of burn was found to be significant and the cause of burn marginally significant with regards to quality of life. The anatomical body areas burnt have large variables and so were unable to be tested statistically with regards to the quality of life.

4.7 **Socio-Economic Factors Predictive of Quality of Life**

A regression analysis was done to determine which socio-economic factors were found to be predictive of quality of life. The results are shown in the table below:

Table 4.7 Regression analysis of socio-economic factors predictive of quality of life

<u>Socio-economic Factor</u>	<u>P value</u>
Mother's partnership status	0.19
Mother's education level	0.11
Type of housing	0.11
Child attending crèche	0.19
Child attending school	0.58
Child attending neither	1.00
Mother having family problem	0.07

It can be seen from the table above that the only factor that was found to be marginally significant with regards to quality of life was the mother reporting family problems.

Table 4.8 illustrates the quality of life scores with children living in the different types of housing.

Table 4.8 Types of housing and quality of life scores

Type of housing	Mean Quality of Life Score	SD
Shack (n=25)	164.29	24.33
Room in a garage (n=9)	146.22	37.89
Home shared with other families (n=16)	149.24	35.68
Home not shared with other families (n=20)	139.95	41.16

After a regression analysis, it was found none of the types of housing were found to be statistically significant to each other or the quality of life ($p=1.00$).

In summary, the results of this study show that the overall quality of life (physical and psychosocial combined) in children three months post burn injury is minimally lower than the expected normal score. Individually the physical and psychosocial health summary scores are similarly minimally lower than the expected scores. The quality of life scores improved from one week post discharge to three months post discharge from the burns unit. The severity of the burn (partial thickness and full thickness) was found to be a significant clinical predictor of quality of life. The poor socio-economic status was clearly evident in demographic data of the subjects. The mothers who reported having family problems was found to be marginally significant and this highlighted the socio-economic impact on burn injury.

Chapter 5: DISCUSSION

In this chapter, the results of this study are discussed. The results will be compared to those recorded in previous studies. The limitations of this study are highlighted, and recommendations for future research and clinical practice are made.

5.1 Quality of Life

The main objective of the PedsQL 4.0 Generic Core Scales is to determine the quality of life in children ages five to eighteen and ages two to eighteen with parent proxy. Various studies on healthy children as well as acute and chronically ill children have been done and the questionnaire has been shown to be a valid and reliable health related quality of life measuring tool (Varni et al, 1999; Varni et al, 2001; Varni et al, 2003; Varni et al, 2007). Currently, the PedsQL has not been used to determine the quality of life in paediatric burn survivors.

In this study, the PedsQL was used on a group of children who had been discharged from the Johnson and Johnson Paediatric Burns Unit. The results show that the overall quality of life improved from the initial visit to the follow up visit and was 10% short of expected 'normal' quality of life three months post discharge. The largest improvement in scores was in the physical section which indicates that as the burn wounds heal completely and the children become more functional and mobile in the household, the physical health summary score improves. The psychosocial health summary score did improve but not to the same extent as the physical health summary score. This may be due to the relatively short period of time post burn injury at which the questionnaires were administered. The physical and psychosocial health summary scores were found to be positively correlated which is to be expected as the assessment tool has been found valid and reliable. It is to be noted that these children's quality of life was slightly lower when compared to the normal values of quality of life expected in first world countries and not third world countries.

The improvement in overall scores suggests that the quality of life for children is good despite being burnt. Although the quality of life scores were slightly decreased, they were only approximately 10% short of expected 'normal' quality of life. This may be due to children being young and so recover from injury quicker than adults. Furthermore some children may be too young to understand and acknowledge the long term psychological aspects of being burnt. The follow up PedsQL questionnaire was done three months post discharge from the burn unit and there possibly would be different scores at six months, one and two years follow up post burn injury. These results could be following the pattern of the findings of Vollrath and Landolt (2005) in Norway which suggest that initially children with superficial to moderate burns had a reduced quality of life one month post burn injury. Nonetheless improvements were shown in quality of life twelve months post burn injury.

It is to be noted in this study that there were only three children with over 40% burn injury and so the quality of life scores may have been different with larger body area percentage burns. Reduced quality of life was commented on by Cucuzzo (2001) that children with severe burn injuries (over 40% body surface area) often experience chronic disabilities and have a high potential of developing diseases related to poor quality life style. However Sheridan et al (2000) found that children who had suffered severe burns did not necessarily experience a different quality of life to those who had not been burnt. Furthermore, children with >80% total body surface area burns have been followed up at the Shriners Burns Institute in Galveston, Texas, USA and the children appeared to be adjusting well psychologically and socially post burn injury (Blakeney et al, 1993).

Quality of life scores may have been decreased prior to the burn injury and may be due to other personal and family factors such as poor socio-economic circumstances. It has been documented globally that poor socio-economic circumstances increase the risk of paediatric burn injuries (Cubbins et al, 2000; Van Niekerk, Reimers and Laflamme, 2006; Forjough, 2006; Edelman, 2007; van Niekerk, 2007; Peck et al,

2008). Therefore the decreased socio-economic circumstances that people are living in globally may affect the general quality of life of children even without being burnt. For example, the child might not have toys to help pick up or may have trouble sleeping at night because of overcrowding in one room.

It has been shown that overall quality of life of burn survivors is similar to the non-burn population although burn survivors do have an increased risk of long-term complications post burn injury and this may decrease their quality of life. Another factor impacting on a burn survivor's quality of life is relationships with caregivers and family post burn injury. Mothers of children with burn injuries suffer high levels of stress which consequently impacts on the parent child relationship (Meyer et al, 2004). This was shown in the results of the study under discussion when a large percentage of mothers reported having family problems. However these family problems could include a variety of other factors such as health, family and socio-economic difficulties.

Currently there is no regular mental health professional working in the Johnson and Johnson Paediatric Burns Unit and it is evident that parents and children would benefit from this holistic service in the recovery of a burn injury.

5.2 Clinical Characteristics of the Sample

Various clinical characteristics of the sample were analysed to investigate if the findings of this study were similar to other studies in the literature.

The results from this study demonstrate that hot water burns were the most common cause of burn injury and the limbs most frequently affected. Pre-school children (ages five to seven) had the highest occurrence of flame injuries and this may be a result of this age group of children spending long periods of time outside the home and experimenting with rubbish, bottles and flammable liquids (Van Niekerk, Rode and Laflamme, 2004). The younger children age group (two – five years old) had the

highest number of hot water burns. This is explained by their curiosity of their environment and an increased yet still developing and unsteady ability to explore their environment (Van Niekerk, Rode and Laflamme, 2004). This result is similar to the findings by McLoughlin et al (1990), Van Niekerk, Rode and Laflamme (2004) and Kai-Yang et al (2008).

Furthermore younger children had the higher number of upper limbs burns which is a result of kettles, pots and pans being pulled off higher surfaces and falling from above over the child. McLoughlin et al (1990) discussed the increased risk of spills by hot food and drinks, especially hot water, by young children. In the study under discussion pre-school children had a high number of trunk and lower limbs burns, which have been commented on by Van Niekerk, Rode and Laflamme (2004). These areas of burns may be a likely reflection of the easy access to cooking pots, kettles or heating equipment often found on the floors or low tables (Van Niekerk, Rode and Laflamme, 2004). The uses of these pots with portable kerosene and gas stoves have been associated with childhood burn injury (Kalayi and Muhammad, 1994).

The length of hospital stay was found not to be significantly different for the three different age groups. This indicates that children of different ages stay similar length of time in hospital and are discharged when their wounds are healing well. The mean length of hospital stay was 22 days (± 20.5) and this links with majority of the children having partial thickness burns which takes 14 – 21 days to heal completely (Campbell et al, 1996). The length of hospital stay was shown to be poorly correlated with burn percentage and an explanation of this could be that the length of hospital stay mostly relies on the severity of the burn wound and what intense management is required. This was shown in the study under discussion where children with superficial and partial thickness burns had a significantly shorter hospital stay than children with full thickness burns. A child may have a smaller percentage full thickness burn injury and require intense treatment prolonging the hospital stay versus a child with a larger more superficial burn injury which heals faster than a deeper burn injury. The more severe burns stay longer in hospital for recovery as the

wounds take longer time to heal and often will need multiple theatre visits (sloughectomies and skin grafts) to close the open wounds. Complications such as sepsis, chest infections and contractures also often occur. These complications prolong the hospital stay which in turn increases the opportunity for nosocomial infections. So ideally, once the burn wounds are healing well, the children are discharged home to complete their wound healing and return weekly for dressing changes.

5.3 Clinical Factors Predicting Quality of Life

Various clinical factors were analysed to determine if these factors were predictive of quality of life.

The severity of the burn (partial thickness and full thickness) was found to be significant predictor of quality of life which is to be expected. This is a similar result to the findings of Cucuzzo et al (2001). Children with hot water burns scored lower in quality of life scores than children with flame burns and this may be a result of hot water scalds and spills resulting from kettles and pots being pulled off tables and falling down over a child causing a large percentage burn injury.

The length of hospital stay was found not to be a significant indicator with regards to quality of life. An explanation for this may be that there were only three children with over 40% burns who stayed more than 60 days in hospital. If there were more children who had stayed longer periods of time, the result may have been different. In a retrospective cross-sectional study by Sheridan et al (2000), the length of hospital stay was found to be a statistically significant factor in quality of life of patients. However, these patients sustained over 70% total body surface area burns and so were in hospital for a prolonged period of time.

Injury factors such total body surface area percentage burnt, number of operative procedures and cause of burn do not have a significant impact of the functional

outcome of burn at six months post burn injury (Tyack and Ziviani, 2003). This is similar to the findings of the study under discussion, the total body surface area percentage burnt, the cause of burn and the different areas of the body burnt did not have a significant impact on the quality of life post discharge and three month post burn injury. The results from this study are similar to findings in the literature which have indicated that there is not a relationship between injury factors and functional outcomes (Tyack and Ziviani, 2003).

5.4 Socio-Economic and Demographic Characteristics of the Sample

Soweto is a large township which is home to a large population of African families in Gauteng. Living in areas characterised by overcrowding, poverty as well as households headed by females and children not being the son or daughter of the household head are all significant risk factors for burn injury (Cubbins et al, 2000; Delgado et al, 2002; Van Niekerk, Reimers and Laflamme, 2006). The mean number of occupants per household in this sample was 5.03 (± 1.87) and most of the subjects were living in shacks.

In South Africa, the African population has been reported to have lower educational levels and high rates of unemployment leading to lower socio-economic statuses of families. These poor socio-economic factors have been linked to an increased level of paediatric burn injuries (Werneck and Reichenheim, 1997; Pomerantz et al, 2001; Van Niekerk, Rode and Laflamme, 2004; Edelman, 2007). In particular, it has been shown that mothers with less than a high school education level (do not graduate from matric/grade twelve) increase the risk of burn injury (Pomerantz et al, 2001). In the study under discussion, although 60% of mothers had a secondary education, 30% of mothers had only primary education which indicates lower educational levels. This is in agreement with the literature that many mothers have lower educational levels which are associated with lower income levels, literacy rates and overall health status as well as higher levels of overcrowding in housing (Van Niekerk, Rode and Laflamme, 2004; Edelman, 2007).

The age of the children in the sample was similar to those of other studies (Iregbulem and Nnabuko, 1993; Morrow, 1996; Kai-Yang et al, 2008) with the majority of children being pre-school children (5- 7 years old) and younger children (2- 4 years old). Children under the age of two years were not included in the study under discussion as the PedsQL has only been shown valid and reliable for children two years and older.

A large number of children with burns are not attending crèche or school and so have an increased risk of burn injury with increased time inside and outside of the home as opposed to activities at crèche or school. This is confirmed by Forjough et al (1995) who found a peak time for burn injury is in the late morning period after breakfast when children had been left at home. Children do not go to crèche/school because of the poor socio-economic circumstances and furthermore the lack of childcare services in the poorer townships also results in children being left alone or with an aged relative caring for a number of children. These factors increase the risk on injury (Van Niekerk, Reimers, Laflamme, 2006; Frenkel, 2008).

Other demographic data from this study showed that 15.7% of mothers reported that their children have often and regularly gone hungry as there was no food in the house. This may be an indication of the poverty in the local community. The majority of caregivers reported they live in a safe area however there were caregivers who reported that their residential area was dangerous and that they worry all the time when their child is playing outside the home. Furthermore, most of the caregivers reported having a refrigerator and a television but video-machines, home telephones, cars, washing machines and microwaves were uncommon in the sample. This is a further indication of the socio-economic status of the local community.

A likely explanation for the high number of paediatric burn injuries presenting to the Chris Hani Baragwanath Johnson and Johnson Paediatric burns unit is a result of the large African community that the hospital services and is situated in Soweto, a poor

socio-economic township. Furthermore, as a developed Burns unit, children are often sent from surrounding hospitals and clinics for further specialised wound care management.

5.5 Socio-Economic and Demographic Factors Predicting Quality of Life

It has been documented globally that poor socio-economic circumstances increase the risk of paediatric burn injuries (Cubbins et al, 2000; Van Niekerk, Reimers and Laflamme, 2006; Forjough, 2006; Edelman, 2007; van Niekerk, 2007; Peck et al, 2008).

Several socio-economic factors were analysed to identify which factors were predictive of quality of life in children post burn injury. The only socio-economic factor which was found to be marginally significant in predicting quality of life was the mothers who reported having family problems. The marginal significance may be explained by the small sample size in the study and there might have been a stronger significance with a larger sample of subjects.

In this sample, 35.7% of the mothers were single and this indicates that these mothers have to look after their children (often more than one or two children), run a household and try to earn an income for the family. The other factor is if the mother has a job, she will leave her younger children (those not attending crèche/school) with an aged relative or alone in the home which increases the risk of burn injury. This is in agreement with the findings of Van Niekerk, Reimers, Laflamme (2006) and Frenkel (2008) who found that the lack of childcare services in the poorer townships results in children being left alone or with an aged relative caring for a number of children. However, the findings of this study show that whether the child was or wasn't attending crèche or school did not influence the quality of life three months post burn injury.

In the study under discussion, the majority of children with burn injuries were of younger ages (two to seven years of age). Tjack and Ziviani (2003) found that the age of the child contributed significantly to the functional outcome six months post burn injury. Tjack and Ziviani (2003) concluded that the younger the child at the time of the burn injury, the better functional outcome of the child six months post burn injury.

It is interesting to note that the mean quality of life scores of children living in the shacks was the highest (mean quality of life score 164.29) and the lower scores were children living in a home not shared with other families (mean quality of life score 139.95). This may be a result of the small sample size as well as most of the children in the study sample were living in shacks. This result may differ if there were an equal number of children living in each type of housing type in the sample of subjects. Nevertheless, none of the types of housing predicted the quality of life of children post burn injury.

The literature has indicated that there is a relationship between pre-morbid factors (behaviour problems, psychological or psychiatric problems, learning disability or developmental delay) and functional outcome, as well as parent factors (anxiety, depression, coping and social support) and functional outcome. However there is no relationship between injury factors and functional outcomes (Tjack and Ziviani, 2003).

5.6 Limitations of the Study

There were a high number of children lost to follow up. The main reason for this was lack of transport money (although mothers and caregivers were advised that transport money would be given to them on their follow up date). Other reasons for high loss to follow up include being out of Gauteng at the time, caregivers working and unable to get off work, losing the appointment cards and caregivers forgetting the date to return. A couple of weeks into the study once high loss of children to follow up was observed, phone numbers for caregivers were documented and caregivers were called telephonically two days before their appointment date as a reminder. This improved the follow up attendance noticeably, however some of the phone numbers were incorrect or always on voicemail and thus not all caregivers could be contacted. Caregivers were given a contact number on their appointment cards and were asked to contact the physiotherapist if they couldn't make their appointment date to re-schedule their follow up visit.

5.7 Recommendations for Further Research

Clinically:

- A mental health professional should be involved in the unit, possibly once or twice a week to offer support and guidance particularly for the older children recovering from burn injuries

Research:

- A long term follow up of the children would be beneficial to show the quality of life score changes with time and what the quality of life is one year post discharge compared to one week post discharge and three months post discharge
- It has been documented in the literature that scar hypertrophy and facial and limb disfigurement have an impact on quality of life and it would be beneficial to see how the local population is affected by these and other long term complications of burn injury
- Developing a standardised functional outcome measure for burn survivors in developing countries

- A study investigating the benefits of having a psychologist as part of the multi-disciplinary team in the holistic management of children with burn injuries in South Africa
- A study looking at demographics and socio-economics of the population being affected by burn injuries in rural settings and comparing this data to urban settings

The results from this study are particularly important for further research that would be beneficial to developing countries and South Africa. There has been limited research done on paediatric burn injuries locally and so there is a large gap in the literature on paediatric burn injury in South Africa. Furthermore, the results from this study will contribute to the development of a more comprehensive management and rehabilitation program for children suffering burn injuries in South Africa.

Chapter 6: CONCLUSION

The purpose of this study was to determine which clinical and socio-economic factors predicted quality of life in children post burn injury. All subjects were from similar socio-economic backgrounds and attended the Johnson and Johnson Paediatric Burns Unit clinic in Soweto, Johannesburg. The assessment tool used was the PedsQL.

The findings of this study show that the quality of life of children three months post burn injury is minimally lower than the expected normal scores. The quality of life scores improved from one week post discharge to three months post discharge from the burns unit. The largest improvement in scores was in the physical health summary score which indicates that as the burn wounds heal completely and the children become more functional and mobile in the household, the physical score improves. The psychosocial health summary score improved slightly but not greatly and may be due to being a short period of time post burn injury. The improvement in overall scores suggests that the quality of life for children is good despite being burnt.

The severity of the burn (partial thickness and full thickness) was found to be a significant clinical predictor of quality of life. However, the length of hospital stay was found not to be a significant predictor of quality of life. The poor socio-economic status was clearly evident in demographic data of the subjects. A marginally significant socio-economic predictor of quality of life was family problems reported by some of the mothers. To some extent this highlights the increased risk of burn injury where there are poor socio-economic circumstances.

The results of this study are important in the move towards more holistic care for paediatric burn survivors. The children and caregivers in the Johnson and Johnson Paediatric Burns Unit may benefit from having a mental health care professional in the unit regularly to provide support and guidance in the rehabilitation of a burn injury.

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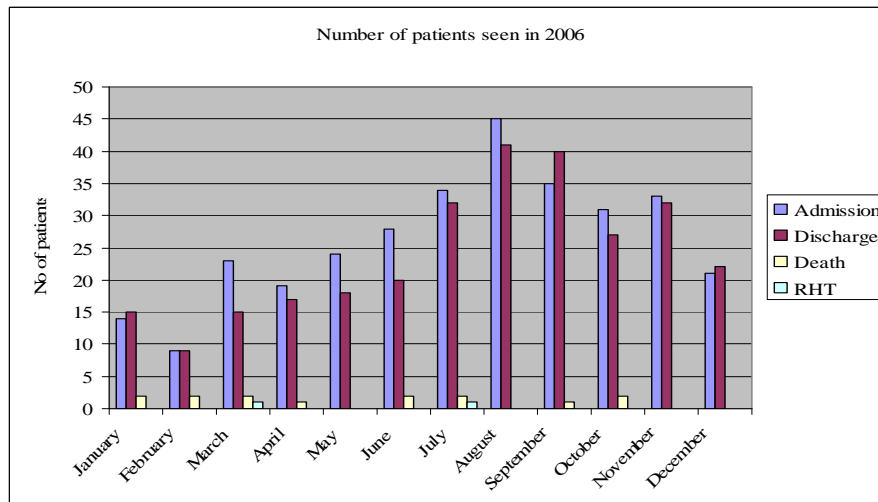
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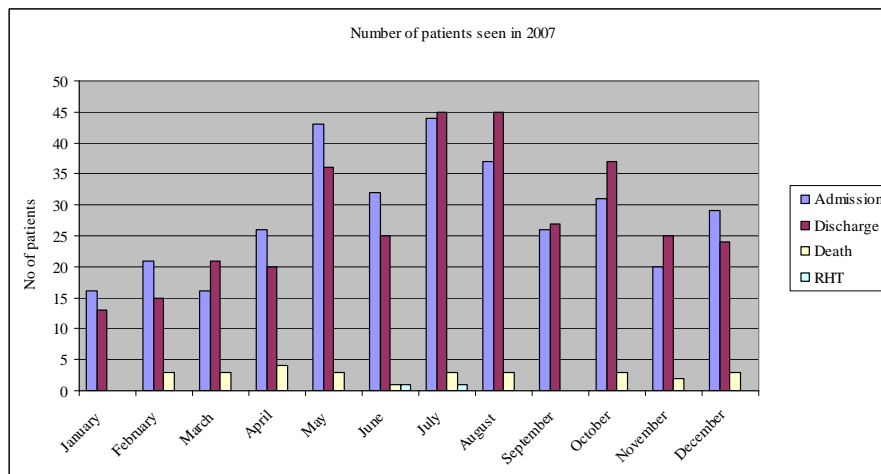
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Appendix Ia



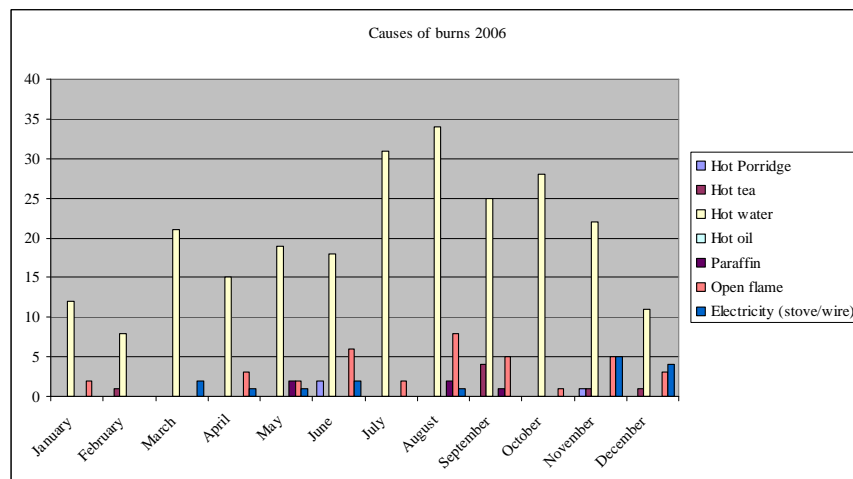
Total number of patients admitted, discharged, number of deaths and refusal of hospital treatment (RHT) at Paediatric Burns Unit, Chris Hani Baragwanath Hospital in 2006

Appendix Ib



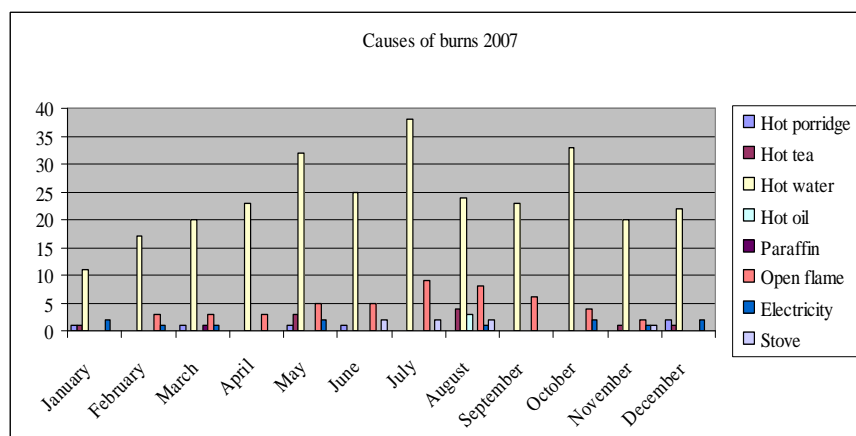
Total number of patients admitted, discharged, number of deaths and refusal of hospital treatment (RHT) at Paediatric Burns Unit, Chris Hani Baragwanath Hospital in 2007

Appendix Ic



Causes of burns in 2006 at Paediatric Burns Unit, Chris Hani Baragwanath Hospital

Appendix Id



Causes of burns in 2007 at Paediatric Burns Unit, Chris Hani Baragwanath Hospital

Appendix II: Ethical Clearance

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

R14/49 Weedon

CLEARANCE CERTIFICATE

PROTOCOL NUMBER M071025

PROJECT

Socio-Economic and Clinical Factors Predictive
of Paediatric Quality of Life Post Burn Injury

INVESTIGATORS

Ms MB Weedon

DEPARTMENT

Physiotherapy Department

DATE CONSIDERED

07.10.26

DECISION OF THE COMMITTEE*

APPROVED UNCONDITIONALLY

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 07.12.07

CHAIRPERSON 

(Professors PE Cleaton-Jones, A Dhali, M Vorster,
C Feldman, A Woodiwiss)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Dr J Potterton

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10005, 10th Floor, Senate House, University.

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix III: Informed Consent

CONSENT FORM

Research Problem: To Determine the Socio-Economic and Clinical Factors Which Predict Quality Of Life in Children with Burn Injuries

I..... understand the purpose of this project and give consent for my child.....to participate in the research. I have read and understand the information and my questions have been answered. I am fully aware of the procedures and the fact that they will not harm my child in any way. I am aware that I may withdraw my child from the research without any prejudice towards my child or myself.

.....
Parent/guardian

.....
Researcher

.....
Date

.....
Date

Appendix IV: Informed Assent

ASSENT FORM: PAEDS BURNS

I.....say that it is okay for the physiotherapist to test me in this project. I understand what this project is about and understand what I am expected to do as part of it. I understand what has been explained to me about answering some questions. My questions have been answered. I know that taking part in this project will not harm me in any way. I am aware that I may say that I do not want to be tested in the project.

.....
Patient

.....
Researcher

.....
Date

.....
Date

Appendix V: Information Sheet – Parent

INFORMATION SHEET

Dear Care Giver

Good morning and thank you for taking the time to read this letter.

Your child has been invited to take part in a study at Chris Hani Baragwanath Hospital Paediatric Burns Unit which is being conducted by Merryn Weedon, Senior Physiotherapist and Nombulelo Sekhu Physiotherapy Assistant.

We would like to find out what things influence your child's quality of life after being burnt. The results that we get from this study will help us to develop a better service for future parents and children in the management of children with burn injuries.

We will be asking your child a few questions about how he/she is feeling and about his/her health after he/she has left the hospital and ask you a few questions about your social conditions and community. We will also give you 3 month follow up date where your child will be asked the same questions again to see if there is change from the first time. We will give you transport money for the 3 month follow up visit. The names of the questionnaires we will use are Paediatric Quality of Life and the Household Economic and Social Status Index. None of the above questions will cause harm to you or your child. It will take about 10 minutes to fill in the questionnaires. We will ask you and your child the questions before your child is washed and dressed so your child should not be in any pain. If you agree to help us, we will ask you to sign a consent form before any questions will be asked. If your child is over the age of 6 years, we will also ask them to sign an assent form where they will write their name. We will explain what we will be doing and why to your child verbally in a language he/she understands.

If you have any questions or worries about this study, please don't hesitate to ask either Merryn or Nombulelo. Whether or not your child takes part in this study, he/she will still receive physiotherapy when you come for follow up visits. You may choose to withdraw from the study at any time and your child will still receive physiotherapy.

Both of us are employed at Chris Hani Baragwanath Hospital and work in the paediatric burns unit daily. Your name and your child's name will not be used on the data collection form, thus your patient confidentiality will be respected. Participation in this study is voluntary and you may withdraw your child from the study at any time.

Thank you for your time. Please feel free to contact me if you have any questions at all, here are my contact details: 011 933 8309, 082 496 4765

Appendix VI – Information Sheet Child

INFORMATION SHEET

Dear Child,

Hello, sawubona, dumela. You have been chosen to take part in our project which Merryn, a physiotherapist and Nombulelo, a physiotherapist assistant working at Chris Hani Baragwanath Hospital in the Children's Burns Unit are doing.

We have chosen you as you are between the ages of two to twelve years, and have been recently burnt.

Why are we doing this? We want to find out what problems you have after you have been burnt once you go home. We will also ask you some questions to find out how you are doing at home since you went home and how you are feeling. All the information we get from you and the other children will help us as physiotherapists to see if we can help you any more than we do now.

What are we going to do? We will ask you a few questions or if you are old enough answer some questions for us on a piece of paper. We will do these questions with you on your first visit back to the hospital for dressings but before you get bathed so you will not be in any pain. It won't take very long to ask these questions. We will also give you a date to come back in 3 months time so we can ask the questions again to see if they have changed from before.

If you don't want to take part in this project you must tell the physiotherapist and she will get you to write your name on a piece of paper and then we won't ask you any questions. Your mom or dad will also have to sign a piece of paper saying that they don't want you to be included in the study.

The people who are going to do this study work at the hospital and you may even know them - Merryn and Nombulelo. Just to make sure that the information stays a secret we won't put your name on the piece of paper with all the results. If you do not want to take part in this study it does not matter and you will still get all your treatment.

Thank you and have a good day

Appendix VII – Household and Economic Social Status Index (HESSI)

Household Economic and Social Status Index (HESSI)		What are the names, occupation and industry of the primary wage earners in the house?	
(Barbarin, et al, 1995)		Name	Occupation
Who provided the information below _____		Industry	
I. Family Structure/Household Composition (Score 1-10) Ia. Marital Status of Mother 1. Never married, not now living with a partner 2. Married, but not living now with a partner (e.g. divorced, separated) 3. Widowed 4. Never married, but now living with partner 8. Married and currently living with partner			
Ib. Household Membership. How many people currently reside in the household? _____ Number 18 and older _____ Number 6-18 yrs old _____ Number under 6 yrs old _____			
Ic. Are there adult relative now residing in the household? 0. No 2. Yes. If yes who are they in relationship to the child? _____			
II. Social Status- (Education, Occupation, [2-18]) A. Mother's Education: What is the highest level of education attained by mother? 1. Less than Standard 3 2. Primary School (Standard 3-4) 3. Junior Secondary (Standard 5-7) 4. Senior Secondary (Standard 8-9) 5. Matric/High School graduate/vocational training diploma 6. 1-2 yr College, Technician 7. 3-4 yrs of University 8. Ph.D., M.D., J.D., D.D.S., or other doctoral degree			
B. Education of Mother's Partner: What is the highest level of education attained? 1. Less than Standard 3 2. Primary School (Standard 3-4) 3. Junior Secondary (Standard 5-7) 4. Senior Secondary (Standard 8-9) 5. Matric/High School graduate/vocational training diploma 6. 1-2yr College, Technician 7. 3-4 yrs of University 8. Ph.D., M.D., J.D., D.D.S., or other doctoral degree			
Access to Finances Who in the family earns money? Check all that apply. _____ BTT mother _____ Partner _____ Parent _____ Parent Pension _____ Sibling/Aunt/Uncle			
III. Housing Accommodation. In what type of housing do you live? 0. None, homeless 1. Shack 2. Hostel 3. Room, garage 4. Flat, cottage 5. Home shared with other family(ies). 6. Home that is <u>not</u> shared with other families.			
B. Does your home have 1) A Separate Kitchen? 0. No 1. Yes 2) A Separate Bathroom? 0. No 1. Yes			
a) In your home how many separate rooms are there <u>just for sleeping?</u> (circle one number) 0 1 2 3 4 or more.			
b) What type of <u>toilet facilities</u> does your home have: 0. None 1. Pit or Bucket 2. Outside flush toilet 3. Inside flush			
c) Do you own or rent a home. 0. Neither 1. Rent 2. Purchasing on Bond 3. Own			

d) How much do you pay monthly for rent or bond? R_____.
For Service Charges R_____

e) For Electricity:
(highest in the last year) R_____
(the lowest) R_____

Does the place you live in have a...?

- | | | |
|--------------------|-------|--------|
| a) Refrigerator | 0. No | 1. Yes |
| b) Television | 0. No | 1. Yes |
| c) Telephone | 0. No | 1. Yes |
| d) Car | 0. No | 1. Yes |
| e) Video recorder | 0. No | 1. Yes |
| f) Washing machine | 0. No | 1. Yes |
| g) Microwave oven | 0. No | 1. Yes |

h) In the past, have your children gone hungry because you did not have food?

3. No, never
2. Rarely
1. Often
0. All the time

Factor VI. Savings: (Score 0-3)

- | | | |
|--|-------|--------|
| a) Do you have savings or participate in a savings plan? | 0. No | 1. Yes |
| b) Do you have life insurance (version 1/25/96) | 0. No | 1. Yes |

Maternal Well-being

Do you have any problems you might like to talk over with a doctor?

0. No
1. Yes (specify)

During the past 3 months have you had any physical or emotional condition for which you have been receiving treatment or taking medication?

0. No
1. Yes (specify)

During the past 3 months Have you been anxious, worried or upset?

Extremely so—to the point of being sick or almost sick

- Very much so
Quite a bit
Some—enough to bother me
A little bit
Not at all

During the past 3 months, have you felt so sad, discouraged, hopeless or had so many problems that you wondered if anything was worthwhile?
Extremely so—to the point that I have just about given up

- Very much so
Quite a bit
Some—enough to bother me
A little bit
Not at all

In any one year have you had at least 12 drinks of any kind of alcoholic beverage? Yes No

Have you ever had any serious physical handicap? 0. No 1. Yes
Have you ever been a patient (or outpatient) at a mental hospital, mental health ward of a hospital, or a mental health clinic for any personal emotional, behavior, or mental problem?

- Yes, during the past year
Yes, more than a year ago
No

Neighborhood Safety

A. In general how safe is the area in which you live?

1. Extremely dangerous
2. Dangerous
3. Safe
4. Extremely Safe

B. How much do you worry about your child getting hurt when s/he is outside of your home?

1. Never
2. Sometimes
3. Often
4. All the time

Satisfaction with Family Life (Support)

My family has a lot of problems:

1. Not True
2. Sometimes True
3. Often True
4. Always True

My family is always there for me when I need them.

1. Not True
2. Sometimes True
3. Often True
4. Always True

Appendix VIII – Paediatric Quality of Life (PedsQL) 4.0 Generic Core Scales

	<div style="border: 1px solid black; padding: 2px; display: inline-block;">ID# _____ Date: _____</div>
<div style="display: flex; justify-content: center; align-items: center;"><div style="text-align: center;"><h1 style="margin: 0;">PedsQLTM</h1><h2 style="margin: 0;">Pediatric Quality of Life Inventory Acute Version</h2><p style="margin: 5px 0;">Version 4.0</p><p style="margin: 10px 0;">PARENT REPORT for TODDLERS (ages 2-4)</p></div></div> <div style="border: 1px solid black; padding: 10px; margin: 20px auto; width: 80%;"><p style="text-align: center; margin: 0;">DIRECTIONS</p><p style="margin: 5px 0;">On the following page is a list of things that might be a problem for your child. Please tell us how much of a problem each one has been for your child during the past 7 days by circling:</p><div style="margin: 10px 0;"><div style="display: flex; justify-content: space-between;"><div>0 if it is never a problem</div><div>1 if it is almost never a problem</div></div><div style="display: flex; justify-content: space-between;"><div>2 if it is sometimes a problem</div><div>3 if it is often a problem</div></div><div style="display: flex; justify-content: space-between;"><div>4 if it is almost always a problem</div></div></div><p style="margin: 10px 0;">There are no right or wrong answers. If you do not understand a question, please ask for help.</p></div> <div style="margin-top: 20px; padding-top: 10px;"><p style="margin: 0;"><i>In the past 7 days, how much of a problem has your child had with ...</i></p><div style="display: flex; justify-content: space-between; font-size: small; margin-top: 10px;"><div>PedsQL 4.0 - Parent (2-4) Acute 03/00</div><div>Not to be reproduced without permission</div><div>Copyright © 1998 JW Varni, Ph.D. All rights reserved</div></div></div>	

In the past **ONE month**, how much of a **problem** has your child had with ...

PHYSICAL FUNCTIONING (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. Walking	0	1	2	3	4
2. Running	0	1	2	3	4
3. Participating in active play or exercise	0	1	2	3	4
4. Lifting something heavy	0	1	2	3	4
5. Bathing	0	1	2	3	4
6. Helping to pick up his or her toys	0	1	2	3	4
7. Having hurts or aches	0	1	2	3	4
8. Low energy level	0	1	2	3	4

EMOTIONAL FUNCTIONING (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. Feeling afraid or scared	0	1	2	3	4
2. Feeling sad or blue	0	1	2	3	4
3. Feeling angry	0	1	2	3	4
4. Trouble sleeping	0	1	2	3	4
5. Worrying	0	1	2	3	4

SOCIAL FUNCTIONING (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. Playing with other children	0	1	2	3	4
2. Other kids not wanting to play with him or her	0	1	2	3	4
3. Getting teased by other children	0	1	2	3	4
4. Not able to do things that other children his or her age can do	0	1	2	3	4
5. Keeping up when playing with other children	0	1	2	3	4

***Please complete this section if your child attends school or daycare**

SCHOOL FUNCTIONING (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. Doing the same school activities as peers	0	1	2	3	4
2. Missing school/daycare because of not feeling well	0	1	2	3	4
3. Missing school/daycare to go to the doctor or hospital	0	1	2	3	4

ID#	_____
Date:	_____

PedsQLTM

Pediatric Quality of Life Inventory Acute Version

Version 4.0

YOUNG CHILD REPORT (ages 5-7)

Instructions for interviewer:

I am going to ask you some questions about things that might be a problem for some children. I want to know how much of a problem any of these things might be for you.




Show the child the template and point to the responses as you read.

If it is not at all a problem for you, point to the smiling face

If it is sometimes a problem for you, point to the middle face

If it is a problem for you a lot, point to the frowning face

I will read each question. Point to the pictures to show me how much of a problem it is for you. Let's try a practice one first.

	Not at all	Sometimes	A lot
Is it hard for you to snap your fingers			

Ask the child to demonstrate snapping his or her fingers to determine whether or not the question was answered correctly. Repeat the question if the child demonstrates a response that is different from his or her action.

Think about how you have been doing for the past 7 days. Please listen carefully to each sentence and tell me how much of a problem this is for you.

After reading the item, gesture to the template. If the child hesitates or does not seem to understand how to answer, read the response options while pointing at the faces.

PHYSICAL FUNCTIONING (problems with...)	Not at all	Some-times	A lot
1. Is it hard for you to walk	0	2	4
2. Is it hard for you to run	0	2	4
3. Is it hard for you to play sports or exercise	0	2	4
4. Is it hard for you to pick up big things	0	2	4
5. Is it hard for you to take a bath or shower	0	2	4
6. Is it hard for you to do chores (like pick up your toys)	0	2	4
7. Do you have hurts or aches (<i>Where?</i> _____)	0	2	4
8. Do you ever feel too tired to play	0	2	4

Remember, tell me how much of a problem this has been for you for the past 7 days.

EMOTIONAL FUNCTIONING (problems with...)	Not at all	Some-times	A lot
1. Do you feel scared	0	2	4
2. Do you feel sad	0	2	4
3. Do you feel mad	0	2	4
4. Do you have trouble sleeping	0	2	4
5. Do you worry about what will happen to you	0	2	4

SOCIAL FUNCTIONING (problems with...)	Not at all	Some-times	A lot
1. Is it hard for you to get along with other kids	0	2	4
2. Do other kids say they do not want to play with you	0	2	4
3. Do other kids tease you	0	2	4
4. Can other kids do things that you cannot do	0	2	4
5. Is it hard for you to keep up when you play with other kids	0	2	4

SCHOOL FUNCTIONING (problems with...)	Not at all	Some-times	A lot
1. Is it hard for you to pay attention in school	0	2	4
2. Do you forget things	0	2	4
3. Is it hard to keep up with schoolwork	0	2	4
4. Do you miss school because of not feeling good	0	2	4
5. Do you miss school because you have to go to the doctor's or hospital	0	2	4

ID# _____
Date: _____

PedsQLTM

Pediatric Quality of Life Inventory Acute Version

Version 4.0

CHILD REPORT (ages 8-12)

DIRECTIONS

On the following page is a list of things that might be a problem for you.
Please tell us **how much of a problem** each one has been for you during the
past 7 days by circling:

- 0** if it is **never** a problem
- 1** if it is **almost never** a problem
- 2** if it is **sometimes** a problem
- 3** if it is **often** a problem
- 4** if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

*In the past 7 days, how much of a **problem** has this been for you ...*

ABOUT MY HEALTH AND ACTIVITIES (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. It is hard for me to walk more than one block	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activity or exercise	0	1	2	3	4
4. It is hard for me to lift something heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I hurt or ache	0	1	2	3	4
8. I have low energy	0	1	2	3	4

ABOUT MY FEELINGS (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad or blue	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

HOW I GET ALONG WITH OTHERS (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I have trouble getting along with other kids	0	1	2	3	4
2. Other kids do not want to be my friend	0	1	2	3	4
3. Other kids tease me	0	1	2	3	4
4. I cannot do things that other kids my age can do	0	1	2	3	4
5. It is hard to keep up when I play with other kids	0	1	2	3	4

ABOUT SCHOOL (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. It is hard to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my schoolwork	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4