

**PRIMARY CAREGIVERS' EVALUATION OF A
BURNS REHABILITATION PROGRAMME
AT THE RED CROSS CHILDREN'S
HOSPITAL**

A PARBHOO



ASSIGNMENT PRESENTED IN PARTIAL FULFILMENT OF THE REQUIREMENTS
FOR THE DEGREE OF MPhil. (REHABILITATION) AT THE UNIVERSITY OF
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SUPERVISOR: MS G. MJI

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DECLARATION

I, the undersigned, hereby declare that the work submitted in this assignment is my own original work, that it has not been submitted in its entirety or in part for any degree or examination to any other university. All the sources I have used or quoted have been indicated and acknowledged by complete references.

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Date:

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ABSTRACT

A burn injury is an injury for life, causing scarring on a physical, emotional and psychological level. For these individuals, rehabilitation is a vital aspect of regaining their lives. The burns unit at the Red Cross Children's Hospital aims to provide a comprehensive health care service to all children who have suffered from a burn injury. The service is enveloped by an interdisciplinary team approach to management. The burns team perceives the rehabilitation programme to be an effective one, but this has never been evaluated. The researcher has the perception that the primary caregivers are the people who could evaluate the burns unit at the Red Cross Children's Hospital.

Hence the aim of this study was to determine how primary caregivers evaluated the rehabilitation of a child at the burns unit of the Red Cross Children's Hospital.

The design of the study was of a retrospective, descriptive and analytical nature. The study population consisted of all primary caregivers of patients who have been managed in the burns unit at the Red Cross Children's Hospital, from the period of 1 June 2001 to 30 July 2003. A sample size of 30 primary caregivers, who suited the inclusion and exclusion criteria, were randomly chosen. They were all interviewed using questionnaires that were compiled by the researcher. Quantitative and qualitative data was collected during the interviews.

Results on the evaluation of aspects such as management in hospital, caregiver involvement, discharge planning and rehabilitation outcome, showed that primary caregivers found most aspects to be satisfactory at the burns unit of Red Cross Children's Hospital. The scores on the level of satisfaction of the above aspects were between 86% and 100% for management, between 94%-97% for discharge planning, 97% for caregiver involvement, and 75%-100% for rehabilitation outcome. Factors that were reported to be unsatisfactory were pain management, the child's psychological outcome and service and fit of pressure garments.

Recommendations regarding pain management and reintegration of the child into the community were made to team members of the unit. The urgent need for a full time psychologist was advocated to the hospital management. These recommendations were based on the findings of this study.

OPSOMMING

'n Brandbesering is 'n lewenslange besering wat liggaamlike, emosionele en sielkundige letsels laat. Vir individue met sodanige beserings is rehabilitasie hoogs belangrik vir die herwinning van hulle lewens. Die brandwondeenheid van die Rooikruis Kinderhospitaal het ten doel om 'n omvattende gesondheidsorgdiens aan alle kinders wat 'n brandbesering opgedoen het, te bied. Die diens word deur 'n interdisiplinêre spanbenadering tot bestuur omsluit. Die brandspan beskou die rehabilitasieprogram as effektief, maar dit is nooit voorheen geëvalueer nie. Die navorser is van mening dat primêre versorgers ons van sienings rakende die bestuur van brandpasiente kan voorsien.

Die doelwit van hierdie studie was om te bepaal hoe primêre versorgers die rehabilitasie van 'n kind by die brandwondeenheid van die Rooikruis Kinderhospitaal geëvalueer het.

Die studie se ontwerp was retrospektief, beskrywend en analities van aard. Die studiebevolking het bestaan uit alle primêre versorgers van pasiënte wat vir die tydperk van 1 Junie 2001 tot 30 Julie 2003 in die brandwondeenheid van die Rooikruis Kinderhospitaal behandel is. 'n Steekproefgrootte van 30 primêre versorgers, wat aan die insluitings en uitsluitingskriteria voldoen het, is ewekansig gekies. Onderhoude is met almal gevoer deur middel van vraelyste wat deur die navorser opgestel is. Kwantitatiewe en kwalitatiewe data is tydens die onderhoude versamel.

In die lig van die aspekte van bestuur in die hospitaal, die betrokkenheid van versorgers, ontslagbeplanning en rehabilitasie-uitkoms is die slotsom bereik dat primêre versorgers met die meeste aspekte van die brandwondeenheid van die Rooikruis Kinderhospitaal tevrede was. Die tellings vir die vlak van tevredenheid van die bogenoemde aspekte was tussen 86% en 100% vir bestuur, 97% vir die betrokkenheid van versorgers, tussen 94% en 97% vir ontslagbeplanning en tussen 75% en 100% vir rehabilitasie-uitkoms. Faktore wat as onbevredigend uitgewys is, was pynbeheer, die kind se sielkundige uitkoms asook die diens en pas van drukkleding.

Op grond van die bespreking en resultate van hierdie studie, was aanbevelings by die eenheid se spanlede asook die hospitaalbestuur gedoen.

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DEFINITION OF TERMS

Accountable clinician

The clinician being responsible for quality of care, patient satisfaction, efficient use of resources, and ethical behaviour (De Lisa and Gans, 1993).

Activity limitation

Difficulty an individual may have in executing activities. Any activity limitation may range from a slight to a severe deviation in terms of quality or quantity when executing the activity in a manner or to the extent that is expected of people with the health condition (World Health Organisation, (WHO) 2001).

Autonomy

A notion of respect for the values and beliefs of other persons. Persons are seen to possess a right to self determination that ensures freedom to make their own choices unfettered by the intervention of others. The principle of autonomy underlies the medical doctrine of informed consent. There is an obligation to provide patients with accurate information about their diagnoses and treatment alternatives and to seek their permission before instituting treatment (Beauchamp & Childress, 1989).

Beneficence

Doing good deeds, acting kindly and with charity to others. It refers to an obligation to help others, refrain from hurting them and attempt to balance benefits with harms. In a medical setting, beneficent behaviour promotes the health and well-being of patients and attempts to ameliorate disease, injury, pain and suffering (Beauchamp & Childress, 1989).

Burn injury

Tissue damage caused by such agents as heat, chemicals, electricity, sunlight, or nuclear radiation (Concise Medical Dictionary, 1980).

Child

For the purpose of this study a child will be any individual from the age of a newborn to under the age of 13 years.

Client

A person using the services of a professional person (The Oxford Paperback Dictionary, 1979). For the purpose of this study *patient* and *client* will be used interchangeably.

Client-centred approach

A humanistic approach of management that acknowledges the patients and their families as capable of participation in patient care issues (Beauchamp & Childress, 1989).

Compliance

The extent to which the actions of patients, their families and other professionals coincide with therapeutic recommendations (Cadman, Shurvell, Davies & Bradfield, 1984).

Debridement

The process of cleaning an open wound by removal of foreign material and dead tissue, so that healing may occur without hindrance (Concise Medical Dictionary, 1980).

Disability

Any restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or within the range considered normal for a human being (WHO, 2001).

Handicap

A disadvantage for a given individual, resulting from an impairment or a disability that prevents the fulfilment of a role that is considered normal (depending on age, sex, social and cultural factors) for that individual (WHO, 1980). This term is no longer used. It has been replaced by the term participation restriction as defined in the ICIDH2, 1999.

Holistic rehabilitation

Integrated, holistic rehabilitation is a continuous effort of all members of the burn team, the patient and his/her family to deal with all functional, aesthetic and psychological sequelae in order to return the patient and the family to daily life at the highest possible level of physical, emotional and social capabilities (European Club For Paediatric Burns (ECPB), 2001).

Impairment

A loss or abnormality in body structure or physiological function (including mental functions).

Abnormality here is used strictly to a significant variation from established statistical norms (i.e. as a deviation from a population mean within measured standard norms) and should be used only in this sense (WHO, 2001).

Interdisciplinary team

Utilises overlapping skills and knowledge of team members of different disciplines to obtain a synergistic effect whereby the outcome is enhanced and more comprehensive than the simple aggregation of individual efforts (Melvin 1980; De Lisa and Gans, 1998).

Medical model

Intervention is provided only by health professionals and is child-focused. Parents are passive recipients of advice and remain dependent on professionals (Bazyk, 1989).

Primary caregiver

An informal caregiver that may be the biological mother or father, grandparents, friends, foster or adoptive parents who provide most of the care to the child at home (Zimba & McInerney, 2001).

Primary intervention and primary centre

A client's first point of entry in a comprehensive community health care system. Primary health care is the first element of a continuing health care process (Denhill, King & Swanepoel, 1999). It occurs at a primarily at a primary health care centre, but may occur at other health care centres.

Participant restriction

Problems an individual may have in the manner or extent of involvement in life situations, (WHO, 1999).

Patient

A person receiving treatment (The Oxford Paperback Dictionary, 1979)

(For the purpose of this study *patient* and *client* will be used interchangeably

For the purpose of this study all patients will be the children who are part of this study.

Rehabilitation

Rehabilitation includes all measures aimed at reducing the impact of disability for an individual, enabling him or her to achieve independence, social integration, a better quality of life and self-actualisation. Rehabilitation includes not only the training of disabled people, but also

interventions in the general systems of society, adaptations to the environments and protection of human rights. Protection of human rights is an obligation for the authorities of each country, for its communities and for every citizen. Disabled people shall have the same rights to a dignified life as others, and there may be no exceptions. Special attention may be needed to ensure the following: access to health and social services; to educational and work opportunities; to housing, transportation and to buildings; to information; to cultural and social life, including sports and recreational facilities; to representation and full political involvement in all matters of concern to them (Helander, 1992).

Secondary intervention and secondary centre

Care aimed at curing and preventing diseases, to prevent the spread of communicable diseases, the prevention of the complications and sequences of disease, thereby shortening the period and extent of disability and preventing chronicity and death (Beaglehole, Bonita & Kjellström, 1993). Secondary care occurs primarily at a secondary health care centre or secondary hospital, but may occur at another health care centre.

Social model

Addresses the disadvantages, which the person with a disability faces in a society, which by physical or attitudinal barriers excludes such a person from the mainstream of social activity (Wirz & Lichtig, 1999).

Team

A group of people, each of whom possesses particular expertise; each of whom is responsible for making individual decisions; who together hold a common purpose; who meet to communicate, collaborate and consolidate knowledge from which plans are made, actions determined and future decisions influenced (Bloom & Parad, 1976).

Tertiary intervention

Utilises intervention that involves treating diseases or conditions in its later stages. The aim is to provide rehabilitation that optimises function, thus preventing or reducing impairment and disability (Katzenellenbogen, Joubert & Abdool Karim, 1997).

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CHAPTER 1

INTRODUCTION

1.1 BACKGROUND

A burn injury has, and will always continue to be, a devastating injury. The very thought of skin disintegrating under a flame or boiling liquid, combined with all the shock and anticipated pain, reinforces this statement. A burn is not just a physical injury to the body. It is also a psychologically, emotionally and spiritually traumatic journey. When that individual is a child, this trauma is made worse by other factors, such as separation from a parent or caregiver and the inability to fully understand what is happening.

A burn injury, irrespective of the cause of the burn, always results in trauma and scarring. Both the trauma and scarring are on a physical, emotional and psychological level. The physical trauma involves the interruption of the integrity of the skin. The burn is emotionally traumatic since the incident often involves the child having nightmares or flashbacks about the incident. Scars often lead to contractures in spite of efforts to counteract them. This leads to a decrease in function, and therefore limited independence.

In children, most of the burns are due to fires, which are made in informal dwellings, or they are due to hot water, often splashed over a patient due to kettle cords accidentally pulled or pots of hot water knocked over. Primary caregivers of children who have been involved in a burn report the chaos that follows immediately after the burn. The child experiences shock, fear and pain, at which point he or she will start screaming, and then crying. Ninety five percent of the time the child calls for their mother. If clothing has caught alight, the child, especially if he/she is trapped in an informal dwelling, will cover their face and start running. Parents and caregivers are dumbstruck and understandably in a state of shock, screaming for assistance from whoever is at hand. Depending on the experience of the primary caregiver, as well as the severity of the burn, a state of order may start to prevail. The primary caregiver may then decide to act or contain the situation by administering some sort of first aid. This is often based on the advice of an older

person in the house, or on hearsay. After they have done this, they may choose to seek assistance from a health care facility.

The Red Cross Children's Hospital (RCCH) in Cape Town, South Africa, is one of the health care facilities with a burns unit. This hospital is the only paediatric hospital in the Southern Hemisphere with a trauma unit. The burns unit, where the study was conducted, is a seventeen-bed ward where approximately 950 patients are admitted each year. For admission the patient has to have a burn of more than ten percent Total Body Surface Area (TBSA). If the burn injury involves the face, hands, or the perineum, or is circumferential, the child will be admitted even if the size of the burn were less than ten percent. The reason for this is the severe consequences of these specific burns.

Children with burns come from all levels of society. Their ages range from a few days old to just before teenaged. They include "street children" who are brought in by fellow homeless people, school going children who have responsible parents, victims of child abuse by caregivers, children from affluent families, e newborn babies to first-time mothers. According to the RCCH mission statement, all children are entitled to the same management, irrespective of age, race, sex and social status. This principle is in line with the South African Constitution, which states, in Section 28 of The Bill of Rights, that all children under the age of 18 have the right to food, shelter and health care (The Constitutional Assembly, 1996). Staff members of the Red Cross Children's Hospital believe all children have the right to the best possible health care available, and especially provide them with the essential tertiary care they require, including rehabilitation (see definition of terms, page vii).

When the RCCH admits a child with a burn injury, the patient goes through various burn management procedures. These include fluid resuscitation, wound management, which may or may not include surgery, and rehabilitation. The focus of this study is on the area of rehabilitation (see definition of terms, page vii) of the paediatric burn.

A burn is a complex injury and involves many aspects, and it is essential that the rehabilitation should be equally integrated and holistic. When a burn injury is treated, it is not only the patient

that is rehabilitated. The entire family, as well as certain members of the community, inclusive of the primary caregivers, siblings, friends and teachers, should be involved, so that the desired outcome of holistic rehabilitation can be obtained. Integrated, holistic rehabilitation is a continuous effort of all members of the burn team, the patient and his/her family. Those involved must deal with all functional, aesthetic and psychological sequelae in order to return the patient and the family to their daily lives at the highest possible level of physical, emotional and social capabilities (European Club For Paediatric Burns (ECPB) workshop 2001).

The researcher is a physiotherapist at the Red Cross Children's Hospital, working specifically with children with burn injuries. Although burn injuries have been around forever, the researcher views rehabilitation as a new entity. According to the World Health Organisation (WHO) 1994, rehabilitation is a process that assists people with disabilities to develop or strengthen their physical, mental and social skills. The definition states that in order for an individual to be able to join in the activities of his/her family and community, the rehabilitation process requires different types of services, as well as community action (WHO, 2001). Helander (1992) states that rehabilitation includes all measures aimed at reducing the impact of disability for an individual, enabling him or her to achieve independence, social integration, a better quality of life and self-actualisation. According to Helander (1992), rehabilitation includes not only the training of disabled people, but also interventions in the general systems of society, adaptations of the environment and protection of human rights.

Within the South African context, the final draft of the National Rehabilitation Policy was only published in December 2001. It is the first of its kind in South Africa. The National Policy for Rehabilitation is based on the principles of development and social integration of persons with disabilities (Department of Health, 2000). These principles underpin the rehabilitation of a patient who has a burn injury, as that individual is cosmetically disfigured and functionally disadvantaged. Burn survivors often feel isolated, since they do not feel comfortable to be in the public eye or to take part in recreational activities (Reported by patients who have returned to school and mothers of these children).

At the RCCH, health therapists treat burn injuries on many levels, starting from the individual who administers the first aid, nurses, occupational therapists, physiotherapists, doctors, dieticians, social workers and psychologists. These team members interact on a daily basis to decide the course of management of each patient. Staff members work in concord, and also with the primary caregivers of children with burns. This has an advantage, since it decreases management time, and it means that staff members can work together to achieve the same goal for the patient. With staff shortages and too many patients, one staff member is unable to cope with the entire caseload of patients. One way of being effective in management is involving and educating primary caregivers. During this time of observation, and hands on practice, there is transference of skill and knowledge from the health care professional to the parent or caregiver. Parents of children with burns learn the activities within the burns unit and as primary caregivers they observe the process of rehabilitation, including the outcomes of rehabilitation, i.e. the integration of the child back into the community.

Although the RCCH is a tertiary hospital, it is linked to primary (see definition of terms, page vii) and secondary centres (see definition of terms, page viii), as well as home-based carers and schools. The Red Cross Children's Hospital operates as part of the health care system of the Western Cape within South Africa, by being responsible for care at various levels. This begins at the acute stage, when the hospital admits patients with a new burn, to the end phase of rehabilitation when scar management has been completed and where the patient needs to be reintegrated into his/her school and community. In this research, the researcher focuses on all stages of the rehabilitation process. The burns unit at the Red Cross Children's Hospital aims to provide a complete health care service to all children who have suffered from a burn injury. This service is enveloped by an interdisciplinary team approach to management, which tries to shift the care from a tertiary institution, to the community setting, which would be the home of the patient. A community reintegration programme provides the patient with an opportunity to increase decision-making skills, self-responsibility, and initiative (Goggins, Hall, Nack & Stuart, 1990).

Though it may appear that the management of children with burns at the RCCH is holistic and sensitive to the needs of the child with burns and the primary caregivers, according to the researcher this was not always the case. Up to the end of 1997, when the researcher started

working in the burns unit, it appeared that individuals in the unit were fulfilling their individual therapy roles for the patient. It seemed as if they were not working together and with the parents of children who have suffered burn injuries. It also appeared that joint decisions were not made with these primary caregivers and staff members. It was a frustrating period for the researcher, staff, and primary caregivers of children with burn injuries.

Patients were not properly medicated due to a lack of, or poor communication between staff members. Historically patients were all medicated at one time and treatments such as dressing changes and physiotherapy would continue irrespective of the patient's pain and anxiety levels. This made it incredibly difficult to perform certain procedures on patients, as they would be constantly crying and screaming when stretching exercises or dressing changes occurred. Lack of communication would result in a patient being discharged without all team members having been consulted, and the patient having to return for a particular part of his/her rehabilitation. This meant that patients would have to visit the hospital for various clinics or outpatient management on separate days for specific treatments. Having to return on different days for management has tremendous financial implications for the patient's family or primary caregiver. This could be a reason for patients defaulting their appointments. Although parents were informed about procedures and informed consent was taken, they were not part of the decision-making process. They were involved in the end stage i.e. the discharge phase, but not in the early acute stage. Parents and caregivers were disempowered, since basic tasks like feeding or assisting with dressing, would be removed from them leaving them with a feeling of helplessness.

Since the middle of 1998 there has been an evolution in the manner of management in the unit, in that the approach to management has become an interdisciplinary team approach. Interdisciplinary teamwork means that there is joint treatment planning, goal setting and decision making. Goals are recorded on one integrated planning document. This happens at a team conference. A case manager, who can be any team member, represents each patient. The case manager has the function of directing the discussion and planning. This meeting would lead to an integrated treatment plan and common goals reached by consensus. This team consists of all health professionals as indicated in the above paragraph, patients and their parents. The researcher sees the power of parent involvement as positive, since parents are, and will be, part of the goal-setting

and decision-making process. It would be encouraging to think that the management of burns at the Red Cross Children's Hospital burns unit has developed from a situation of disempowerment of parents and total reliance on the health professional, to a one of self-dependence and self-motivation. The more primary caregivers are involved and educated about a child's condition, the more likely they are to take part in a child's rehabilitation. This involvement carries on in the home and even the classroom at school. This is realised by carrying out home and school visits as well. Involving educators and fellow-learners assists in them understanding the burned child's individual needs. Visits to classrooms and explaining to classmates that a child is not different inside because he may look different on the outside, sometimes helps them to be more accepting and less cruel with vicious remarks.

This approach of interdisciplinary team management in the burns unit at the RCCH is in line with the hospital's mission statement that embodies principles of treating patients holistically and without discrimination. The hospital's declaration of intent is to treat all patients to the best of the ability of the teams involved in a nurturing and friendly environment (RCCH Mission and Vision statement, 2001).

Such principles are also included in The Patient's Rights Charter of South Africa, 1998(3), that states that individuals have the right to health care, including the choice of health services and treatment by a named health care provider (Department of Health, 1996). Informed consent, confidentiality and privacy are paramount. The patient has the right to continuity of care, as well as to complain about health services.

The Children's Charter of South Africa embodies principles such as the right to health. This charter maintains that all children are created equally and are entitled to basic human rights and freedom, and all deserve respect, special care and protection as they develop and grow (The Children's Rights Charter of South Africa, 1996). Staff in the burns unit embrace all these principles. They treat all patients with equal respect and dignity and as much care as possible. The team recognises that a burn injury is a scar for life. Since each child is a unique individual, they are assessed according to their individual requirements. Placing primary caregivers at the centre of a child's burns management is in line with such principles as stated above. This is as far

as the burns unit at RCCH has evolved, from dealing with clients in the Medical Model (see definition of terms, page vii), to currently using a client-centred approach (see definition of terms, page vi).

1.2. RESEARCH PROBLEM AND AIM

With the changes mentioned above, the burn team perceives the rehabilitation programme in the burns unit at the RCCH to be holistic and integrated, but this system has never been evaluated. The primary caregivers have played a central role as consumers of this burn rehabilitation programme and hence have a right to evaluate and criticise this programme as they could be seen as objective evaluators. The researcher feels that they are the people who could provide valuable information in respect of the management of their children.

The primary aim of this study is to establish how primary caregivers of children with burns, managed at the Red Cross Children's Hospital, evaluate the burns rehabilitation programme. Strict criteria regarding age, area of burn and length of stay in hospital were applied.

1.3. MOTIVATION

Many factors motivated the researcher to embark on a study of this nature.

In the burns unit at the RCCH, within the boundaries of a medical model, the collaboration of staff members to see patients together at the time of follow up appointments was not well synchronised as discussed in the previous section. This resulted in patients and their primary caregivers returning to hospital more than once a week for treatments that could have been arranged for one day. With an interdisciplinary team approach to management, the parents and caregivers are consulted on what time would be suitable for them to return for a follow-up appointment.

Having achieved this milestone, it is not clear to the researcher, or the burn team, whether the current protocol used in the unit at the RCCH is the correct one or whether amendments are

needed. The team of the burns unit is therefore not confident that this is a protocol that can be duplicated and used as a standard rehabilitation burns protocol for children.

The consumers of the programme in the unit, who are the children and their primary caregivers, have never evaluated the efficacy and appropriateness of the rehabilitation programme. The researcher feels that this study affords a good opportunity to evaluate the rehabilitation programme in the unit through the eyes of the primary caregiver. The primary caregiver, as opposed to a caregiver, is someone who has looked after the child on a daily basis or has cared for that child throughout his or her healing process. It is not someone who intermittently "babysits" the child when the parent/parents are unable to do so. The primary caregiver can be one of the parents. The data gathered will enable the team to establish whether management is in fact adequate and more importantly whether it meets the needs of the most important person in this programme – the patient. The patient, through the feedback of primary caregivers, will be placed at the centre of the discussion and will be given a position in the decision-making process.

Goggins *et al.*, (1990) very importantly state that a comprehensive programme includes three phases: a preparation phase, a performance phase, and finally an evaluation phase. This framework allows for ongoing programme evaluation at both clinical and research levels. The researcher feels that the first two phases of this programme are currently being completed in the burns unit at the RCCH, but the final step is lacking, i.e., the evaluation of the programme.

In the burns unit at the RCCH it is vital for the team to set outcome measures with the patient, so that there is the collaboration of working towards a goal. A review of the rehabilitation programme will allow therapists to evaluate treatments that lead to improved outcomes. Staley, Richard, Warden, Miller & Shuster (1996) state that burn therapists need to demonstrate that their interventions work. They also state that there are many questionnaires and evaluations available. According to Staley *et al.*, (1996), the validity, reliability and meaningfulness of these tools have been questioned. They state that since no universal tool is currently available, modification of an existing tool to meet the needs of the population may prove to be more efficacious. Helm (1992) states that there is no formal data collection system for burn rehabilitation. He also states that another serious problem in burn rehabilitation is that only a few clinical studies have compared

various treatment techniques to determine which protocols are best suited for treatment outcomes. He asks how functional outcome relates to the various treatment protocols used in burn rehabilitation. In his article he suggests that comprehensive standards of care need to be developed once sufficient data regarding the outcome is available, and that we need to identify methods of educating third party players about the magnitude of rehabilitation treatment programmes.

The researcher, having an interest in expanding her knowledge in paediatric burns rehabilitation, found a paucity in the literature, both at national and international levels. The paucity lies not only in paediatric burns, but also specifically with rehabilitation of paediatric burns patients. The researcher has not found any studies which explore the caregiver's views on the management of a child who was burnt, how the discharge was handled, what they were satisfied and dissatisfied with, and how the service or the approach to management may be improved. Regarding the South African context of medical management, which has embraced a new philosophy of a client centred approach, information in the literature needs to be renewed. Hence it is important for health professionals other than the doctors to write literature regarding rehabilitation programmes, since it is often the therapist and the nurses who are the ones interacting with the patient long after the doctor has completed his surgery.

Not only is literature pertaining to paediatric burns limited, so is all literature dealing with outcome measures in burn care (Helvig, Upright, Bartelson, Kagan, 1995; Wood, 1995; Staley *et al.*, 1996 & McDonald-Smith, 1998). Brown (2003) adds that of those available, we believe that few measures are reliably transferable, either between countries or centres within a country.

For the reasons stated above, the researcher feels that the results of this study will be able to fill the gap between continued daily treatment and establishing if we need to amend this management.

1.4. SIGNIFICANCE OF THIS STUDY

It is envisaged that this study will validate the assumption that the burns rehabilitation programme at the RCCH is as holistic as it is claimed to be, and to critically assess whether the burns rehabilitation programme is client-centred. The current trend nationally and internationally is to

move from the medical model (see definition of terms, page vii) to the social model (see definition of terms, page viii). This study will expose the model of management used at the RCCH.

The significance of the study would be to perhaps contribute to the existing body of knowledge. If the assumptions are correct, this will affirm that the management of the burn team is practiced within the principles of the Patient's Rights Charter and the National Rehabilitation Policy. This information will be shared with the burn team members. This will assure team members to continue their approach towards holistic rehabilitation. This approach should also be shared with other departments and burns teams in different units and centres. This will be implemented by publishing the study in a local and international journal. If the assumptions are not validated, the areas of weakness will be highlighted. These loopholes will be shared with the team members in the burns unit. Strategies will be developed to address the areas of weakness. It is envisaged that this study will provide important information on the manner in which the team continues to provide a service to patients and their caregivers. Recommendations and amendments can be made to meet the needs of the patients and their primary caregivers.

The study will be conducted in a tertiary academic institution, but can be reproduced in other primary and secondary institutions to enable these centres to evaluate their individual rehabilitation programmes. It is hoped that other centres treating burn injuries will be able to use this study as a tool to evaluate the management of their patients.

1.5. CONCLUSION

The South African Constitution states that "a child's best interests are of paramount importance in every matter concerning the child" (The Constitutional Assembly, 1996). The National Rehabilitation Policy is based on the principles of development, empowerment and the social integration of persons with disabilities (Department of Health, 2000). The Patient's Rights Charter of 1999 states that every patient or client has the right to confidentiality and privacy and, informed consent. He/she may exercise choice in health care, complain, refuse treatment and participate in decision making that affects his/her health (Department of Health, 1996). All these important documents highlight why the patient as the most salient individual in the health care system, in our

case, the child, is at the very nucleus of the argument. Health professionals, if they have not already done so, need to begin the process of evolving from a prescriptive therapist to a therapist who communicates with the client in order to set goals together as a team.

For the first time this burns unit will learn the views of the primary caregivers, as caregivers will be acting as the evaluators of this programme. This is not just a means of empowering them, but also the opportunity for the team to obtain important information that may assist with improving service outcomes. The children in the burns unit may not always get a chance to criticise the staff, but their primary caregivers can be active participants in assisting the team in gaining more insight into the efficacy of the functioning of the burns unit.

Hence, it is pertinent that the primary caregivers evaluate the rehabilitation programme at the RCCH.

The following chapters will include methodology of this study, the results thereof, the discussion of these results and lastly the conclusions, which will incorporate recommendations to the role-players in the burns unit.

CHAPTER TWO

LITERATURE REVIEW

2.1. INTRODUCTION

The purpose of this study was to establish how the primary caregivers of burns patients perceive the burns rehabilitation programme at the Red Cross Children's Hospital. In this chapter on literature review, topics such as paediatric burns and the rehabilitation thereof, the modern models of management as well as rights of the parent and the child that underpin this study, will be explored. On the larger scale, the researcher wishes to discuss modern principles of patient care, since it is felt that key concepts such as human rights principles, autonomy and the client-centred approach to care, are at the core of this study. The researcher wishes to expose current findings on burns and rehabilitation programmes, and concurrently, to look more specifically at paediatric burn management and how parents are allowed to evaluate these programmes. There is an abundance of literature regarding adult burn management, but minimal documentation on the rehabilitation of a child with a burn. Initially, the researcher would like to describe what a burn is, as she sees it as essential to have a common understanding of what this concept is.

2.2. DEFINITION OF BURNS

The Concise Medical dictionary describes a burn as tissue damage caused by such agents as heat, chemicals, electricity, sunlight, or nuclear radiation (Concise Medical Dictionary, 1980). The dictionary describes the different degrees of the burn and basic physiological changes. Burn depth is classified in degrees of injury, based on the amount of epidermis injured and by the physical appearance, pain and skin texture or pliability. A superficial or first-degree burn involves only the outer epidermis and is characterised by erythema and mild discomfort. Pain resolves within 48 to 72 hours and the wound heals spontaneously. A superficial partial thickness burn involves the upper third of the dermis. The burn appears as a light pink, wet wound and heals within 7 to 14 days. A deep partial or second-degree burn extends well into the dermal layer. The wound surface is usually red in appearance with white areas in deeper parts. A full thickness or third degree burn

results in destruction of the entire epidermis and dermis, leaving no residual epidermal cells to repopulate. This will usually require skin grafting. The characteristic appearance is a waxy white colour. If the burn extends into the fat or there has been prolonged contact with a flame source, a leathery brown or black appearance can be seen along with coagulated veins (Demling & La Londe, 1989). A burn injury causes more than an interruption of the tissue. It causes years of psychological scarring and damage. It destroys souls and causes children to take their own lives (Wallace, 2003).

2.3. PAEDIATRIC BURNS

A child is not a small adult. A child has different needs to those of an adult. This is even more precise for a child who has suffered burns. The separation from the primary caregiver and the stay in hospital are often the first experiences of this nature, and this in itself is very traumatic for both parties involved (Herndon, 2002).

The burn injury produces overwhelming physiological and psychological challenges to a paediatric patient. The unique anatomical and physiological attributes of the child require the attention of physicians and nurses trained not only in burn care, but also in the specifics of paediatric care. The most obvious differences between adults and children are in size and body proportion. Shorter lengths, tighter angles, and a smaller diameter of various anatomical structures and spaces make certain manipulations more difficult. These differences also require the provision of special equipment and supplies, which reflect the configurations of paediatric anatomy. In addition to anatomical differences, there are also many physiological differences that must be considered (Herndon, 2002).

In a child under the age of two years, the physiologic differences between the child and the adult may represent a significant handicap when the child is injured (O'Neill, 1979). The word *handicap* (see definition of terms, page vii) is an old term and is no longer used. One of the most important features of the young child is his larger surface area in relation to weight when compared with the adult (Abrahamson, 1966). Surface area is one of the major determinates of water turnover, caloric expenditure, and a number of other metabolic parameters. This is why the burned child has

a greater evaporative water loss relative to weight, than the adult (O'Neill, 1979). Because of the child's increased surface area to body weight ratio, he or she may also be at a disadvantage as regards temperature regulation.

Metabolic demands of infants and young children are high, even at base-line levels. If the stress of thermal trauma, with its obligatory increased metabolic demands, is superimposed, that ability of the pulmonary mechanism to compensate may be exceeded. Thus, inhalation injury or other factors leading to impairment of pulmonary function may necessitate early institution of ventilatory assistance in the child (O'Neill, 1979).

The child is also at a disadvantage with respect to renal function. Glomerular filtration rate in the infant does not reach adult levels until approximately nine to twelve months of age, because of an imbalance in maturation of glomerular and tubular function. Stress accentuates all these differences (O'Neill, 1979).

Stricter criteria for hospitalisation must be applied to children under the age of two years, when large portions of the injury are full thickness in depth, or when the hands, feet, face, or perineal areas are involved (O'Neill, 1979).

The emotional scars are often worse than the physical ones. Children with burns are stared at and are called names and they are not accepted easily by communities. This lack of acceptance by the community often leads to the inability to reintegrate into communities and leaves these little individuals marginalised. Children with extensive burn injuries characteristically undergo a process whereby they revert to primitive behaviour. They may even become hostile towards their parents. This may require a great deal of understanding and support on the part of the doctor or the family (O'Neill, 1979).

As much as the impact of the burn on the quality of life of the child is important, it is difficult to approach the problem and make changes without having looked at the size of the problem. Hence, the researcher feels it is appropriate to briefly review the prevalence of burns in the South African context.

2.4. PREVALENCE OF BURNS IN SOUTH AFRICA:

Burns are prevalent throughout South Africa. There is a higher incidence in informal settlements and informal housing. These are areas with no electricity or water supplies. Heat is made available by using portable gas stoves, which are cheaply available, but are hazardous because of their poor quality. Candles provide lighting but are dangerous since they can be easily knocked over. Water is boiled in pots on fires or on a gas stove. When these pots are left on the ground they create a severe danger. Children playing on the floor and crawling babies are easy targets. Other burns are commonly due to kettle cords being pulled and the contents of the kettle splashing over the child (Child Accident Prevention Foundation of Southern Africa (CAPFSA), 2002). Since most burns are accidental, they can happen in any household, whether the family is affluent or not. These accidents can happen even when parents are well educated, aware of the dangers of a burn, and take precautions to prevent an injury of this nature. Four, of every five burns occur in a child's own home (O'Neill, 1979).

Closer to home, the extent of the problem is enormous. In the Western Cape, large proportions of the habitats of the population are in informal settings. In these areas there is a lack of basic amenities such as the availability of electricity, clean water and adequate sanitation. Fluid burns are by far the most common burn injury that children suffer. These are often due to hot fluid burns from kettles, tea, coffee, baths and boiling water. Second in line are flame burns and other types of burns. Flame burns are particularly problematic in informal settlements where house fires begin easily with a drop of a match or candle, and spread incredibly fast destroying many homes (CAPFSA, 2002).

At the Red Cross Children's Hospital, the burns unit admits approximately 900-1000 children per year. Annually 2000 children between the ages of 1 day to 13 years are managed in the outpatient clinic. These are new cases, as well as children who have been referred for follow-up management (CAPFSA, 2002). Burn injuries are the sixth largest external cause of deaths in South Africa, and were responsible for 3255 deaths in 2001. If we look at the specific age groups, 19 individuals under the age of one year died due to burns. In the categories one to four years and five to nine years of age, 103 children and 44 children respectively died due to burn injuries. In 2001, 23 children in the age group 10 to 14 years died due to burn injuries (Bowman, 2002). On a global

scale, fire related burns were responsible for an estimated 322 000 deaths in 2002. The great majority of these occurred in developing countries (WHO, 2002).

Table 1 below shows the distribution of these deaths in the WHO regions – Africa (AFR), the Americas (AMR), Eastern Mediterranean (EMR), Europe (EUR), South-East Asia (SEAR), and Western Pacific (WPR) (WHO, 2002).

TABLE 1: WHO GLOBAL BURDEN OF DISEASE DATABASE 2002

REGION	AFR	AMR	EMR	EUR	SEAR	WPR	WORLD
DEATH RATE PER 100 000	5.8	1.2	0.8	0.7	11.6	1.1	5.2

Since burns are so endemic, it is important to discuss the modern approach of management. The researcher has already mentioned that there is paucity in the literature. A burn injury occurs in various settings and under various circumstances. Irrespective of that, one has to move from a situation of chaos to one of order. The way in which this can be done is to manage the burn and thereby bring about a state of evolution, from injury, to one of healing, and eventually community reintegration of that individual.

2.5. MANAGEMENT OF THE PAEDIATRIC BURN

Staley, Richard, Warden, Miller & Shuster (1996) state that just ensuring survival is less than optimal. Returning a burn-injured person to society in a condition that he or she can function at work, school, and in recreational and social activities, should be the focus of treatment and the ultimate outcome of burn care.

2.5.1. Initial management

In order to appreciate how good management is today, we have to know how burns were managed in days gone by.

As long as burns have been known, some form of primary management has existed. This however has existed in the application of a range of substances from butter, toothpaste, and shoe polish to eggs. When trying to establish where this information came from, it was apparent that it had been handed down from one generation to the other as "common household remedies" (reported by primary caregivers of patients who had been admitted to the RCCH burns unit).

For many years burns were treated by daily washing, removal of loose dead tissue and some sort of topical nostrum until they healed by themselves, or eventually, granulation tissue appeared in the base of the wound. Superficial dermal burns usually healed in two weeks and deep dermal burns healed over many weeks, if infection was prevented. Full thickness burns lose their eschar in two to six weeks by collagen production from bacteria and mechanically by daily debridement. In the past, when the granulation bed became free of debris and relatively uninfected, split-thickness skin grafts were applied, usually some three to eight weeks after injury. A 50% graft take was considered acceptable. Repeated grafting eventually closed the wound. The prolonged and intense inflammatory response made hypertrophic scars and contractures part of the situation. Vigorous physical therapy, nutritional support, psychological support, and pain management were required on a daily basis for many weeks in order to yield a satisfactory result (Herndon, Rutan, Alson & Cox, 1993).

2.5.2. Current approaches

2.5.2 (a) Acute care

The application of cold tap water, which is approximately sixteen degrees Celsius, is the best primary care advocated today. If water is readily available, the burnt area should be submerged for at least thirty minutes. If there is a limited supply of water, a clean cloth soaked in water should be applied and changed every two to three minutes, so that the cloth is able to absorb the heat of the burnt area (Herndon *et al.*, 1993).

Current approaches to care have altered the mortality curves so much that a child with an uncomplicated burn of 95% total body surface area (TBSA) has a 50% chance of survival (Herndon *et al.*, 1993). The unprecedented survival of these severely injured children can be

attributed to the advances in resuscitation, surgical techniques, infection control, as well as pulmonary and nutritional support.

Immediate care of the patient involves fluid resuscitation and prompt management. Fluid resuscitation is aimed at supporting the patient throughout the initial 24-hour to 48-hour period of hypovolemia. The primary goal of therapy is to replace the fluid sequestered because of thermal injury. The burned child continues to represent a special challenge since resuscitation therapy must be more precise compared to that for an adult with a similar burn. Children have limited physiological reserves (Warden, 2002). In addition to the extent of burn and the age of the patient, the depth of burn is a primary determinant of mortality following thermal injury. Burn depth is also the primary determinant of the patient's long-term appearance and function (Herndon, 2002).

The metabolic consequences of a major burn injury are profound and constitute a major challenge to effective burn treatment. Metabolic rates of burn patients can be twice that of a normal person, and cause tremendous wasting of lean body mass within a few weeks of injury. Failure to satisfy these increased energy and protein requirements results in impaired wound healing, cellular dysfunction, decrease resistance to infection, and ultimately death. Provision of early and aggressive nutritional support throughout the post-burn period can reduce mortality and complications, optimise wound healing, and minimise the devastating effects of hypermetabolism and subsequent catabolism (Saffle & Hildreth, 2002). Monitoring output and managing nutritional intake are among the primary responsibilities of the nursing staff. An accurate record of intake and output is critical to patient care because potential problems can be detected early and alternate options of care can be individualised to help the patient (Gordon & Marvin, 2002). The expected outcome for pain and anxiety management is for the patient to achieve a balance between successful participation in activities of daily living and therapies, and being comfortable enough to rest and sleep as needed. The ultimate goal is for the patient to be satisfied with the pain management plan as implemented. Knowing when and how much to intervene is guided by knowing the baseline pain and anxiety rating for the individual (Gordon & Marvin, 2002).

2.5.2 (b) Anaesthetic and Pain Management

Rational and effective anaesthetic management of acute burn patients requires an understanding of an interdisciplinary approach so that preoperative care is compatible with the overall treatment goals for the patient. The preoperative evaluation must be performed within the context of the planned operative procedure, which will depend on the location, extent, and depth of burn wounds, time after injury, infection and existence of suitable donor sites for autografting. Special attention must be paid to the airway and pulmonary function during preoperative evaluation. If injuries do not preclude conventional airway management, standard induction and intubation procedures are appropriate. Ketamine anaesthesia has been found safe and effective for airway management in infants with difficult airways caused by congenital airway anomalies. Standard monitors include electrocardiography (ECG), measurement of systemic blood pressure, pulse oximetry, capnography, and inspired oxygen concentration. The ability to measure body temperature should be readily available. One of the most important issues in the immediate post-operative period for burn patients is adequate analgesia and sedation, particularly for the intubated and mechanically ventilated patient. Debridement of burned tissue and the harvesting of skin grafts are painful procedures that merit ample analgesic doses in order to ensure patient comfort. Normally burn patients are quite tolerant to narcotic analgesics, especially after they have had several operative procedures and in this case larger doses than normal are required (Woodson, Sherwood, Morvant and Peterson, 2002).

2.5.2 (c) Surgical management

Modern treatment involves early surgical removal of the burn. Rather than waiting for spontaneous separation, the eschar is removed surgically early in the burn course and the wound closed with grafting techniques and acute flaps individualised to each patient. Burns that heal within three weeks generally do so without hypertrophic scarring or functional impairment, although long-term pigment changes are common. Burns, which take longer than three weeks to heal, often produce unsightly hypertrophic scars and frequently lead to functional impairment, as well as providing only a thin fragile epithelial cover for many weeks or months. State of the art care now, at least in patients with small to moderate burns, involves early excision and grafting of all burns which will not heal within three weeks (Heimbach, Mann & Engrav, 2002; First, Ackroyd, Burke & Bondoc, 1985; Deitch, 1985 and Gray, Pine & Harner, 1982).

For the purpose of surgical wound closure, general anaesthesia is usually required. Depending on the magnitude of the wound to be treated, an adequate supply of cross-matched blood must be available. Tangential excision or dermal excision is the method used to sequentially shave the eschar from the wound surface until a viable tissue plane is reached. Healthy skin is obtained from viable and accessible areas on the body. This is done by using a dermatome. This instrument can also be used for debridement of the wound. Skin is taken at the appropriate depth, and if it is to be used for the face or hands, it is not meshed. When the skin is procured for other parts of the body it can be put through a Tanner-Vandeput instrument for the mesh-expansion of the skin (Herndon, 2002). Once the meshed or unmeshed skin has been placed on the recipient area, it is attached with the use of surgical staples, glue or sutures. This grafted area must not be mobilised for five days.

2.5.2 (d) Post-surgical management

Ongoing blood loss is unfortunately a common problem after the excision and grafting of a large burn wound, even when surgical personnel did pay attention to intra-operative haemostasis. Adequate ventilation is essential in the post-operative period in order to minimise hypoxemia and hypercarbia. Blood gases and oxygen saturation can be used as guides to ventilator management. Burn patients must recover in a warm environment. Radiant heaters, blood and fluid warmers, warm blankets, heated humidifiers for gas delivery and high room temperature are all useful in the post-operative period to provide warmth to the recovering patient. A team approach is needed, keeping in mind that perioperative management should be consistent with intensive care unit management and goals. This requires close communication with other members of the burn care team (Woodson *et al.*, 2002).

2.5.2 (e) Nursing management and wound care

One of the keystones of recovery of a burn patient is the nursing care he/she receives. The nurse's duty is multifaceted and she is one of the team members involved from day one to long after the patient has been discharged. In the acute phase when an inhalation injury continues to be the most serious and life-threatening complication to date, early diagnosis and treatment greatly impact the outcome of care. Close observation of the patient and frequent respiratory assessments are made throughout the initial and acute phase after the accident. Age, burn size, and the presence of

inhalation injury and pneumonia have all been identified as major contributors to mortality (Demling & Seigne, 2000). Vigilant nursing care (frequent nursing assessments and aggressive pulmonary toilet) combined with anticipating potential problems and being prepared to deal with the problems, will add to the team effort and possibly improve the patient outcome (Gordon & Marvin, 2002).

Wound care in the burns unit has become an art of burn nursing practice. It can be extremely challenging and complicated and, for a new nurse, it can be the most difficult and misunderstood part of burn nursing. The complexity exists because there are many different wounds that require different interventions in relation to time immediately after the accident or the time after an operation (Gordon & Marvin, 2002).

Wound care comprises but one of the many burn care components, as the size of this volume attests, but it is arguably the most pivotal one. Wound inspection as well as wound care occurs daily unless the patient is newly grafted (Gordon & Marvin, 2002). If wound care is less than impeccable, infection can result. Infection is a most undesirable partner in any operative procedure and more particularly in thermal injury. Resident and transient microbes of the skin are the etiological agents of infection, and antimicrobials have been designed to eliminate the offenders. The use of therapeutic antimicrobials can provide precise delivery of a specific agent to eliminate the offending microbe once its sensitivity has been determined (Herndon, 2002). Burn dressings comprise of topical antimicrobial agents and dressing materials. A burn dressing has three principle functions:

- *Protective.* When skin is thermally injured the physical barrier of the epidermis to microorganisms is lost, as well as its mild antiseptic property. The result is that the environmental flora proliferates readily on the wound surface (Herndon, 2002).
- *Metabolic.* An occlusive dressing reduces evaporative heat loss and minimises cold stress and shivering (Herndon, 2002).
- *Comfort.* Superficial burns are initially extraordinarily sensitive to air currents, and deeper burns become progressively tender with time as nerves are reinnervated. Open wounds drain. A bandage eliminates air currents from the wound surface, absorbs and contains wound

secretions that would otherwise soil bed linen, and if properly constructed, may also provide splinting action to help maintain a desirable position or function (Herndon, 2002).

Wound assessment and care is a learned skill that develops over time. The expert burn nurse must teach these skills to a new burn nurse in the bathroom and the operating room and at the bedside. The bathroom affords an excellent opportunity for teaching the patient and the family about wound care and dressing application. As the patient gets closer to discharge, families are required to do more of the care. The trend for earlier release from the hospital poses additional challenges for nursing since it reduces the time available to prepare the patient for discharge. The more precise the patient and families' education is, the more desired the outcome will be. Early involvement with patient and family helps to identify potential obstacles at discharge and facilitates care coordination in the discharge process (Gordon & Marvin, 2002).

In order for nurses to be competent teachers, they must be competent practitioners with solid theoretical foundations. Continuing education is the key to maintaining competency of staff as educators of patients and families. Reinforcement of the educational process (assess, plan, implement, evaluate and document), characteristics of patient population, updates on educational strategies, age-appropriate interventions, and ways to evaluate learning are topics that will sharpen educator competency (Gordon & Marvin, 2002). Discharge planning and education begins upon admission. It begins with a thorough assessment of the patient's life prior to the injury. Identifying knowledge deficits and barriers to education, prioritising strategies for education, projecting supplemental educational handouts and/or classes as well as developing a plan for evaluating the effectiveness of the teaching opportunity are integral parts of the educational process. Assessment provides essential information for planning an educational programme to meet the specific individual needs for each patient and family. It is also done periodically during different stages of the educational process to determine if the plan remains valid or if changes need to be made (Gordon & Marvin, 2002). The transition from the hospital to home care is often difficult for both the patient and the family. It is important prior to discharge that the patient and the family be educated in the care of wounds and healed skin before they leave the hospital. They also need information about the normal depression that occurs after hospitalisation (Gordon & Marvin, 2002).

2.5.2 (f) Rehabilitation of the Paediatric Burn

As stated in chapter one in the definition of rehabilitation, it is underpinned by such principles as autonomy, rights to choice of management, protection of human rights and dignity and reintegration into society.

2.6. MODELS OF MANAGEMENT

The ultimate goal of a comprehensive programme for the management of children with severe burns is to assure that they grow up to have productive and satisfying lives. The road to recovery is long and complex, requiring meticulous medical and social management after discharge from acute care. The "wellness" of the child and success of treatment should be measured from multiple perspectives, including physical, emotional and social outcomes (Munster, Fauerbach & Lawrence, 1996).

In order to appreciate the modern approach to rehabilitation, it is necessary to look at the evolution of management, as is described by the different models of intervention.

2.6.1. Medical Model of Rehabilitation Approach

Before the expansion of educational programmes for children with disabilities in the mid-1900s, the majority of early intervention services were provided through the health care system in the medical settings (Hanft, 1988). The medical model typically described the helping model used by health professionals during this time. This model viewed the health professional as the expert, the only person able to provide treatment, make decisions, and bring about changes in the child (Dunst & Trivette, 1987).

Intervention was child-focussed, not family centred, with therapists' goals focused on bringing about change in the child separate from the family. Therapists received instructions in an authoritarian manner and were expected to dance to the tune of the doctor without questioning why a certain management was prescribed. This is exactly the way in which therapists involved in rehabilitation also behaved with their clients. Parents had to be passive recipients of the child's intervention programme. Because family members were not expected to take an active role in the child's therapeutic programme, this model encouraged parents to become dependant on health

professionals. As a result many parents were in danger of developing a sense of helplessness about their ability to provide care (Dunst & Trivette, 1987).

A burn injury, if not appropriately managed, can lead to contractures, which can lead to a loss of pre-injury function. Severe or full thickness burns may lead to amputation of digits or limbs, which may also result in the inability to perform certain functions. This state of limited participation in social roles, due to an individual's personal impairment leads to an individual's disability (WHO, 2001). Individuals with obvious visible burns, especially in the face, are marginalised since the community reacts badly to these individuals, creating an attitudinal barrier and thereby increasing their disability.

The Medical Model of Disability means that non-disabled people who provide services to people with disabilities usually controlled disabled people. The aim was to provide treatment, or create alternatives to begging or "hiding away". Dependency on state assistance has disempowered people with disabilities and has seriously reduced their capacity and confidence to interact on an equal level with members of society. The dependency created by the medical model disempowers disabled people and isolates them from the mainstream of society, preventing them from accessing fundamental social, political and economic rights.

Continued reliance on the medical model results in overemphasis of the disease and underemphasis of the complex health-illness continuum affecting the patient and his / her environment (Lowe & Herranen, 1978).

Disability has historically been regarded predominantly as a health and welfare issue and state intervention was, therefore, provided through welfare institutions. The responsibility for "caring" for disabled people thus generally reverted to civil society. There has been little or no commitment to addressing disability in other areas of government responsibility (Final draft of the Integrated National Disability Strategy, 2000) and little involvement of disabled people in this regard.

People with disabilities in South Africa came together in the early eighties of the previous century to mobilise and organise themselves. Their aim was to build a strong civil movement of

organisations controlled by disabled people themselves. Central to the disability rights movement is the assertion of disability as a human rights and development issue. Disabled people saw disability as a social construct due to attitudinal barriers.

The social model of disability suggests that the collective disadvantage of disabled people is due to a complex form of institutional discrimination. This discrimination is fundamental to the way society thinks and operates. The social model therefore emphasises two things: the shortcomings of society in respect to disability, and the abilities and capabilities of people with disabilities themselves (Final draft of the Integrated National Disability Strategy, 2000). Impairments have not prevented disabled people from enjoying full citizenship, but this lack of integration has been due to attitudinal barriers presented by members of society. Society hinders participation because either it creates barriers or it does not provide facilitators (WHO, 2001). For a child, those barriers are created at school or at a facility where children have extramural activities. The social model of rehabilitation addresses these issues by dealing with these barriers, as well as helping the individual to deal with them. By overcoming these barriers, the reintegration into a community could be made more possible.

2.6.2. Client-centred Approach

The role of the patient and his family in decisions regarding patient care has changed dramatically in recent decades. There has been an evolution from an authoritarian brand of medicine to a more secure, humanistic position. This acknowledges the patients and their families as capable of participation in patient care issues. In biomedical ethics circles beneficence versus autonomy continues to be a scholarly and emotional debate (Beauchamp & Childress, 1989).

Within the last two decades there has been a dramatic shift from little to extensive parent participation in a child's intervention programme. One impetus for this change was the enactment in 1975 of the Education for All Handicapped Children Act. This law provided a legal mandate for parents to be included as an integral part of the child's educational programme and defined their participatory rights (Turnbull & Turnbull, 1982). It created new expectations for parents to be part of the decision-making process; to be planners, coordinators, and advocates for the child's

education; and to assume the role of the teacher at home (Roger, 1986). Attitudes and beliefs regarding parent participation have been evolving over the past several years, largely because of two factors: (a) professionals listening to what parents need and (b) recent changes in public policy. When team members have found a particular method of management to be successful, it does not mean that it is the only one that will work in all cases. In addition, team members must strive to capitalise on family-identified activities (Roger, 1986). Parents who are aware of goals and general treatment principles are often able to think of naturally occurring opportunities for therapeutic activities within their daily routine, thereby enhancing their sense of control (Bazyk, 1989).

As stated in chapter one, Chapter Two of the South African Constitution represents the Bill of Rights. The Constitution states that this is the cornerstone of the South African democracy. It enshrines the rights of all people in the country and affirms the democratic values of human dignity, equality and freedom. These supreme rights of a child are found in Section 28 of the Bill of Rights. In this section, it is stated that every child has the right to family care or parental care, or to appropriate alternative care when removed from the family environment, to basic nutrition, shelter, basic health services and social services. These are the rights of every individual to uphold the most basic form of dignity. They are in line with the principles of dignity and human rights as stated by Helander (1992) and the World Health Organisation. The South African Bill of Rights was created in 1994. Since then different organisations have adopted this document and interpreted it in their own way for the purpose of forming charters which will protect individuals' rights. One such charter is the Charter on the Rights of the Patient. For many years the vast majority of the South African population experienced either a denial or violation of fundamental human rights, including rights to health care services. To ensure the realisation of access to health care services as guaranteed in the Constitution of the Republic of South Africa, -Act No 108 of 1996, (The Constitutional Assembly, 1996), the Department of Health is committed to upholding, promoting and protecting this right and therefore proclaims the Patients' Rights Charter as a common standard for achieving the realisation of this right. In this charter it is stated that:

- (a) Every citizen has the right to participate in the development of health policies and everyone has the right to participate in decision making matters affecting one's own health
- (b) Everyone has the right of access to health care services that include:

- (i) timely emergency care
 - (ii) treatment and rehabilitation that must be known to the patient to enable the patient to understand such treatment or rehabilitation and the consequences thereof
 - (iii) a positive disposition displayed by health care providers that demonstrate courtesy, human dignity, patience, empathy and tolerance; and
 - (iv) information that includes the availability of health services and how best to use such services and such information shall be in the language understood by the patient.
- (c) Confidentiality and privacy: This means that information concerning treatment may only be disclosed with informed consent, except when required in terms of any law or order of the court.
- (d) Informed consent: Everyone has the right to full and accurate information about the nature of one's own illnesses, diagnostic procedure, the proposed treatment and the costs involved, for one to make a decision that affects any one of these elements.
- (e) Refusal of treatment: A person may refuse treatment and such refusal shall be verbal or in writing provided that such refusal does not endanger the health of others.
- (f) Complain about health services. Everyone has the right to complain about health care services, to have complaints investigated and to receive a full response resulting from such investigation.

In Part 2, article three of The Children's Rights Charter, it is stated that all children have the right to express their own opinions and the right to be heard in all matters that affect his/her rights and protection and welfare. In the case of the child, it is the parent's voice, which protects the rights of the child, since the child may not be able to speak for themselves, and may not know what he/she is entitled to. Since children cannot always verbally communicate, they are further disempowered, and therefore more susceptible to mismanagement and neglect. The one way in which we can let the children be heard and give them back their power, is by allowing the parent to be their voice.

There is a tendency for parents of children with disabilities and chronic illnesses to make decisions on behalf of their children. These children are rarely consulted or given opportunities to participate in decisions that affect their lives. Parents tend to feel pity and as a result over-protect their children, not transferring skills or equipping them to lead independent lives. There is a need

to meaningfully involve children in all decisions affecting their lives, taking into account their developmental stage (as opposed to chronological age) (Disabled Children's Action Group (DICAG), 2003).

In a specialist tertiary unit, where the child and the parent is cared for these principles, which uphold dignity and all the rights of the child, are paramount if the intention is to work in line with all the charters and validate their rights.

This shift in philosophy was positive in that it changed professionals' attitudes and beliefs regarding parent participation. Professionals began to view parents as capable of assuming numerous roles, including the roles of teacher and therapist (Allen & Hudd, 1987).

Attitudes of professionals and beliefs regarding parent participation and home programmes have changed significantly over the past 30 years. There has been an evolution from believing that therapists are the experts who teach parents what to do with their child, to believing that parents and professionals need to collaborate as equal partners in developing home activities. Today, team members take the time to listen to families in an effort to serve their needs. During listening, attitudes and beliefs regarding parent participation and home programmes continue to evolve. This evolution requires maintenance of a commitment to change and personal growth as we strive to provide family centred care (Bazyk, 1989).

2.7. When does rehabilitation begin and end?

Cromes and Helm (1992) state that comprehensive rehabilitation services are an integral part of the overall treatment of the patient who has suffered burns. Such services begin during admission for acute burn injury and extend beyond discharge for whatever length of time is necessary to achieve maximum functional outcomes with respect to personal, family, social, and vocational activities. To accomplish that objective an interdisciplinary team of trained professionals working within an organised and coordinated rehabilitation programme structure is indicated.

In the introduction the researcher stated that rehabilitation begins on day one of admission and continues long after the patient has been discharged. This means that parents have to be actively involved from day one. A consensus definition of such a programme has not been previously

achieved (May, 1984) but it has been indicated to be a need in determining minimum guidelines for overall burn treatment.

Collings (2003) stated that rehabilitation may either begin in the burn ward on day one after admission, or in the intensive care unit. It progresses through grafting and healing to discharge from the ward, integration into society through the sometimes endless periods of reconstructive surgery to a point when, as Partridge (1994, page 55) noted: "either the patient has had enough, or the surgeon suggests he can do no more, and usually it is the former".

The researcher is of the opinion that there is a need to move from a state of induced disability to an empowering one and to promote the ethos of community based rehabilitation that advocates self actualisation, full and equal participation in society, as well as the removal of attitudinal barriers in communities and staff. Empowerment as it relates to health care implies that patient independence may be optimised by helping patients to assert control over their lives (Gibson, 1991). Faulkner (2001) further states that disempowering care leads to an increased dependence and, secondly, that empowering care optimises independence.

Marion Doctor (1992) affirms in her paper what the researcher feels is happening globally in burns units. Doctor (1992) says that long-term psychological adaptation of burn-injured children begins on the day of admission with crisis intervention and establishment of rapport with the patient and family. She also states that to optimise parents' potential to provide adequate physical and emotional rehabilitation of their burn-injured child, it is imperative to involve them as participating members of the patient care team at the onset. Burn injuries necessitate teamwork.

2.8. TEAM MANAGEMENT

2.8.1. Who is the Team?

When it is recommended that a team approach be used, the researcher feels that it is vital that this term be defined. Pritchard & Prichard (1994) define a team as a group of people from various professions who make different contributions towards the achievement of a common goal. Bloom

& Parad (1976) define a team as a group of people, each of whom possesses particular expertise; each of whom is responsible for making individual decisions; who together hold a common purpose; who communicate, collaborate and consolidate knowledge from which plans are made, actions determined and future decisions influenced. In order to function within the team, each member attempts to maintain equilibrium between his internal values and ideas and the external expectations as a team (Lowe & Herranen, 1978). This is a very important statement and it is an attribute that individuals, especially medical professionals, have to develop. If this development does not take place, it will hinder the functioning of the entire team, as well as delay the outcome expected by the parent/caregivers of the child (Lowe & Herranen, 1978).

The patient is seen as part of the team and is encouraged, and expected to take his/her share in the recovery process, as are family members and primary carers. The team today is large and works because the interest of the patient is central to discussion on how best to achieve healing (Wallace, 2003).

Lowe and Herranen (1978) state that we have to recognise that there will always be potential for overlapping in roles and functions between various team members, and thus conflict. By anticipating problems and by planning joint solutions, it is possible to minimise conflict and maximise productivity. As previously stated, communication is the lifeblood of effective teamwork, but successful collaboration from all parties will result in clearer expectations for both caregivers and staff. The result has been a more cohesive and successful treatment plan for these patients as well as greater team satisfaction (Lowe & Herranen, 1978).

In any rehabilitation programme, communication is the keystone of a functioning team. Ley (1988) & King and Cross, (1989) feel that improved communication between the patient and the physician can result in better patient compliance, decreased stress and improved outcomes. In her study, Doctor (1992) states that a secondary, but equally important benefit of parent participation is wound care and parenting education. For the caregiver lacking in basic parenting skills, staff can provide instruction and modelling of supportive care as well as appropriate limit setting, often improving the overall level of parent-child interaction.

2.8.2. Types of Teams

There are different types of teams for the delivery of rehabilitation services

2.8.2. (a) Multidisciplinary Team

In the multidisciplinary team, each member contributes his or her discipline-specific skills, resulting in a summation of individual members' contributions. There is no intrinsic need for a team member to learn skills or knowledge of other disciplines or of group process (Melvin, 1980). The two advantages of this approach are that it is the easiest, least challenging method and it is most suited in a setting where rigid departmental structures exist. The disadvantage is that it is a fragmented way of service delivery. Confusing or conflicting information may be given to the patient and his/her family, and overlap between disciplines may result in repetition, a waste of time, money and effort. In addition, competition and conflict can arise between team members (Melvin, 1980).

2.8.2. (b) Transdisciplinary Team

All members are involved collaboratively in treatment. It is an excellent method for learning, especially when the information shared between the treating professionals is pertinent and applicable to the moment. The importance of the beliefs of each member can be emphasised and appreciated in a very practical hands-on experience (Pritchard & Prichard, 1994).

In the transdisciplinary team, professional boundaries blend and the team members each learn from one another, thus promoting an increasing overlap of practice and knowledge. This methodology calls for multiple professionals to evaluate a patient simultaneously with family members present and for treatment to occur in a similar way (Dejong & Hughes, 1982; Casalou, 1991, Juran, 1988 and Institute of Medicine, 1991). The relative cost and effectiveness still needs to be demonstrated in rehabilitation settings (Lyth, 1992).

2.8.2. (c) Interdisciplinary Team

When the definition of *team* is taken a step further, a definition of an interdisciplinary team is defined. It is one which utilises overlapping skills and knowledge of team members of different disciplines to obtain a synergistic effect whereby the outcome is enhanced and more comprehensive than the simple aggregation of individual efforts (Melvin, 1980 and De Lisa &

Gans, 1998). Keys to effective interdisciplinary team function include frequent and consistent communication among team members, patient, and family, as well as joint planning and action with shared responsibility for outcomes (Tsukuda, 1990 and De Lisa & Gans, 1998).

In studying interdisciplinary teams it is possible to determine six characteristics that influence team functioning

- (a) goals or tasks of the team
- (b) role expectations – internal or external
- (c) decision-making process
- (d) communication patterns
- (e) leadership
- (f) norms (Rubin & Beckhard, 1972)

Although the interdisciplinary team approach may be a more time consuming process, in the long run it results in fewer mistakes, more satisfactory outcomes, lower overall cost for health care and greater staff morale (Lyth, 1992). The researcher explains further why this is the appropriate type of team to use when managing burn injuries.

2.8.3. What is the rationale for using an interdisciplinary team in the management of paediatric burns?

The nucleus of every team is the patient and the primary caregiver. Surrounding this nucleus are the health professionals consisting of physiotherapists, occupational therapists, dieticians, nurses, doctors, psychologists and anaesthetists. These members work in concord with each other to formulate an integrated treatment approach to rehabilitation. Collaboration between team members is vital to ensure that progress follows through after planning. Modern burn care depends on coordination of a interdisciplinary team including surgeons, intensivists, nurse clinicians, nutritionists, rehabilitation therapists, pulmonary care therapists, and anaesthesia providers. (Woodson *et al.*, 2002).

It is widely accepted today that the care of the burn-injured patient is a team effort that demands the participation and the skills of many and various practices in clinical medicine and surgery. The

idea of team care is best exemplified by the seminal work of Artz and his colleagues, which still remains today as one of the best resources for all aspects of burn care. In general it can be said that the burn care team includes anyone whose skills are relevant to ensuring the patient's recovery (Shakespeare, 1993).

It is important that the rehabilitation programme must be structured on a client-rehabilitator approach. In other words, there must be a give and take relationship. It should not be based on what the rehabilitator thinks the patient needs, but more on what the patient's needs are. Training needs to be on a multi-level basis. Communities need more responsibilities, but they also require training, direction and the necessary tools to accept that responsibility. Those concerned need to accept that primary caregivers are important members of the team.

An interdisciplinary team approach works very well with the client-centred approach. The client-centred approach acknowledges the patient and his/her family as capable of participation in patient care issues. Tsukuda (1990) also state that to have an effective interdisciplinary team, there has to be consistent communication among team members, which include the patient and family, and there must be joint planning and action with shared responsibility for outcomes.

2.9. PRIMARY CAREGIVER INVOLVEMENT

Involving and educating the primary caregivers from day one is a major part of the rehabilitation process. Some authors, such as Fordyce, suggest that since learning plays such an important role in rehabilitation, more treatment should be governed by its principles (Fordyce, 1984). Doctor (1992) states that in the course of normal development, the parents are the initiators and nurturers of positive self-esteem. Their attuned loving exchanges teach young children that they are valuable and lovable. Cahners & Bernstein (1979) add that actively involving parents in the care of their children is a very useful means of helping them deal with their guilt and feelings of helplessness. They can help to feed, aid in physical therapy, and change dressings. The investment of time and energy in the hard work of care and rehabilitation gives them positive feelings and enhances their self-esteem. Korsch (1984) states that the important role of patients as

active participants in clinical encounters has been emphasised. According to this researcher, patient education increases patient compliance. Education enhances the patient's ability to ask appropriate questions and have them answered, to communicate with the provider when instructions are not answered and to become an active participant in decision-making.

In South Africa it has become even more important to place caregivers in high esteem. Since the onset of the Aids pandemic, many parents have died and have left their children in the hands of other family members. It is common for HIV-infected children to be in the care of an elderly grandparent because of the death of biological parents (Nicolas & Abrahams, 2002 and Rotherum-Borus, Leonard, Lightfoot, Fanzke, Tottenham & Lee, 2002).

Primary caregivers should be placed at the forefront of the decision-making process, where what they are satisfied or dissatisfied with is held in high regard. In his article, Staley *et al.*, (1996) state that to report functional outcome goals, a therapist first states the tasks that are most meaningful to a patient or caregiver. Until this point, the course of management has been based on us seeing positive physical results with our patients and on the assumption that the parent is satisfied with the management. This ideology is not without its shortcomings. In his paper entitled *Functional Assessment Measures*, Keith (1984) stated that assumptions about the nature of the individual's disability and what will change it influence the strategies of measurement.

Collings (2003) states that the ethos should be empathetically orientated. It should be one that accepts that the person, not the patient, needs help to take control of his/her life to be able to make choices based on information given about condition, potential, and personal situation. She states further that with the help of staff patients must become their own therapists to understand anatomy, condition and reasons for therapy and ways to achieve it.

In their study "Reducing Paediatric Burn Pain with Parent Participation", George and Hancock (1993) found that a parent participation programme improves parents' coping strategies. They found that those parents had a better understanding of the healing process and the need for specific measures. Intervention at the family level in medical services is not new, but the range of application is increasing (Doherty, 1985). In the family-centred approach, the emphasis is on

enabling the family to maximise function and social integration of a dependent family member (Humphry, Gonzalez, Taylor, 1993). Humphry *et al.*, (1993) say that increased understanding of family systems theory and how families function may lead therapists in other disciplines to recognise the interdependent influences between the family and a member with special needs, regardless of age. Moore (1984) in his study entitled "Impact of family attitudes toward blindness/visual impairment on the rehabilitation process", states that a number of significant differences were found between the groups on a semantic differential scale, which suggests that the family is indeed a major contributing factor to successful rehabilitation and securing gainful employment. McDaniel (1976) concludes that rehabilitation and treatment efforts are conditioned to a large extent by the support a disabled person receives from the family. Jacus (1981) in reviewing strategies for working with families in a rehabilitation setting, suggests that the attitude of the family is largely responsible for the success or failure of rehabilitation efforts. All of these ideas are supported by Dunst (1985); Dunst, Trivette and Deal (1988) and Shelton, Jeppson and Johnson (1987). In their papers, each incorporates the following basic assumptions:

- Children and families are inextricably intertwined. Intentional or not, intervention with children almost invariably influences families. In the same way, intervention with and support of families almost invariably influence children.
- Involving and supporting families is likely to be a more powerful intervention than one that focuses exclusively on the child.
- Family members should be able to choose their level of involvement in programme, planning, decision making and service delivery.
- Professionals should attend to family priorities for goals and services, even when those priorities differ substantially from professional priorities.

Cott, Mellins, Abrams, Reval and Dolezal (2003), in their article, Paediatric HIV Medication Adherence: The views of Medical Providers From Two Primary Care Programs, state that providers suggested having a multidisciplinary plan and approach in order to customise a set of services for one complete intervention. The majority of providers mentioned the importance of

personal communication with the family to assess the barriers to adherence and the need for further “adherence education”.

Available research suggests that enhancing the scope and coordination of care has a positive impact on child and family psychological adjustment, satisfaction with care, pain management, adherence to medical regimens and health care utilisation (Anderson, Loughlin, Goldberg & Laffel, 2001; Drotar, 2001; Kazak, 2001 and Stein, 2001).

Primary caregivers have the potential to be a key resource for children with chronic health conditions and their families, especially in collaboration with medical specialists, psychologists, educators, and other team members (Perrin, Lewkowitz & Young, 2000).

This means we have to empower primary caregivers. Our goal would therefore be to conquer dependence on outside resources and services, to enhance participation and organisation that enable them to control their own destinies. There are however certain conditions necessary for empowerment. These would include mutual knowledge, trust, respect and understanding of all concerned. An atmosphere of dialogue is important, as well as collective decision making and action. To set the necessary conditions for empowerment, those who are to facilitate the process must themselves undergo awareness raising and sensitisation. If not, it could become a situation of professionals leading the way to empower the community, rather than a "we" process of self-discovery for all involved, in which each member is aware of his/her strengths, weaknesses, limitations and the unique contribution that each can make (Purtilo and Meier, 1993).

The ethical principle of "autonomy" helps us to understand how patient involvement leads to full empowerment. According to the philosopher Beck (1949), autonomy requires respect for individuals "as persons with the same right to their judgements as we have to our own ... not for a utilitarian or any other reason, except that another is a person and therefore a rational determiner of his or her own destiny". By honouring autonomy, health professionals show respect for persons and their goals, values, fears and hopes. The importance of patient autonomy has long been recognised in the literature of rehabilitation. Team members are viewed as guides only for the journey patients will choose and ultimately traverse (Beck, 1949). Purtilo and Meier (1993)

highlight the fact that patients are disempowered when their own goals no longer drive the course of their rehabilitation.

In their article entitled “Supporting expert parents”, Sloper and Turner (1992) state that the quality of parent-professional relationships appears particularly important, as even parents who have high levels of contact with professionals can report extensive unmet needs and dissatisfaction with services.

Tyack and Zivian (2003) in their study which looked at what influences the functional outcome of children at six months post-burn found in their results that the unique and significant influence of parent factors on functional outcome lend support to family focussed assessment and treatment. Assessment, counselling and assistance should be provided to ensure parents and caregivers deal with their own emotions, use effective coping strategies, have social support networks, and are satisfied with the support they receive.

The benefits of parent training and home programmes have been recognised in the literature (Allen & Hudd, 1987). By empowering caregivers with skills and knowledge, and by providing them with support, a bridge will be created to reintegrate the child back into the community.

2.10. REINTEGRATION OF THE CHILD

Staley *et al.* (1996) state their definition saying that 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 and spiritual wellbeing. The researcher agrees with these authors since they also state that total rehabilitation of a burn-injured patient begins at hospital admission and ends only when complete reintegration into society has been achieved.

In their article entitled Community Reintegration Program, Goggins *et al.* (1990) state that at the interface between hospital and community, a therapeutic community reintegration programme seeks to potentiate the rate and level of patient recovery by providing a coordinated set of hospital-based training activities and community-based practice sessions designed to supplement standard in-patient rehabilitation efforts.

2.11. IN RESPECT OF A DIFFERENT ANGLE

When we look at the motivation for this study from a different angle, we have to look towards the financial cost of medical care in this country, as well as all the costs that parents and caregivers have to incur before the child is completely rehabilitated. The rising costs of health care have forced a new look at the ways in which such care is delivered. There has been a proliferation and growth of so-called managed care or health maintenance organisations, which are defining new rules and roles for the workplace, as well as new staffing patterns in health care (Weiner, 1994).

Services such as occupational therapy are currently being provided in a health care environment, politically driven by cost containment, accountability, and outcome measurement, as well as being driven by consumer expectations and involvement in decision-making. These political and consumer demands have required many therapists to revisit their professional values, modes of operating, and methods of evaluating services. Improving consumer participation and strengthening accountability processes can help ensure that health care services become more responsive to consumer needs (Christopher & Scheuing, 1993 and Department of Health, Housing and Community Services, 1993). It would seem appropriate, then, that consumers should be contributing to the direction and evaluation of occupational therapy service delivery. Client-centred practice has gained momentum within occupational therapy because quality occupational therapy essentially involves active client participation (Cottle, 1990).

It is becoming more necessary to prove that what we do as health therapists does in fact work, hence the move to evidence based management. A major organisation such as the American Burns Association (American Burn Association, 1990), recognises that comprehensive patient care needs

to be standardised and that we require guidelines for treatment and rehabilitation of the patient with burns. Salisbury (1992), in his article entitled "Burn Rehabilitation: Our Unanswered Challenge", addresses the fact that outcome criteria need to be identified.

2.12. CONCLUSION

This literature review has conjured up three upward spirals for the researcher. One is the evolution of the management in the unit from a medical to a social model, where the concept of an interdisciplinary team has become the key. The other change has been the evolution in the science of burns, where techniques have become more sophisticated and, certainly more evidence based. The third level of this spiral is embracing the client-centred approach to management, where the clients' rights are one of the most salient concepts.

At the other end of this spiral, we have a person, an individual, a child, the patient who has needs. In spite of evolution, these needs do not change. Last, (1988) states that public health activities change with changing technology and social values, but the goals remain the same: to reduce the amount of disease, premature death and discomfort and disability in the population. For a child with burns, the way in which this discomfort can be minimised is by his/her community's acceptance and help to involve them in community activities. This will assist with the reintegration of these individuals. This still poses a challenge for rehabilitation workers.

Together with science, we move in tune with the soul that emerges. Out of a negative and soul-destroying experience, the individual emerges with hope and empowered with knowledge, skills and a voice. The valued individual who has had client-centred hospital management has had his/her rights respected.

Together with a complex team, the soul has been given its due, the individual has been given his/her due, which further reinforces the aim and purpose of the study. The study is geared to allow interaction between the primary caregiver and the researcher to see if parents are the people who validate whether we at the RCCH are correctly managing our patients.

Therapists have liberated themselves. They are no longer just working in their domains. They are the ones who should be making the change and should be working as a team in union with the primary caregivers at the centre of the team.

CHAPTER 3

METHODOLOGY

3.1. AIM

The aim of this study was to establish how primary caregivers of children with burns managed at the Red Cross Children's Hospital, evaluated the burns rehabilitation programme.

3.2. OBJECTIVES OF THE STUDY

1. To describe the burn management protocol in the burns unit at the Red Cross Children's Hospital, during the period 1 June 2001 to 30 July 2003.
2. To determine the demographic details of the patients and their caregivers who participated in this study.
3. (a) To determine the level of satisfaction experienced by the primary caregivers of patients regarding their child's management in hospital during the burns rehabilitation programme.
(b) To establish perceptions and beliefs held by the primary caregivers of patients regarding the child's management in hospital during the burns rehabilitation programme.
4. (a) To determine the level of satisfaction experienced by the primary caregivers of patients regarding the child's discharge planning in the burns rehabilitation programme.
(b) To establish perceptions and beliefs held by the primary caregivers of patients regarding the child's discharge planning during the burns rehabilitation programme.
5. To establish and analyse the level of satisfaction, and the perception of primary caregivers regarding their inclusion in the management of the child.
6. To assess whether there was a correlation between the level of satisfaction of the primary caregivers of the child's management in hospital and:
 - (a) The area of living of the primary caregiver

- (b) The educational level of the primary caregiver
 - (c) The age of the primary caregiver
 - (d) The age of the child
 - (e) The length of stay of the child in hospital
7. To establish how primary caregivers perceived the rehabilitation outcome of the child.
8. To make recommendations to the burns unit at the Red Cross Children's Hospital.

3.3. STUDY DESIGN

The design of the study was of a retrospective, descriptive and analytical nature, using quantitative and qualitative methods of data collection. A retrospective study design was elected, as the researcher wanted to include caregivers whose children had already encountered the rehabilitation process. As the main aim of this study was to establish perceptions and beliefs of the caregivers, this information could only be obtained if the candidates were presented with a chance to express themselves without encumbrance. This was achieved by using open-ended and closed-ended questions.

3.4. STUDY POPULATION

This consisted of all primary caregivers of patients managed in the burns unit at the Red Cross Children's Hospital from 1 June 2001 to 30 July 2003. This study period was chosen since the researcher required patients to have completed the entire rehabilitation process.

3.5. STUDY SAMPLE

Permission to carry out this study and to access medical information from the hospital was obtained from the medical superintendent of the RCCH, as well as the head of the burns unit at the RCCH (see addenda A and B). The ethics committee from the University of Stellenbosch and the University of Cape Town approved this study.

References numbers are 2003/068/N and DRC# 04/135 respectively.

Using the admission book of the ward, all patients who sustained a 10% burn or more and who had stayed in hospital more than 5 days were selected as possible candidates. Those folders were ordered from the medical records at the Red Cross Children's Hospital.

According to the inclusion and exclusion criteria, 88 candidates were suitable. Letters explaining the purpose of this study and requesting participation in the study were sent to all 88 candidates, as the researcher was uncertain as to the number of positive responses she would receive.

A total of 41 people responded positively, 1 responded negatively, and 46 did not respond. A sample size of 33 was deemed suitable, allowing three of those respondents to be part of the pilot study. Their results would not be included in the main study. Due to financial constraints, it was not possible to interview more participants. Of the 41 individuals that responded, 30 participants were chosen using a computer generated random table of numbers. The 30 participants were contacted telephonically and a time was determined to interview them. Each candidate was given a reference number for anonymity.

3.5.1. INCLUSION CRITERIA

Primary caregivers were included in the study sample on the basis that they consented to be interviewed, and their child had:

- Sustained a burn of 10% Total Body Surface Area (TBSA) or more, including an area on the upper or lower limb
- Been admitted to the burns unit at the Red Cross Children's Hospital
- Spent a minimum time of five days in hospital
- Had a skin graft
- Attended at least one follow-up appointment allocated to them
- Been admitted at the age of one year or older. There are developmental variations between a child under 1 year and one that is older than a year. The researcher did not want these variations to influence the results in terms of the child's functional outcome.
- Been rehabilitated within the scheduled period, which was 1 June 2001 to 30 July 2003.
- Only been treated at the Red Cross Children's Hospital

3.5.2. EXCLUSION CRITERIA

Primary caregivers were excluded from the study sample if:

- They did not consent to take part in the study
- Their child had received treatment at a centre other than the Red Cross Children's Hospital
- Their child died in hospital, post burn injury, or during the rehabilitation period

3.6. INSTRUMENTATION

Data was collected by means of completion of a self-compiled questionnaire, which had structured and unstructured aspects. This questionnaire was divided into Section A, B, C, D, and E.

Section A: Demographic data of the primary caregiver and child.

See Addendum D, page 127

Section B: Patient history

See Addendum E, page 131

Section C: Management in hospital

This questionnaire consisted of 18 structured questions that made use of a numerical scale, score 4 being positive and score 1 being negative. There was an unstructured component to this questionnaire, where the participant had to provide an explanation for each choice. See Addendum F, page 133

Section D: Discharge planning

This questionnaire consisted of seven questions to establish the degree to which primary caregivers understood information regarding the discharge planning of their child and to which degree they were satisfied. The participants had to select an answer using a numerical scale, score 4 being positive and score 1 being negative. There was an unstructured component to this questionnaire where the participant had to provide an explanation for each choice.

See Addendum G, page 138

Section E: Rehabilitation outcome of the child

This section consisted of 23 questions and the participant had to select an answer using a numerical scale, score 4 being positive and score 1 being negative.

See Addendum H, page 140.

Other physical resources included a mini-cassette recorder and mini cassettes. To ensure that data was valid, all interviews were recorded, played, and transcribed.

3.7. DATA COLLECTION

Objective 1, which was to describe the burns management protocol in the burns unit was accomplished by compiling information from already existing protocols in the ward (ward C2 burns management protocols, 1999), observation of the setting and activities of the burns unit at the RCCH as well as discussing management with team members. The researcher obtained this information.

Objective 2, which was to describe the demographic details of the patients and their caregivers participating in this study and patient history respectively, was done by reviewing folders of patients for information pertinent to this study. Details of participants were recorded on section A (Addendum D) and section B (Addendum E). This was done by the researcher.

Verification of information and absent medical information from the medical files was gained in the direct interviews conducted by the research assistant in the language of the participant.

The information for objectives 3, 4, 5, 6, and 7 were collected during the direct interviews utilising section C (Addendum F), section D (Addendum G), section E (Addendum H).

Information for Addendum F, G and H was collected by means of direct interviews with participants. Interviews were conducted in the language of the participant by the research assistant.

The method for collecting information in the interviews was as follows:

Participants were telephonically contacted and informed of the following.

1. The purpose and procedure of the study, as had been indicated to them on the information sheet.
2. That they shall be reimbursed for travel expenses to and from the hospital.

The date and time of the appointment were determined.

- Interviews took place in an office in the hospital where the environment was quiet and where there were no disturbances during the interview.
- Interviews took place on a one to one basis involving the research assistant and the participant.
- At the interview, the participants were thanked for participating and were briefed again about the purpose, procedure, and the length of the interview.
- They were re-assured of anonymity, confidentiality and safeguarding of their information.
- They were also made aware that publications and presentations of this study might arise.
- They were asked to sign consent for participating in the study.
- The research assistant used addenda D, F, G and H when interviewing the participants.

Interviews were conducted in the language of choice of the participant (English, Afrikaans or Xhosa). Each question was posed to the participant, and they were given the opportunity to answer. They were allowed to ask questions whenever they wished, as well as to offer additional comments at the end of the interview.

- All interviews were recorded and transcribed by the research assistant for the purpose of reliability.
- Refreshments were offered to the participants at the end of the interview.
- Participants were given their travel money when the interview had been completed.
- At the end of the interview each participant was thanked for participating.

3.8. PILOT STUDY

3.8.1. The purpose of the pilot study was to:

- (a) Assess the wording and clarity on the questions of the questionnaires
- (b) Determine how long each interview would take
- (c) Identify if any modifications had to be made to the research instruments

After obtaining written permission from the management of the hospital and the burns unit (see addendum A and B), the researcher conducted a pilot study with three participants.

3.8.2. Implementation of the pilot study:

The research assistant was trained by the researcher in terms of the method of interviewing and the procedure of recording, so that standard practice could be established throughout the interviewing process. Role-play was applied to ensure that the research assistant understood and implemented the correct procedure of the interview. The researcher indicated to the assistant to be patient during the interview and not to coerce the participant during the time that they were answering questions. Questions that required explanation during the interview were explained in the same manner at all times.

The pilot study was conducted in July 2004 with three Xhosa speaking participants. Full explanations were given to the participants and consent to take part in this study was obtained from them. The Xhosa speaking research assistant conducted the interviews. The researcher was present at all times during the interviews. All interviews were recorded and transcribed.

3.8.3. Adjustments to the methodology and instrumentation

- (a) No adjustments were necessary.
- (b) Each interview took between 40 minutes and 65 minutes, which was deemed to be acceptable.
- (c) No modifications to the instrumentation were required.

3.9. DATA ANALYSIS

Responses from the questionnaires were captured by the researcher on an Excel spreadsheet.

Objective 3 (a), 4 (a) and 5 aimed to quantify the actual percentage of satisfaction with management in hospital, discharge planning and caregiver inclusion respectively. To achieve these objectives, sections C and D of the questionnaire were used. Each question had two components. The first component of each question had a scale of level of satisfaction, where the participant chose a score on a level from 4 to 1, where 4 was the most satisfied and 1, the least satisfied as indicated in Table 2 below. Responses were converted to percentages to quantify levels of satisfaction. The second component required a response to the choice made in the first component.

TABLE 2: CATEGORIES OF LEVELS OF SATISFACTION

SCORE	GRADING	LEVEL OF SATISFACTION
4	Completely satisfied	75%-100% satisfaction
3	Mostly satisfied	50%-74% satisfaction
2	Mostly not satisfied	25%-49% satisfaction
1	Not satisfied at all	0%-24% satisfaction

A statistician assisted with the quantitative analysis from the questionnaires. Objective 6 was aimed at assessment of the correlation between the levels of satisfaction of the caregiver and specific demographic information of the caregiver and child. A one-way ANOVA was done to analyse the non-categorical data, (where the residuals were normal) and a Kruskal-Wallis non-parametric ANOVA was done on the data that was not normally distributed. In all cases a $p < 0.05$ was considered statistically significant. The statistician used line, bar and scatter plot graphs to illustrate the results of the data from the questionnaires.

Objectives 3 to 7 used content analysis, thereby identifying, coding and categorising the views and evaluations of the management in hospital and discharge planning. The raw data, which was recorded and transcribed, was organised into a readable narrative description with categories and illustrative case examples extracted through content analysis.

CHAPTER 4

RESULTS AND DISCUSSION

4.1. AIM

The aim of this study was to establish how primary caregivers of children with burns managed at the Red Cross Children's Hospital, evaluated the burns rehabilitation programme

4.2. PRESENTATION AND DISCUSSION OF RESULTS

For the purpose of clarity, each result will be followed by the discussion.

4.2.1 OBJECTIVE 1

To describe the burn management protocol in the burns unit at the Red Cross Children's Hospital, from 1 June 2001 to 30 July 2003.

The description of a protocol is important, but can be meaningless if the reader does not know where the protocol is used, and in what context it is used.

The setting of the study was the Red Cross Children's Hospital (RCCH). This hospital is the only dedicated specialist paediatric hospital in sub-Saharan Africa. The RCCH is situated in Cape Town, in the suburb of Rondebosch. The hospital opened its doors in 1956 (RCCH general information document 2000). At the time it was a general paediatric hospital, caring for the needs of all children, from primary care to tertiary care. It has always been a public hospital, which is state funded. New building developments were made possible through private funding.

In 1994, In the light of the government's plan to provide free health care to all children under the age of six and the move of primary care closer to the people who needed it, and the making it more accessible, primary management became the responsibility of primary care centres, which

were situated in all major suburbs. The RCCH gradually evolved into a tertiary care paediatric hospital.

The hospital services the entire Western Cape. Many parents travel from the Eastern Cape, almost 750 kilometres away, to have their children treated at the RCCH since they feel that appropriate care is not available in this area.

The hospital has an obligation to treat every child in the same way and to respect a patient irrespective of age, race, sex and social status. It is a child's constitutional right and it is part of the mission statement of the Red Cross Children's Hospital (Red Cross Children's Hospital, 2001).

The hospital is accessible by taxi, by bus and private transport.

The burns unit is situated on the second floor of the original hospital building. The ward is accessible via the main hospital entrance and there are elevators to the second floor for those people who are not able to use the stairs.

4.2.1 (a) BURNS PATIENTS ADMISSION CRITERIA TO THE RCCH.

Patients are admitted via the RCCH trauma unit, the RCCH burns clinic, day hospitals or a general practitioner.

The burns unit at the RCCH has specific criteria for admitting children with burn injuries.

Admission criteria include the following:

- Facial burns
- Inhalation or suspected inhalation burns
- Hand burns
- Circumferential burns
- Electrical burns
- Perennial burns
- Burns greater than 10% Total Body Surface Area (TBSA)

Admission criteria to the intensive care unit include the following:

- Confirmed or suspected inhalation burns
- Electrical burns
- 30% or more TBSA burns
- Post Split Skin Graft (SSG) or Debridement 30% TBSA or more with donor area

4.2.1 (b) ADMISSION PROCEDURE IN THE BURNS UNIT

Patient admission occurs when the doctor and sister in charge of the ward accepts that the patient, according to the admission criteria qualifies for admission. The sister or nurse welcomes the patient and caregiver to the ward as they enter and explain to them what the procedure will be. The procedure is as follows. The nursing sister checks the patient's folder and details are noted in the admission book. This is to record that the patient has been admitted. The ward clerk will then record admittance data of the patient on computer. The first priority is to make the patient comfortable. A patient identity tag is placed on the patient's arm or ankle to identify the patient at all times. Hospital clothing, which is a T-shirt and pyjama pants or a nightgown is provided to the patient. The patient is shown to his/her bed or cot. Babies and toddlers are placed in cots. Bigger children sleep in beds. Primary caregivers have a chair next to the child's bed and may stay indefinitely. Parents are informed that nursing and medical procedures will occur and that they will be informed of the procedure prior to it happening.

If one looks at the population that the burns unit services, one could argue that the setting of the burns unit is central and accessible for all those who require it. Since the hospital is a tertiary referral centre that only admits children according to strict criteria, it would make sense that not every child who sustains a burn, comes here, but only those of a serious enough nature. The criteria also follow international standards from major burns units such as the Shriners Institute for burn care.(Herndon, 2002). When the criteria for admission are examined, they are found to be in line with the government's plan to manage non-serious burns in the community as part of primary health care. The reality is that only some of the primary care centres have the necessary resources to treat these non-serious burns. In many cases, patients still come to the Red Cross Children's Hospital outpatient clinic to have minor burns managed, since they are not happy with the local clinic.

4.2.1 (c) SETTING AND DESCRIPTION OF THE BURNS UNIT

The burns unit does not look like an ordinary hospital ward. Upon entering, one can immediately see that this is a children's ward. The ward is decorated with animated characters that children can identify with, in spite of the differences in background or culture.

CENTRE PASSAGE

There are benches situated outside the cubicles as indicated in the diagram. Visitors or parents as well as the patients can use these. On the outside of cubicles two and three there is a child- sized table where patients can sit at meal times and during playtime. The other table indicated on the diagram outside the sister's office is where the staff can sit to write notes.

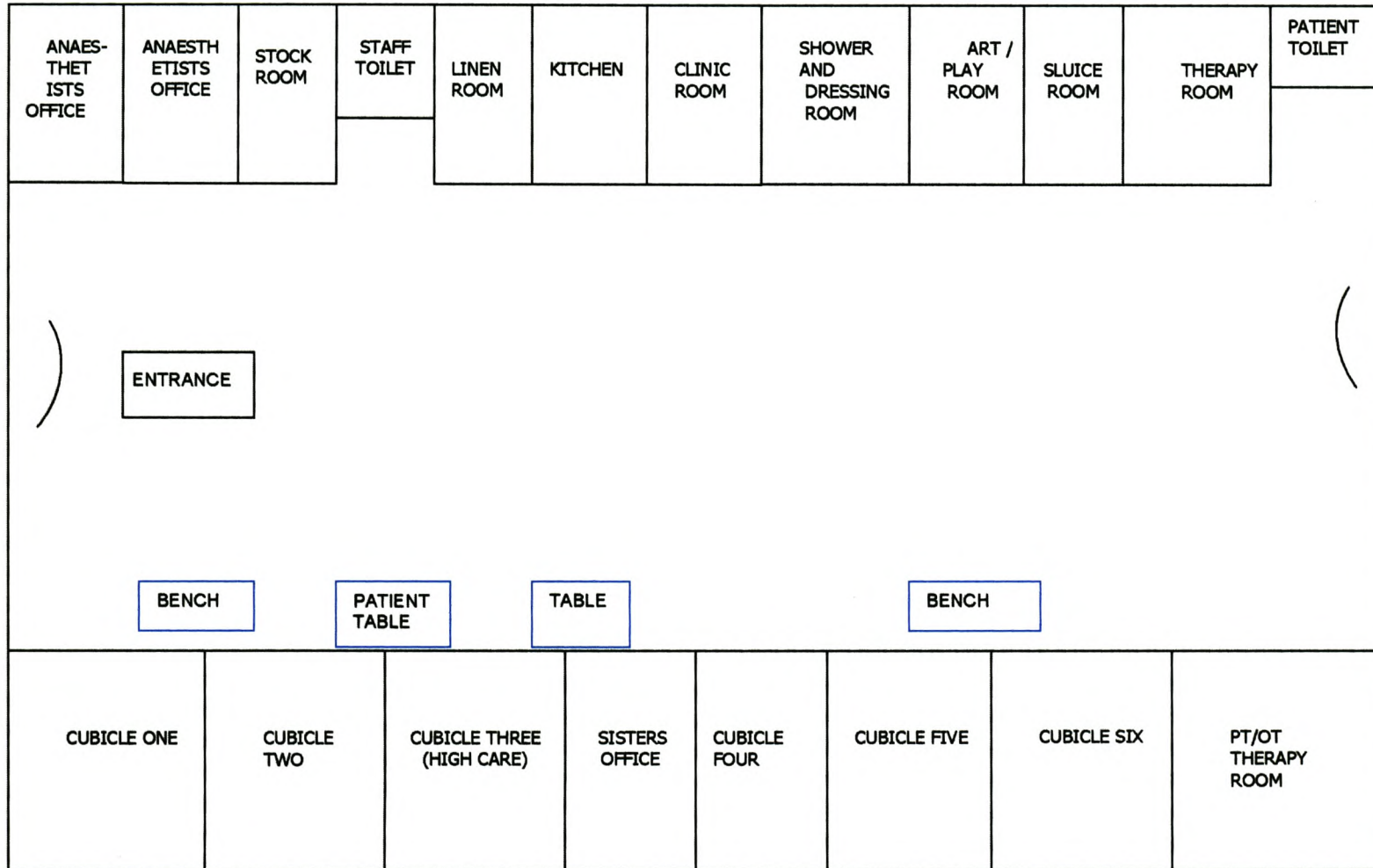


FIGURE 1 SETTING AND DESIGN OF THE UNIT

(DIAGRAM NOT DRAWN TO SCALE)

PATIENT CUBICLES

Each cubicle door has been painted a different colour and given a name such as "Goldilocks Cubicle" or "The Three Bears Cubicle". Each cubicle has six cots or beds or a combination of both, depending on the age of the children in the cubicle. Each cot has been brightly painted in the primary colours. At the foot end of each bed there is a box for the patient's medical folders. Each bed is the sanctuary of the occupant. This means that no painful procedures may be performed whilst the child is in bed unless it is necessary. In this way the child feels safe and protected in bed. Children who may not move, or cannot move, have their meals in bed. Each child has a locker next to the bed where he/she and the caregiver can keep personal goods. There are curtains in bright colours around each bed, which are tied back at the head end of the bed when not in use. They are used when a child cannot come to the dressing room, and a dressing change has to be done in the patient's bed and privacy from the other patients and parents are required. The windows of the cubicle face the entrance of the hospital, and each window has roller blinds, which are closed during resting time. Each cubicle has a bin for refuse disposal.

There is a hand basin in each cubicle near the window. At the basin there is a box of gloves and disinfectant spray. Cubicles two and five are exactly the same. Cubicle three is for "high care" and normally has two bed spaces. In times of crises it can accommodate four cots. If patients require more intensive care, but are not sick enough to be in the ICU, they are monitored in this cubicle. The sister's office is adjacent to the high care cubicle. Cubicles four and five can accommodate a single bed or two cots. These cubicles are used when there is an infected patient that needs to be isolated.

Each bed space has oxygen and suction apparatus attached to it. There is a railing above each bed to attach fittings such as suction bottles or fluid pumps. There is a comfortable chair for each caregiver next to the bed of the patient.

Glass panels separate the cubicles from the centre passage. Each panel has been decorated in brightly coloured animals, toys, numbers or letters. This glass panel also has roller blinds, which can be closed for the patient's privacy.

The sister's office is the central point of the ward and everyone usually congregates there. The office is tiny and at the best of times overcrowded, since it is the only place where the doctor, the sister, the ward clerk and sometimes other staff members congregate when necessary.

PHYSIOTHERAPY AND OCCUPATIONAL THERAPY ROOM

Room number six is the physiotherapy and occupational therapy assessment and treatment room. There is a mirrored wall for patients to see what they are achieving. There are bright vinyl-coloured mats on the floor where exercises can be done. There is an exercise bicycle for bigger children and a number of toys for children of all ages. There are child-sized tables and chairs for the patients to use when they wish to draw or paint.

PATIENT TOILET

Room number 6 is the patients' toilet.

THERAPY AND SPLINTING ROOM

The room adjacent to that is the splinting room and passive exercise room. There is a plinth in the room and two walls are partially mirror-covered. There is an array of splinting material and equipment in this room.

SLUICE ROOM

The sluice room, next to splinting room, is used for the soiled linen and for bedpans.

ART AND PLAY ROOM

The art room adjoins that room and is used for supervised art with an art therapist and is also used when children want to play with the toys that are in that room. This room is also used by the social worker, psychologist and psychiatrist as a counselling facility for the parents and patients.

DRESSING-ROOM

The shower and dressing facilities are in room number twelve. There is a special shower table and trolley, used for cleaning patients' wounds and applying new dressings. There is also a workbench for the nurses and cupboards for all their equipment.

CLINIC/PROCEDURE ROOM

Next to the dressing-room, there is a clinic room, where the patients are examined and minor procedures are done. Those include taking of blood and wound specimens. As said previously, each patient's bed is his/her sanctuary and no painful procedures are done when a patient is in their bed. Primary caregivers are allowed to be present, but it is their choice, as sometimes these procedures are too traumatic for the parents to observe. There are special containers for the disposal of these items, thereby reducing the spread of infection. Since infection could be a problem, it is necessary to be careful when disposing of infected needles or bandages.

KITCHEN

Adjacent to the clinic room is the ward kitchen. The housekeeper serves the meals from here. All meals are received from the main kitchen. There is a microwave oven so those parents who have brought food from home for their child may warm it up. Meals are also warmed up if, during mealtimes, the patient has left the ward for a procedure and has missed their meal.

Adjoining the kitchen is the linen room and a staff toilet. At the entrance to the ward, opposite the first cubicle, are the anaesthetists' offices.

The ward is neat and clean. Floors are mopped daily and cots and lockers are washed regularly. Linen is changed daily or sooner if it is soiled. Since there is a shortage of cleaning staff, primary caregivers are asked to assist with keeping the ward clean and neat. Caregivers may not eat in the cubicles. They have to go to the cafeteria or to the caregivers' rooms, where meals are provided. If a child needs a bedpan or needs to use the toilet, they are asked to assist with that.

The ambience of the ward is friendly and peaceful. There is a radio/compact disc player and music is played throughout the day, except during resting time. From 12:00 to 14:00, a pin can be heard dropping.

The positive aspect of the design of the unit is that all the amenities are available and up to date with international standards required for optimal burn care (Herndon, 2002).

There is a dire need for a staff office, where staff members are able to write notes, plan treatment and consult with other staff. It is not appropriate for medical staff to be writing notes on the clinic room plinth. Furthermore, there is not an area where issues of a sensitive or confidential nature can be discussed when they are done by telephone. This impinges on the rights of patients to have all matters pertaining to them confidentially handled.

There is a need for a counselling-room where therapist, parents and patients can sit in an environment conducive to receiving psychological intervention. This area must be quiet and should allow for privacy.

There is no parent toilet in the ward. Parents have to go the ground floor (two floors down) to have access to a toilet. The researcher feels that basic amenities should be more accessible to primary caregivers, especially since many of them are only there for a short time.

4.2.1 (d) ACUTE MANAGEMENT

When patients are admitted to the unit, there are a number of procedures that have to be implemented. The patient's TBSA has to be assessed using the universally accepted Lund and Browder chart (O'Neill, 1979). All patients have their wounds swabbed to see if there is any infection present. Blood specimens are taken to check blood parameters.

Immediate care of the burn patient involves fluid resuscitation. This is done according to fluid replacement formulae in the first 48 hours to achieve haemodynamic stability. Every patient who has been burned 20% TBSA or more requires a nasogastric tube placement and resuscitation, plus maintenance fluid via a nasogastric tube. Monitoring output and input are primarily nursing responsibilities. The aim is to achieve 1-2 ml/kg/hr urine output for the first 48 hours.

As soon as the patient is stable and a thorough assessment has been performed, primary caregivers are informed about the child's condition, the severity of the burn, what management is envisaged and approximately how long the child will be in hospital. The parents are then given

the opportunity to ask questions or voice opinions regarding the management of the child. On the day of admission, due to the state of shock of the parents, they usually do not ask questions, but on subsequent days parents feel more comfortable doing so. Caregivers are also informed of the open visiting policy in this unit. The only time they may not interact with the child is during the resting period, when children are placed in their cots or beds and no visitors are allowed. Primary caregivers may stay with the child for most part of the day, except during resting time. They may even sleep at the bedside. Comfortable chairs have been provided for the parents. For parents who do not live in the city, accommodation and meals are provided. It is recommended to the primary caregivers that they use their child's resting time for their own resting time to recharge their batteries.

4.2.1 (e) INFORMED CONSENT

When the patient has been admitted to the unit, the doctor in charge will obtain consent from the mother or father if they are legally married, from the mother if the parents are unmarried or from the legal guardian, if they have proof thereof. Procedures, which require consent, are dressing changes, removal of staples and stretching and splinting under general anaesthesia, as well as desloughing and skin grafting. All procedures are explained to the person giving consent in the language of choice and then consent is obtained. Two witnesses are present. Keeping in line with the Patient's Rights Charter, elements such as refusal of treatment and the right to complain about health services as well as confidentiality and privacy are upheld.

4.2.1 (f) POST-ACUTE MANAGEMENT

Up to this point the patient still wears his or her own clothing. If the patient has been referred by a doctor or has been brought in by emergency services, he/she will have a first aid dressing, which is left on for 24 hours. Once patients have been resuscitated and properly sedated, they are showered and the necessary dressings are applied. When patients are placed back into bed, they will be positioned in a way to reduce their oedema. Patients with superficial burns or burns that are superficial partial thickness, may have the burns dressed and are sent home, with instructions to return to the bi-weekly clinic. This is not a rigid rule as it depends on the area and size of the burn. When patients are sent home, they are given a letter to attend the day hospital

for a dressing change every second day. Certain dressings do not require changing. In this case the parent does not have to visit the day hospital. They only have to return to the clinic at the RCCH for a follow-up appointment. In this case parents are instructed not to bath the child or get the dressings wet. They are given a follow-up date on an appointment card and told where to go.

4.2.1 (g) PREOPERATIVE MANAGEMENT

Burns which appear as an indeterminate depth and which heal spontaneously within three weeks do not require grafting. Burns which are unquestionably full thickness or partially deep burns will require grafting. For the purpose of skin grafts, general anaesthesia is required. Pre-operative management includes checking the patient's haemoglobin. All patients are kept nil per mouth for four hours prior to the procedure. If excision and grafting are planned, blood may be required in theatre.

Parents are allowed to be with their child until they have to be anaesthetised. They are allowed to assist the anaesthetist during the child's period of anxiety, when the child is afraid to hold the mask. This is the primary caregiver's choice and he/she is not compelled to do so.

4.2.1 (h) POST-OPERATIVE MANAGEMENT

Post-operative management includes a haemoglobin recheck. Overhead heaters are used to dry the dressings and warm the patient. Nasojejunal feeding starts immediately after theatre procedures. All patients with peri-anal burns receive constipating agents and need to be placed on a metabolic bed. Nasal prongs administer oxygen until the patient is haemodynamically stable, the temperature is above 36,5 degrees Celsius, the patient is awake and the airways are clear. Antibiotics are administered for three days after major excisions and grafting. Parents are informed that the child may be disorientated post theatre, and it would be a normal reaction for them not to respond to the parent. This state may last from 30 minutes to a few hours.

The researcher has found that the acute, sub-acute and surgical management is on par with burn centres around the world. The protocols that the unit has developed meet international standards. Moreover, they are agreeable with the local setting and population. Certain

products, which should be, but are not used regularly, are artificial dermis products. They should be used since the cosmetic and functional outcome is superior, but due to financial constraints imposed by the administrative management of the hospital, they are not freely available. This is in spite of burns a unit manager motivating these products.

4.2.1 (i) WHO IS THE TEAM?

Each member of the interdisciplinary team of the unit is an equal shareholder. Members of the team are firstly and foremost, the patient and the primary caregivers. Professionals such as a doctor, nurse, dietician, anaesthetist, occupational therapist, physiotherapist, social worker, psychiatrist, psychologist, pharmacist, microbiologist and plastic and reconstructive surgeon all form part of this team. Figure 2 represents the way interaction and management occurs within the team.

The entire team meets once a week to discuss each patient's present and future treatment. Each team member, including primary caregivers has the opportunity to give input into the management of each patient as well as indicate how the management has been thus far. Decisions are recorded in a book that everyone has access to. Primary caregivers are updated on current decisions and alterations to the child's management.

Figure 2 on page 61 illustrates the various team members as well as the interaction that occurs between these team members. Interaction can occur between two members, or multiple role players. The patient and primary caregiver are counted as salient as all other team members. They are at the centre of focus of management and form the nucleus of this cell. This process of interaction and communication is geared toward the client centred approach to management.

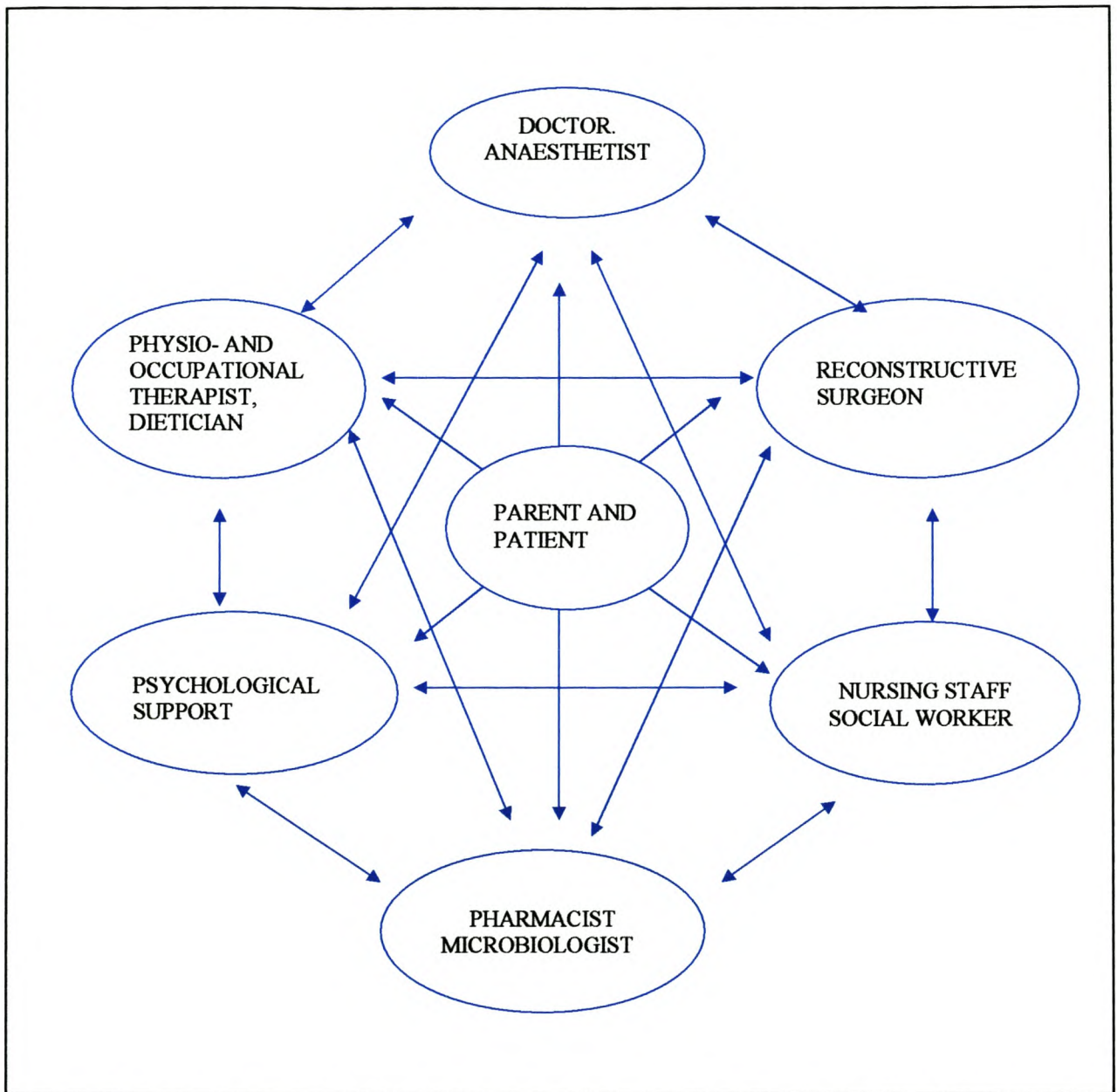


FIGURE 2: INTERACTION OF AN INTERDISCIPLINARY TEAM

4.2.1 (j) ANAESTHETIC AND PAIN MANAGEMENT

Woodson *et al.* (2002) has stated that rational and effective anaesthetic management of acute burn patients requires an understanding of the multidisciplinary approach. All patients receive background analgesia. Valaron, Brufen, and Panado must be given to each patient on admission to maintain pain at an endurable level. This is reassessed every two weeks, and alternatives prescribed. Pain management depends on the team, as any team member can question whether a patient's pain medication is effective or not. Combinations of drugs for sedation and analgesia are given 45 minutes prior to change of dressings or procedures, such as physiotherapy. In this way, the pain and anxiety levels of the child are controlled. If the patient has become tachyphylactic to the medication, they may need a general anaesthetic to have a procedure performed.

4.2.1 (k) NURSING MANAGEMENT

The nurse's function in the burns unit is multifaceted. Observation of the patient and frequent assessment of the patient's vital signs are made throughout the initial and post-burn phase. Wound assessment and care is of paramount importance. This is one of the keystones of the nurse's diverse functions. Wound inspection is vital and should be impeccable, since the undesirable effect of infection can result if it is not. All patients in the unit have to shower and have a daily dressing change. The exception to the rule is if a patient has had a skin graft. In that case, replacing of clean outer dressings occur on day 2, after the skin graft. When the patients are old enough, they may wash themselves. Parents are informed that the child receives analgesia and sedation before the dressing changes. Owing to anxiety, some patients react negatively during dressing changes. Nurses are always present to deal with the concerns of primary caregivers, whether these concerns are large or small. They are the ones who build strong relationships with the parents and the ones parents trust, or feel the most comfortable talking to without having the feeling that they are being judged.

4.2.1. (I) PHYSIOTHERAPY AND OCCUPATIONAL THERAPY

Physiotherapy and occupational therapy are integral components of a patients' treatment. The treatment begins on the day of admission and continues long after the patient has been discharged from hospital and wound healing has occurred.

The physiotherapist assesses the patients' chest condition especially if an inhalation injury has occurred or is suspected. This ensures that the already existing infections do not worsen. It is also important to maintain a clear chest in a patient, so that he/she is in optimal condition for an anaesthetic.

Depending on the age of the child, it is important to assess at which level he/she is. In performing daily activities with a baby, the level of play is important to tell us about the development of the baby.

The physiotherapist and occupational therapist are responsible for:

- Involving the primary caregiver from the onset of therapy
- Assessing and appropriately treating the physical, functional, developmental and psychosocial needs of the patient
- Preventing contractures and encouraging good posture and maximum mobility. All patients are mobilised from the day of admission, unless contra-indicated. This ensures that the patient does not adopt the position of comfort or the flexed position. All joints are positioned in the functional position. If the active range is not adequate, a specific activity has to be decided on to achieve a required movement. The active range is compared on the affected and unaffected side and is recorded. Movement of the joint, affected by the graft occurs the day the staples are removed from the grafted area, which is usually on the fifth day after grafting. This occurs under sedation or under general anaesthetic if the patient has extensive burns and the procedure is going to be too painful. All grafted areas are delicately handled to preserve the graft, and gently mobilised so that full range of movement can be achieved.
- Interacting with the burn team to ensure a holistic treatment of the patient.
- Building a rapport with a child and family and educating them about prevention of further burn injuries as well as teaching them about treatment of the existing burns.
- Educating students, team workers, and the community about the role of physiotherapy and occupational therapy in the burn patient.
- Ensuring ongoing treatment when the patient has been discharged.

It is important to make patients realise that they can be as functional and independent as possible after a burn injury. Since play is a child's primary function, it is used in all treatments to obtain as much movement as possible. Movement therapy is done incorporating imaginative play and distraction techniques. Therapists encourage normal movement and activities of daily living (ADL) such as eating, dressing, and playing as much as possible. Activities are not forced but are integrated into the activity that the patient chooses. Assistance with ADL is gradually reduced. A variety of possibilities are offered to the patient so that he or she can choose an activity which will encourage active movement.

Scar management begins once the skin has completely healed. Daily massage with a lanolin-based cream is important to soften the skin and make it more pliable for stretching.

The parents are shown how to initiate activities and how to perform passive movements, apply splints and massage the scar as soon as possible. The management of each patient pertaining to the burnt area is the responsibility of the parent when the patient has been discharged. If at any time the parents experience problems with the child's management, they are told to come back to the team member to seek advice. Written home programmes are given to the caregivers, as the team understands that the parent is already coping with a new and emotionally draining responsibility, and may not remember verbal instructions.

4.2.1 (m) PSYCHOLOGICAL INPUT

Even a small burn can have an enormous psychological impact on a child, causing them to act differently and to start displaying new emotions. It is for this reason that the psychologist and psychiatrist need to meet with the parents and the child to assist them with coping skills. This input, if required, can continue even after the patients have been discharged. These professionals help the parents to deal with guilt issues and conflict within the family after the burn.

4.2.1 (n) SOCIAL WORKER

The social worker does not deal with every patient. She only sees those patients whose primary caregivers have social problems. She deals not only with the patient and the caregivers, but with the entire family. She is often the individual who the parents feel they can disclose sensitive information to. Since the social worker is not always present in the ward, she relies on the team members to provide her with information the family may have brought to the attention of other professionals. The social worker also has to investigate whether the burn was the child's first or not, and whether it was accidental or not. This may have implications for child abuse and must be followed up.

4.2.1 (o) PLASTIC AND RECONSTRUCTIVE SURGEON

Despite reconstruction only happening once healing and scar maturation have occurred, plastic surgeons are involved in the acute stage. The reason for this is that they are able to advise the general surgeon as to what the best operative choices are and realistically what the chances for reconstruction are. The plastic surgeon has to look at the patient's function and then the cosmetic outcome. The plastic surgeon, the occupational therapist and the physiotherapist work in concord with each other, as it is important to gain the therapists input as to what the patient's function is before and after surgery. The plastic surgeon will recommend to the primary caregivers what the necessary procedures are, but if the primary caregivers feel they do not want the reconstruction done, it is their choice. This team member may see the patient for many years, as those patients who require and have consented to having more surgery, have a long road ahead, as operations have to be done in stages.

4.2.1 (p) DIETETIC INPUT

The dietician has a vital role to play in the patient's physical well-being. Since the burn injury increases the patient's metabolism and uses the available stores of glucose and glycogen, as well as proteins, these have to be replenished immediately. Furthermore, for healing to occur, the patient's nutritional state has to be kept optimal. According to the RCCH burns unit, nutritional protocol, all patients with burns 20% TBSA and larger must have a nasojejunal tube in place and be fed continuously. This is to ensure that patients receive the correct amount of nutrients in the

right consistency for them to digest it adequately. When the patient's skin grafts have taken and their blood parameters have returned to normal, they are taken off the continuous feed and are offered a ward diet, which can be supplemented by oral feeds.

4.2.1 (q) THE MICROBIOLOGIST

The microbiologist is critical, as he/she is the individual who analyses the wound swabs taken twice a week. He/she is then able to tell the doctor if there is infection present and what specific infection there is. Moreover, he/she will be able to say which bacteria are sensitive to which specific medications. This is very important, because if it is not done, wound healing may not occur. Not having the correct sensitivity to medication would mean that patients would also receive medications that were not necessarily appropriate.

4.2.1 (r) "FRIENDS VOLUNTEERS"

One of the fundraising organisations in the hospital is the Friends of The Children's Hospital, in short known as "FRIENDS". They have a number of volunteers who play with the children daily in all wards. They wear bright yellow aprons and bring with them a trolley of toys with which the children can play. They bring age appropriate toys for the children and ask the child, if they are old enough, what he/she would like to play with. Before they leave, each toy is cleaned with a liquid sterilises, to minimise the spread of infection between children.

The "Friends" are also involved in providing mothers with basic clothing and toiletries when they have lost all their possessions in the fire. If that has happened, they also provide the child with clothing and toys.

The researcher has said that the team in the burns unit functions as an interdisciplinary team. If the definition of *team* is looked at according to many authors such as Melvin JL (1980), De Lisa JA *et al* (1998) and Tsukuda RA (1990), the team in the burns unit is functioning as interdisciplinary team as stated in the literature.

4.2.1 (s) GENERAL RULES OF THE BURNS UNIT

All staff must wear a clean coat when treating patients (coats are kept on a rail outside the linen room). Soiled coats must go to the sluice room.

All staff must wear gloves when treating patients.

All caregivers must wear plastic aprons when handling their child.

Resting time for the patients is between 12:00 and 14:00. During this time caregivers are not allowed in the cubicles. No treatments are done either, unless they are absolutely vital and cannot wait.

All visitors must report to the sister or nurse in charge.

Caregivers may not eat in the cubicles.

4.2.1 (t) DISCHARGE PROTOCOL

Patients are discharged when their wounds have healed enough to be managed at a day hospital or the burns clinic at the Red Cross Children's Hospital. Primary caregivers are included in this decision, since they must feel comfortable to take the child home. This means that they must be able to travel to the clinic or day hospital every second day for their child's dressing change. Caregivers must also feel that they will physically and mentally cope with their child, and that their social circumstances will allow them to take the child home.

4.2.1 (u) THE CIRCLE OF REHABILITATION

Rehabilitation begins on day one in the burns unit at the RCCH. Parents are encouraged from the onset to interact with the child, touch them and help the child to understand that they need to start moving and doing activities, even if the movements are limited. The parents often feel helpless and have feelings of guilt, especially when they were present at the time of the burn. In order to empower them, they are embraced as part of the team, and are involved in decision-making and activities. When the patients are old enough, they too are given choices regarding therapy and pain management.

Parents are urged to treat their children as normally as possible, especially if the child has a facial burn. The sooner the parent accepts how the child looks, the easier it is for the child to accept their differences.

Ongoing management after discharge of the patient occurs at a bi-weekly burn clinic where the team is available to make decisions, to plan future management, as well as to terminate treatment.

Rehabilitation ends when the child and the parents feel that they are coping with activities in the community like going back to school without any problems, physical or otherwise. When they feel they are satisfied with the cosmetic outcome, it is their choice to terminate the treatment. Rehabilitation ends when the child is able to walk in a public place and is able to cope with people staring or asking unwarranted questions. All these factors have to be taken in to account and discussed with the primary caregiver before a conclusive decision is taken.

When a setting has been described, it is necessary to look at the individuals who utilise this area. These would be the primary caregivers and the patients partaking in this study. Their demographic details have been described in the next section.

4.2.2. OBJECTIVE 2

To determine the demographic details of the patients and their caregivers participating in this study.

4.2.2 (a) PATIENT DEMOGRAPHICS

Patient Age

Age of the patient was measured as a continuous variable from 1 to 11 years

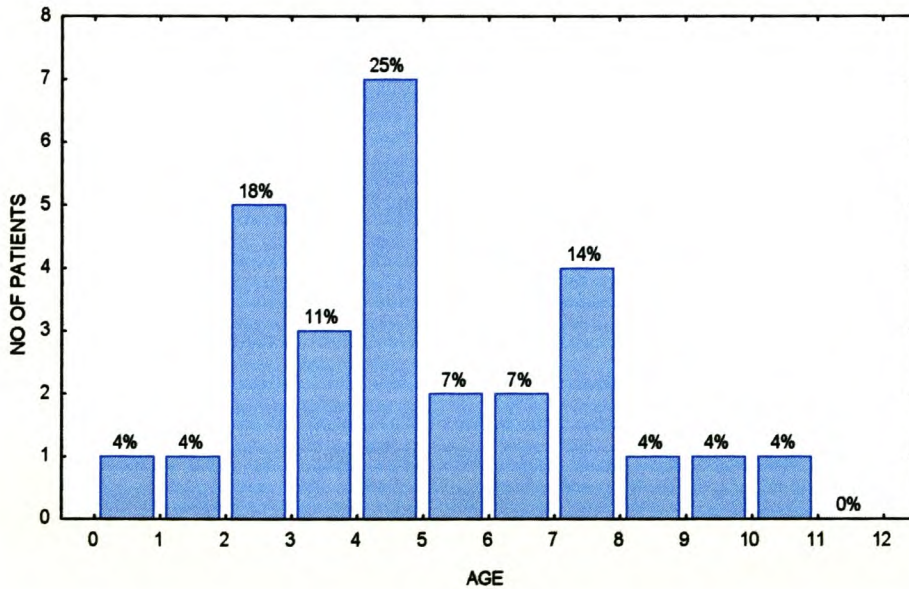


FIGURE 3: DISTRIBUTION OF PATIENTS' AGES

Ages of patients ranged from 1 to 11 years with the mean age of 5,28 years.

The total percentages in figure 3 add up to 102%. The reason for this is that the percentages were in decimal point format, and were upscaled to integers.

Patient Gender

Gender of the patient was measured as a dichotomous variable that was coded for regression analysis as male and female. Patients' gender was equally distributed between male and female. Fifteen were male and fifteen were female.

Burn history: Injury factors

In all patients (100%), this was the first burn they had experienced.

In all patients (100%), this was an accidental burn.

50% (n=15) of the patients were burnt with hot water and 50% (n=15) with fire.

93% (n=28) of the patients were at school, preschool, or crèche, 7% (n=2) were not.

Burn severity was measured using the % TBSA burn. The TBSA burn was visually estimated by a medical officer and mapped out on the Lund and Browder chart providing an estimate of the percentage of body surface area burnt from 0% to 100%. This record was completed upon the child's admission to the RCCH burns unit or in the trauma unit at the RCCH.

Percentage of the burns ranged from 12% to 48% TBSA burn, with the mean size of burn being 29.71% TBSA burn.

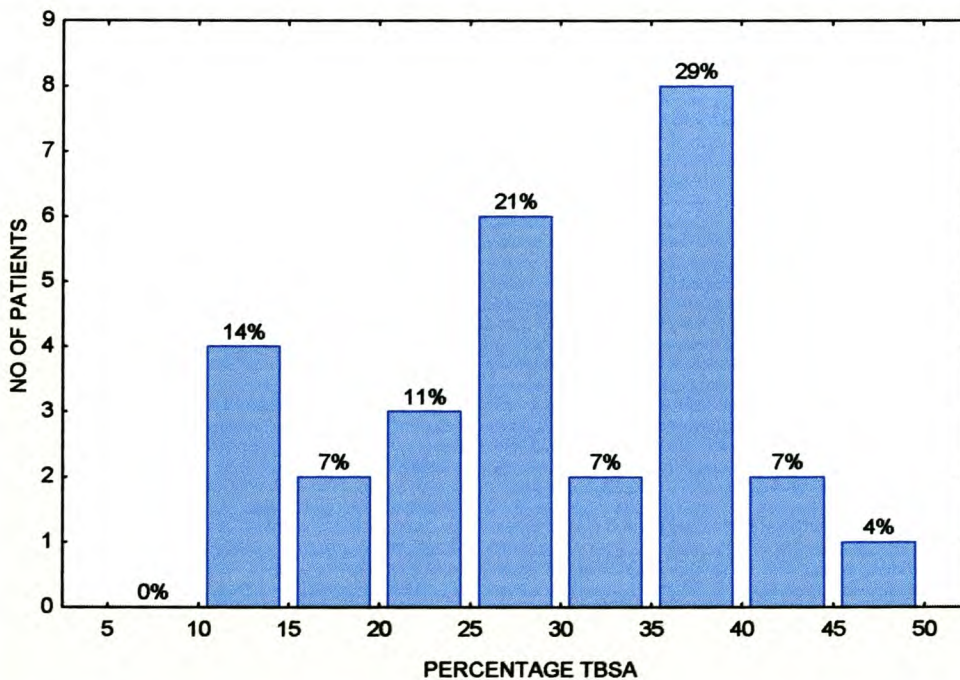


FIGURE 4: PERCENTAGE TBSA BURN IN PATIENTS.

Figure 4 represents the different sizes of burn injuries. It was found that the greatest percentage of patients (29%, n=9) had a burn which was between 35% TBSA and 40% TBSA. The second largest TBSA burn was in the category of 25% TBSA to 30% TBSA, represented by 21% (n=6),

of the study population. Only 4% (n=1) of the population has sustained a burn in the 45% TBSA to 60% TBSA category.

Area of burn

The area of burns the children suffered, were as follows:

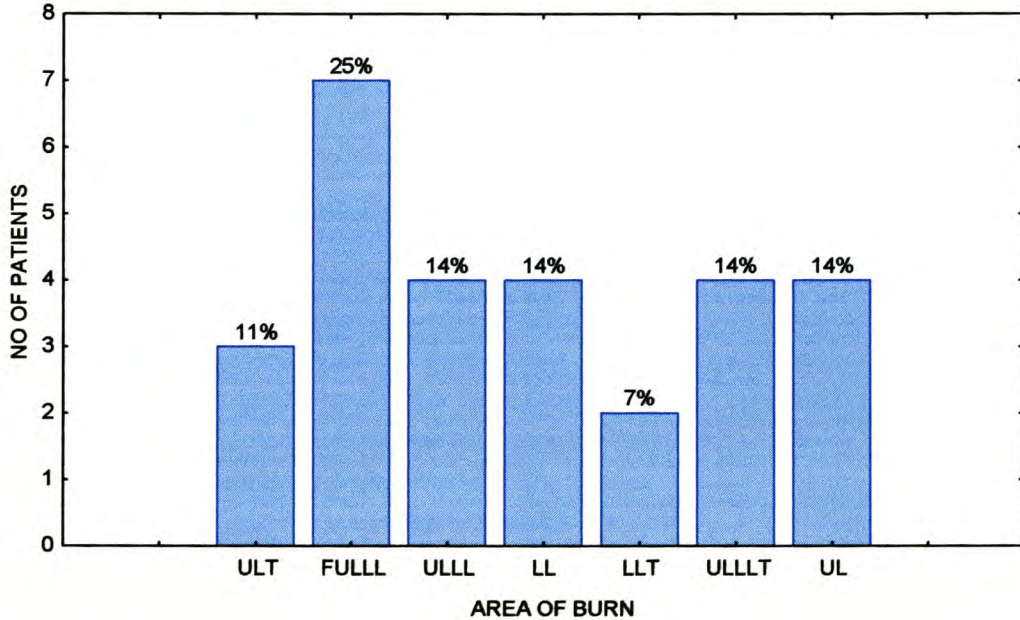


FIGURE 5: AREA OF BURN IN PATIENTS

The total percentages in figure 5 add up to 99%. The reason for this is that the percentages were in decimal point format, and were downscaled to integers.

- ULT = both upper limbs and trunk
- FULLL= face and one or both upper and/or lower limbs
- UL = one upper limb /both upper limbs
- ULLL = one/both upper limbs and one/both lower limbs
- LL = one lower limb/both lower limbs
- LLT = both lower limbs and trunk
- ULLLT= one/both upper limbs and one/both lower limbs and trunk

The most common burn was found to be the FULLL, which occurred in 25% (n=8) of the population. This is in line with the total population of children that the unit admits per year. The

mechanism of this injury is a child pulling a kettle cord, pot handle, or tablecloth, and having boiling water, fall over him/her, resulting in the face, and one or both upper and/or lower limbs being burnt (CAPFSA 2002).

Thickness of burn

The thicknesses of the burns were as follows:

50% (n=15) of the patients had deep partial thickness burns and full thickness burns.

50% (n=15) of the patients had full thickness burns.

Since the inclusion criteria requested that the patients spend a minimum of 5 days in hospital, and must have had skin graft it was expected that the burns would be deep partial and full thickness burns.

Length of stay in hospital

The length of stay in hospital represented in figure 2 ranged from 11 days to 59 days, with the mean stay of 26,32 days. This is represented in figure 6 below.

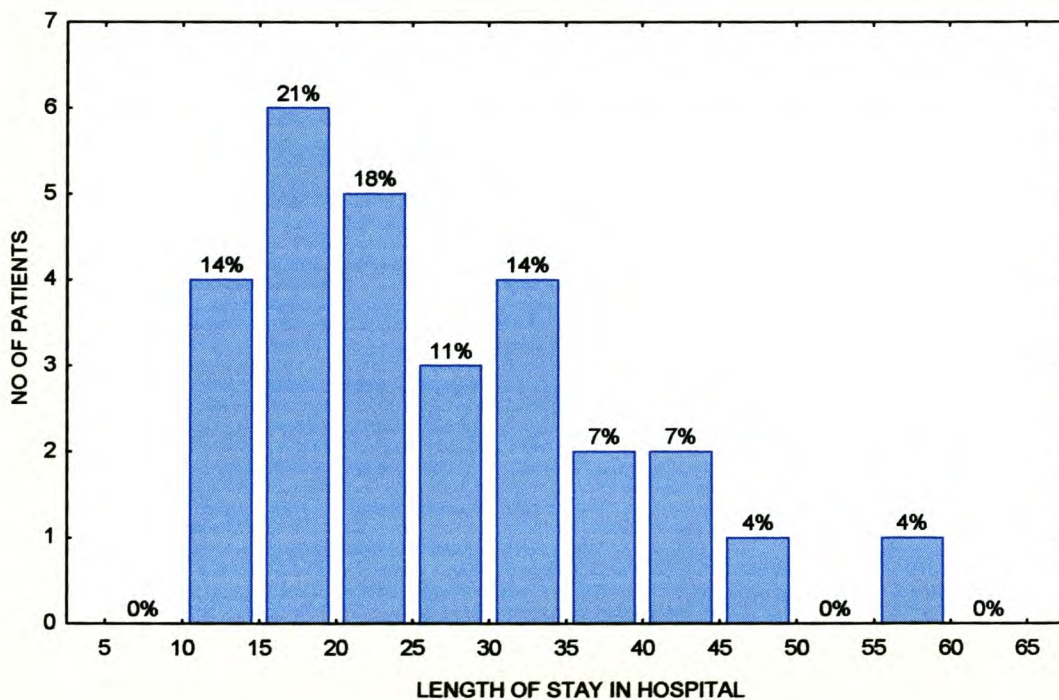


FIGURE 6: LENGTH OF STAY IN HOSPITAL

When the length of stay is to be determined, doctors calculate one day per percentage burn. For example, a patient with a burn with a 15% TBSA should spend 15 days in hospital (Herndon, 2002). In this project the mean percentage TBSA burn is 29,71%, and the mean stay in hospital of 26,32 days. It can therefore be said that the percentage burn and length of stay in hospital are on par with international standards.

Factors that could increase the length of patient stay in hospital are infection and sepsis. This could increase the stay by a few days to a couple of weeks. Other determinants of length of hospital stay include social factors (social problems in the household and the unavailability of resources), as well as the unavailability of centres to refer to, once the patient is discharged.

First aid applied

The type of first aid applied by the caregivers is represented in figure 7 below.

70% (n=21) of the patients had some sort of first aid applied by the first contact person

30% (n=9) had no first aid applied by the first contact person.

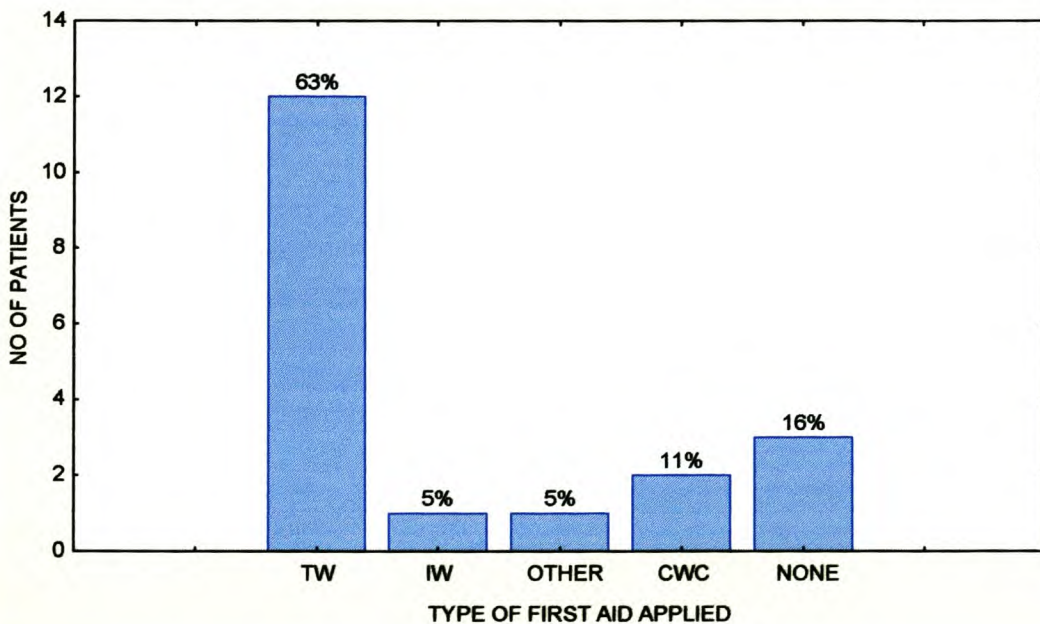


FIGURE 7: TYPE OF FIRST AID APPLIED

TW	=	tap water
IW	=	ice water
OTHER	=	other
CWC	=	cloth soaked in tap water and changed every few minutes
NONE	=	none

*Other refers to egg, which was applied to n=1 patient.

70% (n=21) of the primary caregivers reported that they had applied some type of first aid. Of these, 13 had applied cold water, and 2 a cold-water cloth, changed every couple of minutes, both of which are the correct first aid. Within this study, 70% is a relatively high percentage of caregivers applying first aid. The reason for not having applied any first aid or the incorrect type of first aid, such as ice water or egg could be multifactorial. Reasons such as a lack of knowledge, a lack of resources in informal settlements, and the inability to react at the time of the incident due to shock, were provided. This is an area that requires further investigation.

4.2.2 (b) CAREGIVER DEMOGRAPHICS

Thirty caregivers were present at the interviews (n=30).

Primary caregivers' age

The ages of the primary caregivers were measured as a continuous variable.

Ages of the primary caregivers ranged from 25 years to 55 years, with the mean age of 34,82 years.

Caregivers' educational level

The educational level of the caregivers was assessed using the measure of the education level and applying the categories of primary, secondary and tertiary education.

20% (n=6) of the primary caregivers had primary education.

63% (n=19) of the primary caregivers had secondary education.

17% (n=5) of the primary caregivers had tertiary education.

Home areas of caregivers

Caregivers' home areas were categorised using informal settlements, Cape Flats and southern suburbs.

60% (n=18) lived in informal settlements.

27% (n=8) lived in the Cape Flats.

13% (n=4) lived in the southern suburbs.

Informal settlements are defined as settlements where the land used is not approved, and where the construction is unauthorised and not to prescribed standards. The Cape Flats is literally the flat expanse of land that stretches east of Table Mountain. It is where most of the coloured and black people were relocated under the system of apartheid. The Southern suburbs refers to the suburbs south of the City bowl of Cape Town (Institute for democracy in South Africa (IDASA), 2004).

These figures are representative of the total population of patients that are admitted to the RCCH unit. Most of the burn injuries do happen in informal settlements and occur because of poor socio-economic circumstances (CAPFSA 2002).

4.2.3 OBJECTIVE 3

4.2.3(a) To determine the level of satisfaction from the primary caregivers regarding their child's management in hospital during the burns rehabilitation programme.

Table 3 below represents the questions asked and the level of satisfaction in each category. Scoring was done according to categories as described in the data analysis. The participant had to choose a score on a level from 4 to 1, where 4 was the most satisfied and 1, the least satisfied. Responses were converted to percentages to quantify levels of satisfaction.

TABLE 3: LEVELS OF SATISFACTION WITH MANAGEMENT

Q NO	QUESTION	% SATISFACTION	N =	SCORE
1	Explanation and information given to the primary caregiver on admission	86% found the explanation fully understandable 14% found the explanation mostly not understandable	26 4	4 2
2	Staff competence displayed when treating your child	90% felt that staff members were always competent 10% felt that the staff were not competent at all	27 3	4 1
3	Pain management	67% felt that the pain was always well managed 3% felt that the pain was sometimes well managed 30% felt that the pain was mostly not well managed	20 1 9	4 3 2
4.	Noise levels	93% found the level always acceptable 7% found the level sometimes acceptable	28 2	4 3
5.	Dressings	100% found the dressing always were correct and neat	30	4

6	Surgery needed	100% felt that the surgery was 100% needed	30	4
7	The way consent was obtained	100% agreed that the manner in which consent was obtained was 100% understandable and appropriate	30	4
8	Psychological support given to your child	80% felt that the psychological support given to the child was excellent 3% felt that the psychological support given to the child was good. 3% felt that the psychological support given to the child was satisfactory. 14% felt that the psychological support given to the child was poor.	24 1 1 4	4 3 2 1
9	Caregiver concerns	100% agreed that the manner in which consent was obtained was 100% understandable and appropriate	30	4
10	Exercises done	93% agreed that exercises were always correctly and carefully handled. 7% thought that exercises were sometimes correctly and carefully handled.	28 2	4 3

When looking at the scoring for satisfaction with the child's management, primary caregivers mainly scored a 4 in the questions asked. The two scores of concern were pain management of the child (67%, n=20), and psychological support to the child (80%, n=24). This was an important finding for the researcher. This could indicate that caregivers were not adequately prepared for the procedures that the child would have to endure, or it is possible that they witnessed the child having a procedure on a day, that the pain was not optimally managed. The same applies to the psychological support, meaning that caregivers were not present when support was given, or that this is one area that they, as well as the child struggled with in hospital and at home.

The positive findings such as the high level of professionalism and concern for the parents and children have meaningful implications for the staff of the unit. It affirms what they are doing in terms of patient care within a specific model. Furthermore, it is motivating for staff to hear how the RCCH burns unit has been evaluated, and positively criticised. The researcher feels that state hospitals do not always get the recognition they deserve and staff members often feel that they are not appreciated. Through this study, it will be possible to inform staff of the positive feedback from evaluators of the burns rehabilitation programme.

4.2.3 (b) To establish perceptions and beliefs, from the primary caregivers of patients regarding their child's management in hospital during the burns rehabilitation programme.

Recurring words were identified from the responses that were obtained in the unstructured part of the questionnaire.

Recurring words were classified as major if they were identified by a minimum of 50% or 15 of the participants.

TABLE 4: RECURRING WORDS DERIVED FROM RESPONSES TO QUESTIONS ON MANAGEMENT IN HOSPITAL

Q NO	QUESTION	RECURRING WORDS EMERGING FROM THE QUESTIONNAIRE	% PARTICIPANTS	N
1	Explanation and information given to the primary caregiver on admission	<ul style="list-style-type: none"> ▪ Privacy ▪ Honesty ▪ Openness ▪ Allowed to ask questions ▪ Appropriate language 	<p>66%</p> <p>70%</p> <p>70%</p> <p>60%</p> <p>53%</p>	<p>20</p> <p>21</p> <p>21</p> <p>18</p> <p>16</p>

2	Staff competence displayed when treating your child	<ul style="list-style-type: none"> ▪ Friendliness ▪ Professionalism ▪ Patient handling ▪ Patience ▪ Good Attitude ▪ Trust 	73% 77% 53% 60% 50% 60%	22 23 16 18 15 18
3	Pain management	<ul style="list-style-type: none"> ▪ Professional ▪ Comfort 	73% 66%	22 20
4.	Noise levels	<ul style="list-style-type: none"> ▪ Child-friendly 	66%	20
5.	Dressings	<ul style="list-style-type: none"> ▪ Neat ▪ Professional 	57% 70%	17 21
6	Surgery needed	<ul style="list-style-type: none"> ▪ Pain ▪ Severe looking wound ▪ Quick healing ▪ Infection ▪ Good explanation 	57% 73% 50% 50% 73%	17 22 15 15 22
7	The way consent was obtained	<ul style="list-style-type: none"> ▪ Good explanation ▪ In their language ▪ Inclusion 	77% 50% 77%	23 15 23

8	Psychological support given to your child	<ul style="list-style-type: none"> ▪ Compassion ▪ Kindness ▪ Encouragement ▪ Words of comfort ▪ Honesty ▪ Dealing with children according to their age 	57% 57% 66% 53% 77% 66%	17 17 20 16 23 20
9	Caregiver concerns	<ul style="list-style-type: none"> ▪ Friendliness ▪ Prompt reply ▪ Good explanation ▪ Patience ▪ Openness 	57% 67% 70% 60% 70%	17 20 21 18 21
10	Exercises done	<ul style="list-style-type: none"> ▪ Fun ▪ Helpful ▪ Important ▪ Inclusion 	50% 53% 60% 73%	15 16 18 22

From the most prominent recurring words, themes were derived which would represent what the primary caregivers felt was the most important to them. From their response it was clear that certain factors such as professionalism, honesty and openness of the staff, friendliness, good explanation and inclusion were most vital to the primary caregiver.

The focus on staff professionalism was highlighted many times in several of the questions that were asked. From the time that the child was admitted, parents found that staff members were professional in their manner of speaking and in handling the child. They found that the staff did not talk down to them and treated everybody the same. Parents noted that even when the ward

was very busy the staff tried to accommodate all the primary caregivers. This was applicable even during busy periods.

One of the participants said: "As a nursing sister myself, I was impressed with the way in which the information was given to me and my family and I liked the fact that we were called into a separate room where the details were explained to us".

Caregivers appreciated the honesty and openness of the staff. When it came to transference of information or discussing a child's management, parents found that they received all necessary information, so that they were always aware of what was happening with the child. Primary caregivers found that if they asked the staff certain questions and staff members could not answer, they would say that they did not know. As regards severity of the burn or infection of the child, they were told the truth, even though it was hard to hear sometimes. Caregivers felt that it was better that staff members were honest and open from the start as the injury to the child was difficult to accept. The earlier they heard the truth, the easier it was for them to come to terms with the child's condition. They also found that hearing the harsh reality made it easier to deal with the child's scars later on. One caregiver said: "They told me that the child was badly burnt. They told me that they were not sure if his eyes could be saved, because it was too early to say. They said his face was very swollen then and it would get better every day. They told me that he is in intensive care now, but when he gets better, he will go to the ward. I was scared when I saw my child on a machine. The doctor told me that it was to help him breathe because his lungs had been damaged because of the burn. The doctor told me my son was not going to be able to talk to me now because they had given him pain medication to make him sleep". She added that: "It was good that they told me everything, so I could prepare myself from the beginning".

Although caregivers found that there was much information that they had to deal with, the results indicate that they benefited from being given this information. From the day that the child was admitted, they were told what was happening with the child and what was going to happen on a daily basis. Throughout this time, caregivers found that it helped that the explanations were clear and in a language they understood. Information was given to them in simple terms and if they did not understand, staff members were happy to explain it to them again. One caregiver added: "They called someone to speak to me in Xhosa because I could not understand English or

Afrikaans. They asked me afterwards if I understood everything and if I wanted to know anything or whether I had any questions”.

When the child was admitted to the burns unit, and to post-surgical procedures, caregivers found themselves in a state of shock. They felt that they always had questions and concerns. They found staff friendly and easy to approach to answer their questions. Caregivers added that they found that the staff looked after them and their children. Due to the friendly nature of staff members, caregivers said that the staff had an inherent caring nature. "We got the feeling they really wanted to look after our children," one parent said. Caregivers felt that staff always greeted them and spoke to the child in a kind and caring manner. Parents agreed that staff members were also interested in their well-being and, not only in that of the child.. "The staff members were always friendly. Even when they were busy, they had time to talk to me," said one parent.

One negative view of the primary caregiver who felt that the staff were not competent at all related that, " the sister insisted that the child eat with his own hands, when his hands were burnt and it was not easy to hold anything. I was shocked when she shouted at him because he did not want to hold his own cup. That nurse was not professional".

At the end of the questionnaire, primary caregivers were asked if they had any other comments, views or information to share with the researcher. On analysing this data, it was found that certain key themes had emerged and were identified as major if they appeared in 50% (n=15) or more of the caregivers’ responses.

TABLE 5: THEMES EMERGING FROM ADDITIONAL COMMENTS BY PRIMARY CAREGIVERS

KEY THEMES	% PARTICIPANTS	N
Professionalism of staff	77%	23
Ward atmosphere	70%	21
Primary caregiver support/Psychological support/Staff concern	73%	22
Quality of work,	77%	23

Professionalism of staff was once more highlighted in this area. Caregivers found that staff members were helpful, experienced, trained and experts in what they did. They compared this to the quality of work done by the staff at the day hospital or at their local clinic. The question of being treated at another centre prior to being admitted was not asked in the questionnaire. These comments were self-initiated by the primary caregivers. Caregivers took note of the small things like being greeted by the staff and the friendliness of the staff. This made them feel respected and was important to them. They found that staff members were knowledgeable in the information that they gave to the primary caregivers. These views connected with quality of work of the staff, which was a theme reported in 77% (n=23) participants. Caregivers felt that the standard of care provided was high. They felt that staff members were very capable and they would rather come to the RCCH burns unit than go anywhere else. They felt that they did not receive the same level of care at the day hospital. They did not feel confident taking the child to the day hospital.

One of the factors that did not come out in the structured questions, but did come out in this last question was the atmosphere of the ward. Views regarding this topic had arisen in 70% (n=21) participants. Caregivers felt that the burns ward was clean and neat. They found the atmosphere pleasant and positive. Primary caregivers thought this atmosphere was very child-friendly and different to other hospitals, because it was colourful and staff members were dressed in bright colours. They thought the idea of getting volunteers to play with the children was a good one, because it occupied the patients and they did not miss their parents so much. They had not seen this concept anywhere else and thought it contributed to the child being happier in hospital. They felt this was important for the proper healing of the child. When they compared this to the other hospitals and clinics they had visited, they felt that this hospital was the cleanest.

Seventy three percent (n=22) reported that the staff had a high level of concern for the parents and the patients. Parents reported that staff encouraged the patients and motivated the parents to think positively and not to give up hope. They found the staff would help them with their concerns and not ignore that the parents experienced problems. They felt that the staff became involved in their lives.

Some recurring words did not arise often enough to fit into a category, but are important to mention. Two caregivers said that staff members were judgemental. This arose since a caregiver

said that she and her child burned at the same time. She was therefore not able to visit her child as often as she would have liked to. Comments from the staff, to her were not understanding in that respect. They wanted to know why she did not visit more often. She felt that staff members should first hear why she was not able to come, prior to judging her.

Two caregivers also commented on the rudeness of the staff. The researcher was also made aware that on occasion nursing staff shouted at the children when they did not want to do something, or spoke rudely to them when they were non-compliant.

The primary caregivers demonstrated a positive response to the management of the child. Primary caregivers were articulate and clear on the need for comprehensive and simple information. They valued the honesty and openness of the staff. Many professionals underestimate the parents' need for a volume of information that must be shared with them. Staff may feel that parents will not be able to cope with the seriousness of information. However, it was clear from this study that caregivers in fact preferred the openness and straight facts from the beginning. Although they were not major themes, negative factors that were of concern were connected to questions on pain management and psychological support as is indicated by the percentage satisfaction in these two categories. Caregivers, who felt that the pain management was inadequate, felt that too little medication was given or that it had not become effective by the time the procedure was done. Caregivers that felt that the psychological support was lacking, also felt that more support could have been given during the child's stay in hospital.

4.2.4. OBJECTIVE 4:

4.2.4. (a). To determine the level of satisfaction from the primary caregivers of patients regarding their child's discharge planning in the burns rehabilitation programme.

Table 6 below represents the questions asked and the level of satisfaction in each category. Scoring was done according to categories as described in the data analysis. The participant had to choose a score on a level from 4 to 1, where 4 was the most satisfied and 1, the least satisfied. Responses were converted to percentages to quantify levels of satisfaction.

TABLE 6: SATISFACTION WITH DISCHARGE PLANNING

Q	QUESTION	PERCENTAGE SATISFACTION	N	SCORE
1	Completeness and adequacy of discharge information	97% said adequate and complete 3% said mostly adequate and mostly complete	29 1	4 3
2	The clearness and understandable level of the home instructions	94% said totally clear and understandable 3% said partially clear and partially understandable 3% said not really clear and difficult to understand.	28 1 1	4 3 2
3.	The clearness and understandable level of the home programme	97% said understandable and easy to follow. 3% said mostly not understandable and mostly not easy to follow.	29 1	4 2
4	Pressure garments – service and fit of garment	50% felt it was excellent 10% felt it was bordering on bad. 40% felt it was not at all acceptable.	15 3 12	4 2 1

5	Discharge from hospital – right time or not?	97% of primary caregivers felt their child was discharged at the correct time. 3% of the primary caregivers felt that the patient should stay in hospital, but that the staff did not agree.	29 1	4 1
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The responses to the discharge planning was very positive with between 94% to 97% (n=28-29) rating the discharge information a score of 4 which is equivalent to 75%-100%, clearness and comprehension of the home programme and home instructions a score 4 which is equivalent to 75%-100%.

The views in response to the service and fit of the pressure garments were of concern. Only 50% (n=15) felt that the service and the fit of the pressure garment were excellent, 10% (n=3) felt that the service and fit of the pressure garment bordered on bad, 40% (n=12), felt that the service and the fit of the pressure garment were not at all acceptable. This has serious implications for future management of pressure garments. The researcher feels that there are solutions to these challenges. Therefore, to ensure improved future outcomes, recommendations (see chapter 5) will be made to the team members.

4.2.4. (b) To establish views and beliefs from the primary caregivers of patients regarding their child's discharge during the burns rehabilitation programme.

Recurring words were identified from the responses that were obtained in the unstructured part of the questionnaire (Addendum G- Section D).

Recurring words were classified as major if they were identified by a minimum of 50% or 15 of the participants

TABLE 7: RECURRING WORDS FROM RESPONSES TO QUESTIONS ON DISCHARGE PLANNING

Q NO	QUESTION	RECURRING WORDS EMERGING FROM THE QUESTIONNAIRE	% PARTICIPANTS	N
1	Completeness and adequacy of discharge information	<ul style="list-style-type: none"> ▪ Clear and understandable ▪ Written 	73% 66%	42 20
2	The clearness and level of understanding of the home instructions	<ul style="list-style-type: none"> ▪ Clear and understandable ▪ Able to cope 	77% 70%	23 21
3	The clearness and level of understanding of the home programme	<ul style="list-style-type: none"> ▪ Clear and understandable ▪ Written instruction ▪ Inclusion ▪ Able to cope 	67% 53% 73% 73%	20 16 22 22
4	Pressure garments – service and fit of garment	<ul style="list-style-type: none"> ▪ Clear and understandable ▪ Fit was unacceptable 	53% 50%	16 15
5	Discharge from hospital – right time or not?	<ul style="list-style-type: none"> ▪ Inclusion ▪ Able to cope 	77% 67%	23 20

The themes that emerged from this question were derived by looking at the recurring words and their frequency as used by primary caregivers during the interview session. In terms of the discharge planning, it was noted that primary caregivers found that it was important that the instructions be clear and understandable. They said what caused this, was that it was given to them in a simple way in a language that they could understand. Furthermore, they found it helpful that certain information, such as dates and times, as well as the type of dressing, was given in writing. This also applied to certain home programmes they had to follow with the child. There were drawings that made it easy for them to know what to do.

They found that what they were told when it was time to go home, were things they had been shown in hospital and that they had practiced and were comfortable doing them on their own at home. They felt they could cope well with these matters at home.

When it came to decisions regarding discharge and home programmes, inclusion played a huge role. They indicated that it was important for them to have a say as to when the child was going home, because they needed to know whether they would cope at home. The same applied to the home programme. As regards both the discharge from hospital and the home programme, they felt that they coped better because they had been part of that decision.

As was stated in the first part of this objective, 50% of the primary caregivers reacted negatively to the fit of the pressure garments. This was mostly applicable to the fit of the facemasks.

4.2.5. OBJECTIVE 5

To establish and analyse the level of satisfaction, and the perception of primary caregivers regarding their inclusion in the management of their child.

This question had a scale of level of perceived inclusion where the participant chose a score on a level from 4 to 1, where 4 was the most satisfied and 1, the least satisfied. Responses were converted to percentages to quantify perceived level of inclusion.

97% (n=29) of the caregivers felt that they were always included in the child's management.

3% (n=1) felt they were sometimes included in the child's management.

Caregivers felt included because they had been consulted at every step of the burns rehabilitation, such as dressing changes, surgery, the child going to theatre, and exercises. They felt that they were informed before procedures of what was going to happen. The staff also gave them the reason for the procedure. Staff members asked them if they understood the information and if they have any questions. On the ward rounds, discussion regarding their child occurred in their

presence, with them participating and they felt they were part of the team. Caregivers liked the fact that they participated in decision making regarding management in the hospital. The idea that they were asked whether they thought the child was ready to go home or not, appealed to them. They appreciated this, as they were confident to go home with the child at a time when they felt they had better coping skills.

One mother said: "I was always called by the doctor when they wanted to do anything to my child. When my child went to theatre, they would tell me my child was going and I could go with him. I could put on theatre clothes and even go with him into the operating theatre until he fell asleep".

Another primary caregiver said: "The doctors and sisters would always call me, especially when they were doing their rounds. They would tell me what was happening with my child. On the rounds, when my child's dressings were open, they would ask me if I wanted to look at the wounds".

The results indicated that primary caregivers feel included in the child's management throughout the different phases of the rehabilitation programme.

Including primary caregivers in the decision-making process can only add value to the functioning of the team and reinforce the need for caregiver involvement as part of an interdisciplinary team. Collings (2003) states that the ethos should be empathetically orientated. It should be one that accepts that the *person, not the patient* needs help to take control of his life, or her life, to be able to make choices based on information given to them about their condition, their potential, and their personal situation. She states further that with the help of staff, patients must become their own therapists, to understand anatomy, condition and reasons for therapy and ways to achieve it. The researcher is in agreement with this idea, and it is the same idea that the team at the RCCH has tried to instil in parents. In this way, self-reliance can triumph over dependence on professionals.

4.2.6 OBJECTIVE 6

To assess whether there was a correlation between the primary caregivers' level of satisfaction with the child's management in hospital and:

- (a) The area of living of the primary caregiver
- (b) The educational level of the primary caregiver
- (c) Age of the primary caregiver
- (d) Age of the child
- (e) The length of stay of the child in hospital

Looking at the data of the level of satisfaction with management, two outliers (candidates 1 and 11) were detected in an outlier test and were therefore removed. The reason for this is that these 2 sets of data were 3 standard deviations from the mean. Removing these two outliers resulted in data that was normally distributed.

4.2.6 (a) Correlation between the level of satisfaction with the management in hospital and the area of living of the primary caregiver

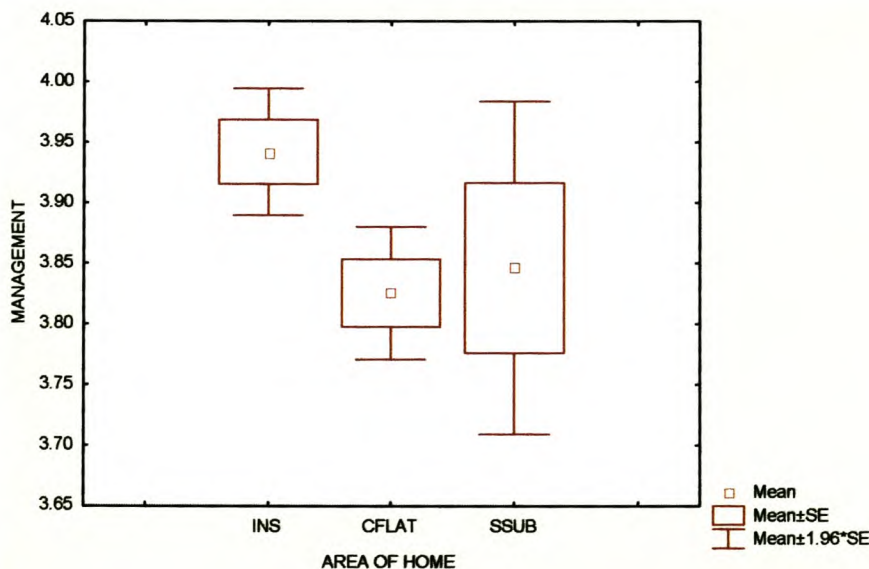


FIGURE 8: CORRELATION BETWEEN HOME AREA OF CAREGIVERS AND SATISFACTION WITH MANAGEMENT

INS = INFORMAL SETTLEMENTS
CFLA = CAPE FLATS
SSUB = SOUTHERN SUBURBS

When the satisfaction with the overall management in hospital was investigated in terms of the area where the primary caregivers lived, it was found to be statistically significant, using the Kruskal-Wallis test: $H(2, N=28) = 7.313347$ where $p = .0258$.

It was found that the caregivers living in informal settlements were the most satisfied with the child's management in hospital. The participants living in the Cape Flats were the least satisfied. It could be that the parents living in the informal settlement had lower expectations of the overall level of management than the primary caregivers living in the Cape Flats. Moreover, it is possible that the parents living in informal settlements had prior negative experiences in other health care facilities and rated the burns unit as excellent, since they were comparing treatment to the one that had been received at another facility. A question relating to management in other centres was not asked. They were responses volunteered by participants.

4.2.6 (b) Caregivers' level of satisfaction with management in correlation with the caregivers' educational level.

Using the Kruskal-Wallis test: $H(2, N=28) = 4.086726$ $p = .1296$, these results were not statistically significant. A non-parametric test was used due to the non-normality of the residuals.

It can therefore be said that irrespective of the caregivers' educational level, it had no influence on the level of satisfaction with the patient's management in hospital.

4.2.6 (c) Caregivers' level of satisfaction with management in correlation with the caregivers' age.

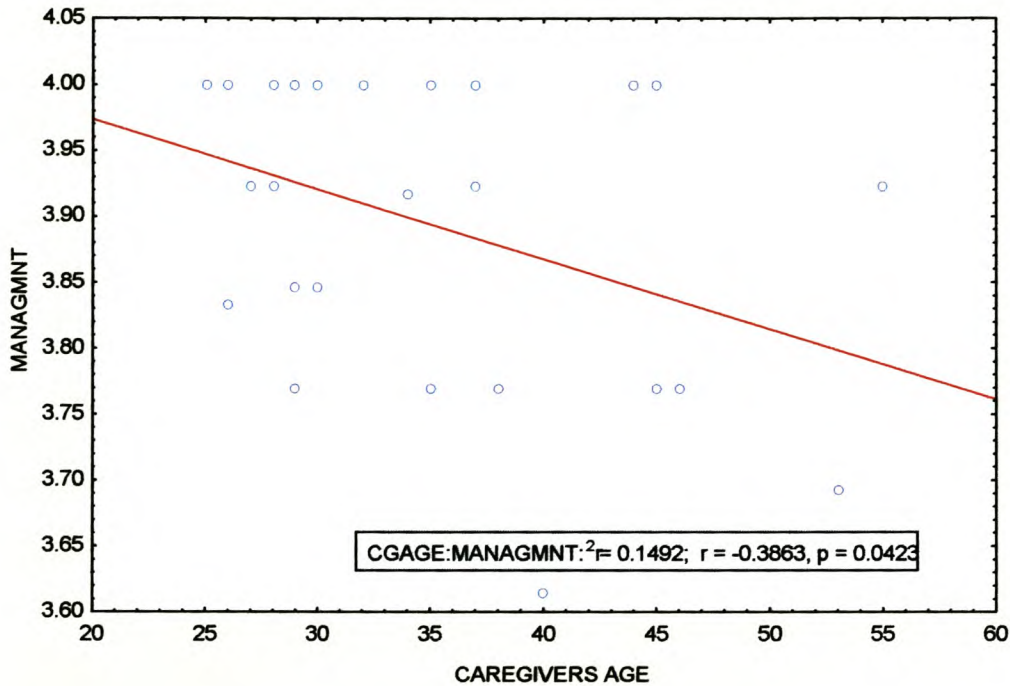


FIGURE 9: CORRELATION BETWEEN THE LEVEL OF SATISFACTION WITH MANAGEMENT AND THE CAREGIVERS' AGE.

When looking at the correlation between the level of satisfaction with management and the caregivers' age, it was found that the younger caregivers were more satisfied with the management of the child in hospital than the older ones. Using a one-way ANOVA, there is a regression of management versus the caregivers' age. The data was widely distributed, but it was significant where $P = 0.04$ and $r = 0.38$.

This could perhaps be attributed to prior expectation from an older individual to expect more, and the lack of experience in a younger caregiver, or the patient being a first child of a young caregiver.

4.2.6 (d) Correlation between the satisfaction with management in hospital and the patient's age.

When looking at the correlation between the level of satisfaction of management of caregivers and the patient's age, it was found that there was no correlation. These results were not statistically significant ($P = 0.58$ and $r = -0.10$).

As was stated before, a burn injury has such a hard-hitting emotional impact that it is possible that irrespective of the child's age, it affected caregivers in the same way.

4.2.6 (e) Correlation between the primary caregivers' level of satisfaction with their child's management in hospital and the length of stay of the child in hospital.

When looking at the relationship between the level of satisfaction with management and the child's duration of stay in hospital, there was no statistically significant correlation found ($P = 0.17$ and $r = 0.266$).

This study has shown that, irrespective of the duration of the child's stay in hospital, it did not impact on the level of satisfaction with the child's management in hospital. This result must be interpreted with care, as it is open to many biases. The actual size and depth of the burn, as well as previous treatment in another health care facility, may have influenced this result.

4.2.7. OBJECTIVE 7

4.2.7 (a) To establish how primary caregivers rated the rehabilitation outcome of their child.

Section E (Addendum H), page 139 of the questionnaire was used to evaluate this. This questionnaire had 23 questions.

The participant was asked about their child's function related to the rehabilitation outcome. They had to score the child using a scoring system in table 8 below.

TABLE 8: SCORING TO MEASURE REHABILITATION OUTCOMES

SCORE	GRADING	LEVEL OF PERCEIVED INVOLVEMENT
4	Able to do this independently	75%-100% perceived outcome
3	Able to do this with some difficulty	50%-74% perceived outcome
2	Able to do this with a lot of difficulty	25%-49% perceived outcome
1	Not able to do this at all	0%-24% perceived outcome

TABLE 9: CAREGIVERS' RATING OF THE REHABILITATION OUTCOME

QUESTION	RATING 4		RATING 3		RATING 2		RATING 1	
	% RESPONSE	N	% RESPONSE	N	% RESPONSE	N	% RESPONSE	N
1	70	20	22	6	4	1	4	1
2	96	27	4	1	0	0	0	0
3	70	20	25	7	4	1	0	0
4	68	19	25	7	7	2	0	0
5	96	27	4	1	0	0	0	0
6	96	27	4	1	0	0	0	0

7	96	27	4	1	0	0	0	0
8	100	28	0	0	0	0	0	0
9	96	27	0	0	4	1	0	0
10	100	28	0	0	0	0	0	0
11	100	28	0	0	0	0	0	0
12	70	20	22	6	8	2	0	0
13	100	28	0	0	0	0	0	0
14	70	20	4	1	25	7	0	0
15	100	28	0	0	0	0	0	0
16	70	20	14	4	12	3	4	1
17	100	28	0	0	0	0	0	0
18	96	27	0	0	0	0	4	1
19	100	28	0	0	0	0	0	0
20	100	28	0	0	0	0	0	0
21	96	27	0	0	4	1	0	0
22	96	27	0	0	4	1	0	0
23	96	27	0	0	4	1	0	

When looking at the scoring of the rehabilitation outcome of the child, primary caregivers indicated that the child was able to perform most functions independently (score 4) or only with some difficulty (score 3). These activities centred on maintaining basic hygiene, playing, interacting with people and performing basic activities of daily living. They comprised of the physical functions a child has to perform normally. Questions that scored lower than 75% were identified as pertaining to functions that the child may have performed with difficulty. These scores are highlighted in Table 9 and are represented in the form of questions below.

These were the questions:

1. Was the child able to play with other children again?
3. Was the child able to return to crèche/preschool/school?
4. Was the child able to interact with other people?

- 12. Was the child able to play with his/her friends?
- 14. Was the child able to answer questions about its burn?
- 16. Was the child able to walk in a public place?

The above questions are related to the areas where the scores were lower than 75%.

Question 1 tried to determine if the child was able to play with other children again

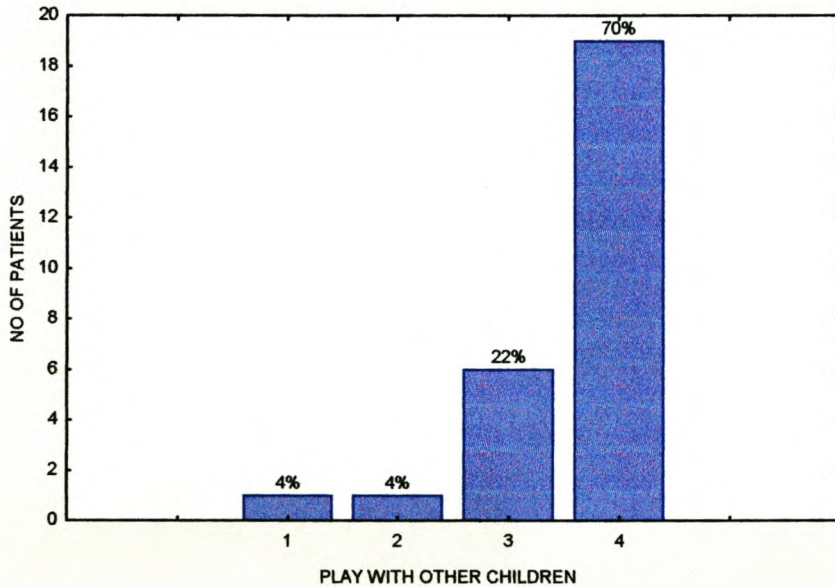


FIGURE 10: SCORING OF PATIENTS BEING ABLE TO PLAY WITH OTHER CHILDREN

These results indicate that only 70% (n=20) were able to play with other children without any problems, while six children had some difficulty, one child had much difficulty, and one child was not able to do this at all.

Question 3 tried to determine if the child was able to return to crèche/preschool/school

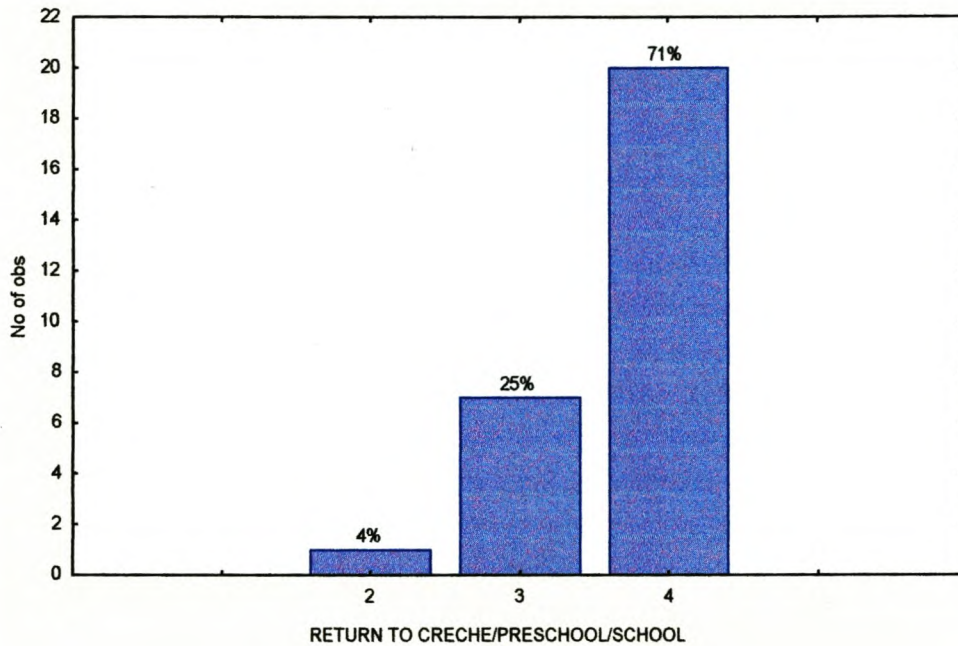


FIGURE 11: SCORING OF PATIENTS WHO WERE ABLE TO RETURN TO CRÈCHE/PRESCHOOL/SCHOOL?

These results indicate that only 71% (n=20) were able to play and return to crèche/preschool and school without any problems, while seven children (25%) had some difficulty, and one child had much difficulty with this. It is possible that some children did not want to return to school as they were being teased by other learners, and did not know how to deal with the torment.

Question 4 tried to determine if the child was able to interact with other people?

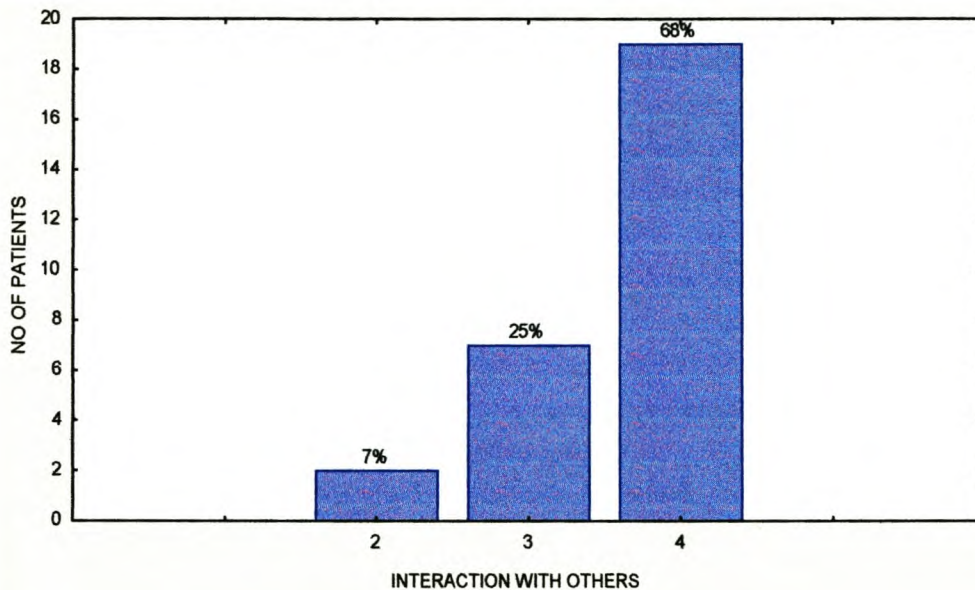


FIGURE 12: SCORING OF PATIENTS' INTERACTION WITH OTHERS

According to the scores, these results indicate that only 68% (n=19) were able to have meaningful interaction with other individuals, seven children (25%) had some difficulty, while two children had a lot of difficulty interacting with others.

Question 12 tried to determine if the child was able to play with his/her friends after the burn

70% (n=20) indicated that they were able to do so without any problems, 22% of the primary caregivers said that their children experienced some difficulty with this. Two children, according to their primary caregivers, experienced much trouble doing this.

It is possible, that they experienced being teased by other children, hence the reluctance to play with them.

Question 14 tried to determine if the child was able to answer questions about the burn. 70% (n=20) indicated that they were able to do so without any problems, 4% (n=1) of the primary caregivers said that their children experienced difficulty with this. Seven children (25%), according to their primary caregivers, experienced much trouble doing this.

It is possible that these children did not feel comfortable talking about their burns, as they were shy, or they were embarrassed about the way their scars looked. It is also possible that they were not equipped with the skills necessary to face the challenge of answering questions about their burn injury.

Question 16 tried to determine if the child was able to walk in a public place. 70% (n=20) indicated that they were able to do so without any problems, 14% (n=4) of the primary caregivers said that their children experienced difficulty with this. One child (4%), according to their primary caregivers, experienced much trouble doing this.

If the questionnaire of rehabilitation outcome is examined, the two focus elements are the physical and psychological outcomes of the child. The 17 questions evaluating the physical outcomes were rated with a score between 75% to 100%. The six questions rated below 75% were all related to the psychological functioning of the child.

These six questions focussed on interaction with friends and family, and reintegration into the child's daily life and functions. It is possible that there may not be enough focus on these aspects during the rehabilitation phase. Further investigation will be required to establish more detail on this topic. Doctor, (1992) affirms in her paper what the researcher feels is happening globally in burns units. Doctor, (1992) says that long-term psychological adaptation of burn-injured children begins on the day of admission with crisis intervention and establishment of rapport with the patient and family. In addition she states that to optimise parents' potential to provide adequate physical and emotional rehabilitation of the burn-injured child, it is imperative to involve them as participating members of the patient care team from the onset. Regarding management of burns at the RCCH, the question of what is best for the patient, needs to be asked.

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4.2.7 (b) Correlation between the rehabilitation outcome and caregivers' educational level

With regards to the rehabilitation outcome and the educational level, using a Kruskal-Wallis ANOVA by Ranks, it was found that caregivers with tertiary education rated the child's rehabilitation outcome higher than that envisaged by the caregivers with primary or secondary education, although the results were not statistically significant since $p = 0.2066$.

4.2.7 (c) Correlation between the patient's rehabilitation outcome and

- (i). Caregivers' age,
- (ii). Home area,
- (iii). Patient's age,
- (iv). Patient's percentage TBSA,
- (v). Length of stay in hospital.

When each of the correlations was looked at individually, using a one way ANOVA, all five had p-values which were much larger than 0.05 indicating statistical non-significance.

In this section the researcher also examined the relationship between the rehabilitation outcome as rated by the caregivers, and some of the demographic details (as stated above). It was found that none of these factors made any difference to the caregivers' perception of the rehabilitation outcome of the child.

Recommendations to the burns unit at the Red Cross Children's Hospital will be discussed in chapter 5.

4.3. SUMMARY OF RESULTS AND CONCLUSION

The results for the satisfaction with the management were positive except for factors dealing with pain, management, the fit of the pressure garments, and the psychological input to the child in hospital.

The results from discharge planning were very positive and caregivers were satisfied with all aspects in this section.

When the level of perceived caregiver inclusion was looked at, the results indicated that 97% of the participants felt that they were always included in the management of their child.

According to this study, the results on rehabilitation outcomes (objective 7) indicate that the rehabilitation outcome was worst in the areas that involved mental and psychological coping skills. Furthermore, the results have indicated that there is a need for the team to reintegrate the patient into the community and school. Further investigation will be required to establish how the team will do this with the current resources.

With regards to the rehabilitation outcome and specific demographic factors, it was found that none of these factors made any difference to the caregivers' perception of the rehabilitation outcome of the child.

4.4. POTENTIAL BIAS

- The potential for bias in measuring satisfaction is high and results should be viewed with caution.
- The possibility exists that those primary caregivers who agreed to take part in the study had been easily satisfied, and therefore rated the various categories higher than was actually true - volunteer bias, (Sackett DL, 1979).
- The researcher was familiar with some respondents and this may have influenced their responses.
- The researcher used self-compiled questionnaires and did not use a standardised tool.

- The researcher collected information on the description of the unit and could have been biased since she is currently working in this area.
- The low percentage of individuals who responded to the first letter from the researcher - non-respondent bias, (Sackett DL, 1979).

4.5. LIMITATIONS OF THIS STUDY

- The retrospective nature of this study is a possible limitation, as ratings could have been influenced by selective memory.
- The retrospective approach could most likely have measured representations in the memory of the subject of methods of management that were used and does not indicate how subjects actually viewed the management of the burns team at the time of admission or discharge.

CHAPTER 5

RECOMMENDATIONS AND CONCLUSION

5.1. INTRODUCTION

Some health professionals might view the exposure of the reality of a situation from another source, such as the consumer, as a threat to their careers. The positive comments are always wonderful to hear, but how do the negative perceptions affect us? It was important that both sides of the coin should be examined if the bold step to make changes, to develop and to become more skilled in our workplace is to be taken. Moreover, the RCCH is seen as a beacon of hope for many children and primary caregivers. In order to keep stating that we are upholding the constitutional rights, of children and parents, this journey was much needed.

The researcher feels privileged that participants so generously were able to share their views and opinions with an open mind and an open attitude. Most staff members in the burns unit have not had this remarkable opportunity. However, with all this information, the researcher sees herself in a position to advocate the needs and challenges of primary caregivers. In order to do this, the researcher will make recommendations to the following groups and individuals.

5.2. RECOMMENDATIONS

5.2.1 Recommendations in respect of the setting and design of the unit.

The researcher has described the burns unit and its functioning. This interpretation as stated before is open to bias. This bias could be reduced if the caregivers of the patients were to do the description of the burns unit.

With the architectural shortcomings of the ward, some amendments are not possible at this stage. The researcher recommends that when the unit is structurally changed or upgraded that a parent toilet, a doctor's office, and a counselling room be added.

5.2.2 Recommendations to the team of the burns unit at the RCCH.

63% of the study population applied the correct first aid. The Child Accident Prevention Foundation (CAPFSA) is doing excellent work in schools and in the community to propagate the correct type of first aid with a burn injury. The researcher recommends that they continue this work, and that they further investigate where the loopholes are so that they are able to proceed with more in-depth teaching in the community.

A third of the caregivers in this study have highlighted the fact that they were not satisfied with the pain management. The views and perceptions articulated were strong enough for the researcher to feel that this area of management must be investigated within the burns unit. Staff members of the unit have an obligation to re-visit the pain management protocol, in the ward and the burns clinic. Moreover, school-aged children are able to describe their physiological and psychological feelings of pain. It is important to listen to children and ask them about their feelings. It is important to alleviate the child's fear, because fear increases the physiological feelings of pain. It is important to teach children about relaxation and distraction and to encourage active participation in the painful situation Pölkki, Pietilä & Rissanen, (1999). An example of this is to encourage the children to remove their own dressings before the dressing change is due.

Although caregivers have emphasised the manner in which staff displayed their concern for them and the child, the researcher was also made aware that there were times when staff members were not as considerate as they should be. One caregiver said it was important to show concern for the parent and the child. The researcher felt this was a valid statement. She (the researcher) had found herself guilty of sometimes managing the patient, but not really asking what the concerns of the parents were. A lack of concern may be seen as unprofessional and needs to be addressed.

The recommendations to the staff would therefore be to be more empathetic, sensitive and understanding of the primary caregivers and the challenges that they have to endure.

Although 24 of the 30 participants indicated that the psychological support from all team members was excellent, it is apparent from the results of this rehabilitation outcome, that this is where most children require input. This applies to the stay in the hospital and to the period after discharge.

Currently there are no measures in place in the burns unit to assist children with reintegration back into their communities. There is a definite need for team members to go to schools and talk to the parents of children, the teachers, and the other learners and to explain to them what has happened. Questions must be answered. The team cannot presume that integration is going to happen spontaneously.

Some mothers indicated that when the child went back to school, they spoke to the children and teachers. The team has to remember that not every mother may be mentally strong enough to do this. The researcher would therefore like to recommend that team members start a programme to equip mothers so that they will be able to manage a school reintegration programme.

In addition, these results of the child's rehabilitation outcome could be a rationale for the team to work together more collaboratively and discuss more of the patients' rehabilitation in terms of future planning and reintegration

The researcher would like to recommend that the unit use the resources, which are available to them. This means that they could utilize the expertise of previously burned patients who have been rehabilitated, to start a community reintegration programme. These individuals can be empowered by to teach coping skills and learn through motivational programmes. In this way, that individual/s could be seen as more approachable when dealing with specific problems related to the burn injury.

With regards to the discharge time, the team needs to look more closely at social circumstances especially where entire families or communities are involved. Homes and members of family may have been lost and the burns team needs to take greater cognisance of this.

A high percentage (n=15, 50%) of the participants indicated non-satisfaction with the pressure garments. It is unacceptable that caregivers have to report that these garments do not fit properly and hence the children are not wearing them. This has an impact on the outcome of the child's scarring. The burns team will be made aware of these results and recommendations will be made as to how they are able to improve service and fit of garments.

The researcher has stated that one of the limitations of the study was its retrospective nature, and that rating could have been influenced by selective memory. In order to manage this, the researcher recommends that an evaluation regarding level of satisfaction be done at the time of discharge, at a 6 months post discharge, as well as when the patient has been reintegrated back into the community. The researcher is aware that due to staff shortages, this might pose as a challenge and therefore recommends it as a follow up study.

5.2.3 Recommendations to hospital management

From the results on the psychological input to the children while they are in hospital as well as the rehabilitation outcome results, it is evident that there is a greater need for a full-time psychologist to be part of the team. Hospital management needs to realise the importance of this team member and should allocate funding to employ someone who is qualified to deal with the psychological challenges of the burns team. The researcher recommends that the burns team again motivate for a psychologist to be employed full-time.

5.3 CONCLUSION

Many children, who have had the misfortune of being burnt, have also sustained impairments. In spite of this, they are able to go back to school and to take part in community programmes, and do not have any form of disability. Some patients who have sustained a burn injury, who are with or without impairments, are not able to live a wholesome life since environmental barriers inflicted by their society do not allow them to do so.

The researcher recommends that strategies be implemented to address the shortcomings of this burns unit that was highlighted in this study. This can be done in the form of an informal

meeting or workshop. A study of this nature or an evaluation of the burn rehabilitation programme, needs to be done regularly. Every two years is the suggested period.

The literature supports the interdisciplinary team as one that functions optimally in a burns unit. From the valuable comments and views that have arisen from the primary caregivers, it is vital that the RCCH burn team continues to operate as an interdisciplinary team where the parents and patients are part of the nucleus, and are not passive recipients of decisions made by health professionals.

The unit strives to work within the social model, and to reintegrate the patient into the community. This is an area of concern and more in-depth study is required. If we look at the bigger picture, this is ideal in the SA health system. If there were the resources and these were accessible to the entire population, it would have been wonderful.

Unfortunately this is not the case. Many of the primary centres are not equipped to deal with the challenges they have to face.

The interaction, honesty and openness within the team must continue to ensure that family members trust the staff and the staff are able to meet the needs of the caregivers and the child.

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ADDENDUM A - PERMISSION LETTER: MEDICAL SUPERINTENDENT

The Medical Superintendent
Red Cross Children's Hospital
Klipfontein Road
Rondebosch
7700

Attention: Dr K Ramiah

Primary caregivers evaluation of a burns rehabilitation programme, at the Red Cross Children's Hospital, from the period of June 2001 to July 2003.

I am the principal physiotherapist working in the Burns unit. As a part - time master's student at the Faculty of Health Sciences at the University of Stellenbosch, I plan to conduct a study in this unit in 2004.

The aim of the study is to determine the primary caregiver's evaluation of the rehabilitation of the child at the burns unit in Red Cross Children's Hospital, from the period of 1 June 2001 to 30 July 2003. I feel that this study will bring an understanding of the parent's views of the burns unit and how they perceive the rehabilitation programme to be.

I would like to ask for your permission to conduct this study, which will span over the year 2004. All information will be handled with confidentiality.

Should you have any questions regarding this study, please do not hesitate to contact me at the following number

- Work: 021- 6585130 (office)

Yours sincerely

A. Parbhoo, Ms

(G.Mji, Ms) Supervisor

ADDENDUM B - PERMISSION LETTER: HEAD OF BURNS UNIT

The Head of Department of Surgery
Department of Paediatric Surgery
Red Cross Children's Hospital
Klipfontein Road
Rondebosch
7700

Attention: Prof. H Rode

Primary caregivers evaluation of a burns rehabilitation programme, at the Red Cross Children's Hospital, from the period of June 2001 to July 2003.

I am the principal physiotherapist working in the Burns unit. As a part - time masters student at the Faculty of Health Sciences at the University of Stellenbosch, I plan to conduct a study in this unit in 2004.

The aim of the study is to determine the parents / primary caregiver's evaluation of the rehabilitation of the child at the burns unit in Red Cross Children's Hospital, from the period of 1 June 2001 to 30 July 2003. I feel that this study will bring an understanding of the parent's views of the burns unit and how they perceive the rehabilitation programme to be.

I would like to ask for your permission to conduct this study, which will span over the year 2004. All information will be handled with confidentiality.

Should you have any questions regarding this study, please do not hesitate to contact me at the following number:

- Work: 021- 6585130 (office)

Yours sincerely

A. Parbhoo, Ms

(G.Mji, Ms) Supervisor

ADDENDUM C (I) - PARTICIPANTS INFORMATION AND CONSENT FORM

A study is being done to investigate the primary caregivers views of the burns rehabilitation programme, at the Red Cross Children's Hospital. This has not previously been done in the unit, and the researcher feels that information learned from this study will help us to validate the current rehabilitation programme.

During this study, information will be obtained from the patient's folders, as well as through direct interviews with parents and caregivers. All information will be recorded and then analyzed. All information will be handled with the strictest confidentiality and anonymity.

STATEMENT IN LIEU OF PARTICIPANT

I, the undersigned _____, confirm that:

1. I have been asked to participate in the above- mentioned project.
2. The objectives of the study have been explained to me.
3. It has been explained that a questionnaire regarding information about my child's burn needs to be completed.
4. I am aware that all information will be handled with the strictest confidentiality
5. It has been explained that I may have full access to information that has been gathered in this study.
6. I am aware that findings from this study may be published.
7. I am aware that I may withdraw from the study at any time
8. The information has been explained to me in English/Afrikaans/Xhosa, of which I have a good command and understanding by _____, and that my questions have been answered satisfactorily.
9. There has been no force on me to consent to participation in this study.

I HEREBY DECLARE THAT I WILL VOLUNTARILY PARTICIPATE IN THE ABOVE STUDY:

Signed at _____ on _____ / _____ / 200

Participants signature

Witness

STATEMENT BY RESEARCH ASSISTANT

I _____, declare that I:

1. have explained the information in this document to _____ in their appropriate language
2. Have invited him/ her to question any aspects of the questionnaire which are unclear.

Signed at _____ on _____ 200

Research representative

Witness

FURTHER IMPORTANT INFORMATION

Thank you for agreeing to participate in this study. Should you have any other questions regarding

- problems as a result of the project, or
- Questions regarding information about the project.

Please contact me the following number

- home 021 6386724 after 19h00
- work 021 6585130 (19h30-16h00)

Miss Asha Parbhoo

AANHANGSEL C (II) - DEELNEMERS INLIGTINGS EN TOESTEMMINGSVORM

'n Studie word gedoen om die ouers/primêre oppassers se opinie van die Brand Rehabilitasie program by die Rooikruis Kinderhospitaal te evalueer. Dit is nooit voorheen by hierdie eenheid gedoen nie en die navorsingswerker voel dat hierdie inligting sal help om die huidige rehabilitasie program te waarmerk.

Gedurende hierdie program sal inligting versamel word uit die pasiente se mediese leers sowel as deur direkte onderhoude met ouers en primêre oppassers. Die vraelyste sal voltooi word in die taal wat die ouers/primêre oppassers verkies. Alle inligting sal opgeneem en geanaliseer word. Alle inligting sal streng vertroulik en anoniem hanteer word.

VERKLARING VAN DEELNEMER:

Ek,..... die ondertekende, bevestig die volgende:

1. Ek is gevra om aan hierdie projek deel te neem.
2. Die doelstelling van die studie is aan my verduidelik.
3. Dit is aan my verduidelik dat 'n vraelys voltooi sal word oor my kind se brandwonde behoefte.
4. Ek is bewus daarvan dat alle inligting streng vertroulik en anoniem hanteer sal word.
5. Dit is aan my verduidelik dat ek volle toegang mag hê tot die inligting wat in hierdie studie versamel is
6. Ek is bewus daarvan dat die uitkoms van hierdie studie moontlik gepubliseer sal word.
7. Ek is bewus daarvan dat ek op enige tyd uit hierdie studie mag onttrek.
8. Die inligting is aan my verduidelik deur in Engels/Afrikaans/Xhosa, waarmee ek goed vertrou is/dit is aan my vertaal en verduidelik deur..... en al my vrae is bevregigend beantwoord.
9. Daar is geen druk op my geplaas om aan hierdie studie deel te neem nie.

EK VERKLAAR DAT EK VRYWILLIG DEELNEEM AAN DIE BOGENOEMDE STUDIE.

Geteken te op...../...../200

.....

Handtekening van Deelnemer _____ Getuie

VERKLARING VAN NAVORSINGSASSISTENT:

1. Ek, verklaar dat ek die bogenoemde inligting aan verduidelik het in haar/sy toepaslike taal.
2. Ek het hom/haar genooi om vrae te vra oor enige deel van die vraelys wat vir hom/haar onduidelik was.

Geteken te op...../...../200

.....
.....

Handtekening van Navorsingsassist. _____ Getuienis

VERDERE BELANGRIKE INLIGTING:

Dankie dat u ingestem het om deel te neem aan hierdie studie. As u enige vrae het oor:-

- Probleme as gevolg van die projek; of
- inligting oor die projek,

is u welkom om my te skakel by die volgende telefoonnommers:

- Tuis 021 638-6724 (na 19H00)
- Werk 021 658-5111 Bleep 4180 (09H30 – 16H00)

Mej. Asha Parbhoo

**ADDENDUM C (III) – IFOMU YOLWAZI NEYESIVUMELWANO
SOMTHATHI NXAXHEBA**

Isifundo esenzelwe ukuphanda izimvo zabantu abahoye abantwana malunga nenkqubo elungiselelwe abantwana abatshileyo ekuqhutywa ngayo kwisibhedlele sabantwana iRed Cross. Asizange senziwa esi sifundo ngaphambili kweli candelo, kwaye umphandi uziva ngathi ulwazi oluthe lwafunmaneka kwesi sifundo luyakunceda ukuphuhlisa inkqubo esetyinziswayo ngokwelithuba.

Ngeli xesha lesi sifundo, ulwazi luyakuthi lufumaneka kwiincwadi zabaguli zesisibhedlele, kwakunye nokuthetha-thethana komphandi nabazali kunye nabantu abahoye abantwana. Lonke ulwazi luyakushicilelwa luze luhlalutywe. Lonke ulwazi luyakuphathwa ngendlela efihlakeleyo nengazokufaniswa namntu uthile.

ISIQINISEKISO SOMTHATHI-NXAXHEBA

Mna mntu osayinileyo....., ndiqinisekisa ukuba:

1. Ndiceliwe ukuba ndithathe inxaxheba kule projekthi ingentla.
2. Inkcunkaca zesifundo zicacisiwe kum.
3. Icacisiwe into yokokuba imibuzo malunga nolwazi lokutsha nkomntwana wam kufuneka ndiyiphendule.
4. Ndiyayazi ukuba lonke ulwazi luyakuphathwa ngendlela efihlakeleyo.
5. Icacisiwe into yokokuba ndinelungelo kulwazi oluthe lwaqokelelwa kwesi sifundo.
6. Ndiyayazi into yokokuba iziphumo zesi sifundo zingapapashwa.
7. Ndiyayazi into yokokuba ndingarhoxa kwesi sifundo nangaliphi na ixesha ndithanda.
8. Ulwazi lucacisiwe kum ngesiNgesi/ngesiBhulu/ngesiXhosa, kunjalonje ndinolwazi olwaneleyo ngolwimi oluthe lwacaciswa ngalo olulwazi, yaye, imibuzo yam iphendulwe ngendlela eyanelisayo.
9. Bekungekho sinyanzeliso kum semvume yokuthatha inkxaxheba kwesi sifundo

NDIYANGQINISISA UKUBA NDIYAKUTHI NDITHATHE INXAXHEBA KWESI SIFUNDO SINGENTLA

Isayinelwe e ngomhla we //200.

.....
Umsayino womthathi-nxaxheba

.....
Ingqina

ISIQINISEKISO SOMNCEDI WOMPHANDI

Mna,, ndiqinisekisa ukuba mna:

1. Ndilucacisile ulwazi lomqulu ku kulwimi olulungele yena.
2. Ndimmemile umthathi nxaxheba ukuba abuze nokuba ngeyiphi imibuzo ethe ayamcacela.

Isayinelwe e ngomhla we...../...../200.....

.....
Umncedisi womphandi

.....
Ingqina

OLUNYE ULWAZI OLUBALULEKILEYO

Ndiyabulela ngokuvuma ukuba ubeyinxalenye yesi sifundo. Ukuba uthe wabanayo eminye imibuzo malunga:

- Iingxaki ngenxa yale projekthi, okanye
- Imibuzo malunga nolwazi lwale projekthi.

Nceda ndiqhakamishela kwezi nombolo:

- Ekhayeni: 021-6386724 (emva kwentsimbi yesi xhenxe malanga)
- Emsebenzini: 021-6585130 (ngo 07H30 – 16H00)

Ufune uMiss Asha Parbhoo

**ADDENDUM D
SECTION A**

**PRIMARY CAREGIVERS EVALUATION OF THE BURNS REHABILITATION
PROGRAMME, AT THE RED CROSS CHILDREN'S HOSPITAL**

INFORMATION CHART FOR DATA COLLECTION FROM THE MEDICAL
FILE/INTERVIEW

RECORD OF DEMOGRAPHICS OF PRIMARY CAREGIVERS AND PATIENT

PATIENT DETAILS

Folder number: _____

Family name of patient: _____

First name of patient: _____

Address: _____

Telephone: (home) : _____

Date of birth: _____

1. Age of child at time of admission

2. Gender:

1. Male

2. Female

3. Was this the child's first burn?

1. Yes

2. No

Identification number		

Y	Y	M	M	D	D

--	--

--

--

4. Was the injury an accidental burn?

1. Yes

2. No

5. Who was the first contact person who managed the burn?

1. Primary caregiver

2. Health care worker at the clinic

3. Neighbour /friend

4. Health care worker at the hospital

5. Other (specify) _____

6. Is the child at school / crèche / preschool?

1. Yes

2. No

7. Is the child involved in any extramural activities?

1. Yes

2. No

If yes please specify _____

NEXT OF KIN

FATHER

Fathers surname: _____

Father's first name: _____

Father's occupation: _____

8. Father's age: _____

--	--

Contact details:

Telephone: (home): _____

(Work): _____

(Mobile): _____

9. Highest level of education of father:

1. No schooling
2. Primary school
3. High school.
4. Tertiary education

MOTHER

Mother's surname: _____

Mother's first name: _____

Mother's occupation: _____

1. Mother's age: _____

--	--

Contact details of mother:

Telephone: (home): _____

(Work): _____

(Mobile): _____

11. Highest level of education of mother:

1. No schooling
2. Primary school
3. High school
4. Tertiary education

PRIMARY CAREGIVER:

Primary caregivers surname: _____

Primary caregiver's first name: _____

Primary caregiver's occupation: _____

12. Primary caregivers age: _____

Contact details:

Telephone: (home): _____

(Work): _____

(Mobile): _____

13. Highest level of education of primary caregiver:

1. No schooling
2. Primary school
3. High school
4. Tertiary education

--	--

--

**ADDENDUM E
SECTION B**

PRIMARY CAREGIVERS EVALUATION OF THE BURNS REHABILITATION PROGRAMME, AT THE RED CROSS CHILDREN'S HOSPITAL.

INFORMATION CHART FOR DATA COLLECTION FROM THE MEDICAL FILE

PATIENT HISTORY

STATUS OF BURNS

14. Date of burn:

Y	Y	M	M	D	D

15. Date of admission:

Y	Y	M	M	D	D

16. Cause of burn:

1. Hot water/ hot tea coffee/ hot soup.
2. Fire.
3. Electrical.
4. Chemical.
5. Other (please specify)._____

17. Percentage of burn:

--	--

18. Area of burns

1. One upper limb /both upper limbs.
2. One lower limb/ both lower limbs.
3. One /both upper limbs & one / both lower limbs.
4. Both upper limbs and trunk.
5. Both lower limbs and trunk.
6. One /both upper limbs & one / both lower limbs and trunk.
7. Face and one or both upper and/or lower limbs.

19. Thickness of burns:

1. superficial
2. superficial partial
3. full thickness
4. deep partial and full thickness

20. First aid applied

1. Yes
2. No

If the answer to this question is NO, go to question 22.

21. Type of First aid applied:

1. Tap water.
2. Cloth soaked in tap water and changed every few minutes
3. Ice water.
4. Warm water.
5. None.
6. Don't know.
7. Other (please specify) _____

22. Person/ persons present at the time of burn

1. Mother
2. Father
3. Siblings
4. Neighbour
5. Caregiver
6. Nobody
7. More than one (please specify) _____

23. Length of stay in hospital (in days):

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ADDENDUM F

SECTION C

PRIMARY CAREGIVERS EVALUATION OF THE BURNS REHABILITATION PROGRAMME, AT THE RED CROSS CHILDREN'S HOSPITAL.

INFORMATION CHART FOR DATA COLLECTION FROM THE PRIMARY CAREGIVER.

MANAGEMENT IN HOSPITAL

Please read each statement and choose the statement, which you agree with the most

24. The explanation and information given to you on admission of your child was

- 4. Fully understandable
- 3. Mostly understandable
- 2. Mostly not understandable
- 1. Not understandable at all

Please provide a reason for your choice

25. With regard to the staff's competence displayed when treating your child, you felt they were:

- 4. Always competent
- 3. Mostly competent
- 2. Mostly not competent
- 1. Not competent at all

Please provide a reason for your choice

26. When you think about the pain management of your child, do you feel

4. It was always well managed
3. It was sometimes well managed
2. It was mostly not well managed
1. It was never well managed

Please provide a reason for your choices

27. Do you feel that the noise levels in the ward

4. Were always acceptable
3. Were sometimes acceptable
2. Were mostly not acceptable
1. Were never acceptable

Please provide a reason for your choice

28. According to you, were your child's dressings?

4. Always correctly, and neatly applied
3. Sometimes correctly, and neatly applied
2. Hardly ever correctly, and neatly applied
1. Never correctly, and neatly applied

Please provide a reason for your choice

29. Do you feel that surgery performed on your child was?

- 4. 100% needed
- 3. Maybe needed
- 2. Mostly not needed
- 1. Not necessary at all

Please provide a reason for your choice

30. The way in which consent was taken for the procedures performed on your child was :

- 4. 100% understandable and appropriate
- 3. Slightly understandable and appropriate
- 2. Not really understandable and not really appropriate
- 1. Not at all understandable and not at all appropriate

Please provide a reason for your choice _____

31. According to you, the manner in which exercises were done with your child were:

4. Always correctly and carefully done
3. Sometimes correctly and carefully done
2. Mostly not correctly and carefully done
1. Never correctly and carefully done

Please provide a reason for your choice

32. The psychological support that your child was given in hospital was:

4. Excellent
3. Good
2. Satisfactory
1. Poor

Please provide a reason for your choice

33. With regard to your child's management, do you as a primary caregiver feel that:

4. You were always included
3. You were sometimes included
2. You hardly ever included
1. You were never included

Please provide a reason for your choice

34. The manner in which your concerns were dealt with, were

4. Professionally handled
3. Sometimes professionally handled
2. Hardly ever professionally handled
1. Never professionally handled

Please provide a reason for your choice

35. The explanation and training that was given to you about the splints was:

4. 100% clear and understandable. I was able to apply the splints at home
3. Clear and understandable. I was unable to apply the splints at home
2. Partially clear and partially understandable. I attempted to apply the splints at home
1. Totally unclear and not understandable. I was unable to apply the splints at home.

Please provide a reason for your choice

ADDENDUM G

SECTION D

PRIMARY CAREGIVERS EVALUATION OF THE BURNS REHABILITATION PROGRAMME, AT THE RED CROSS CHILDREN'S HOSPITAL.

INFORMATION CHART FOR DATA COLLECTION FROM THE PRIMARY CAREGIVER

DISCHARGE PLANNING

36. Do you feel that the information that was given to you on discharge was

- 4. Complete and adequate
- 3. Mostly complete and adequate
- 2. Mostly incomplete and inadequate
- 1. Totally incomplete and inadequate

Please provide a reason for your choice

37. The home programme that was given to you and your child

- 4. Understandable and easy to follow
- 3. Partially understandable and easy to follow
- 2. Mostly not understandable and mostly not easy to follow
- 1. Not understandable at all and not easy to follow at all

Please provide a reason for your choice

38. When your child was fitted with, and received pressure garments, did you think:

- 4. The service, and fit of the garment was excellent
- 3. The service, and fit of the garment was good
- 2. The service, and fit of the garment was bordering on bad
- 1. The service, and fit of the garment was not at all acceptable

Please provide a reason for your choice

39. The home instructions for your child:

4. Were totally clear and easy to understand
3. Were partially clear and partially understandable
2. Were not really clear and difficult to understand
1. Were not all clear, and not understandable

Please provide a reason for your choice

40. Do you feel that the review time of the pressure garments?

4. Was correct
3. Not sure it was correct or not
2. Was sure it was incorrect, but attended appointment
1. Was totally incorrect

Please provide a reason for your choice

41. When your child was being discharged from hospital, you

4. Agreed that he was being discharged at the correct time
3. Thought he should be discharged, but the staff did not agree
2. You were not sure if he should be discharged at that time or not
1. Thought he should stay in hospital, but the staff did not agree

Please provide a reason for your choice

ADDENDUM H

SECTION E

PRIMARY CAREGIVERS EVALUATION OF THE BURNS REHABILITATION PROGRAMME, AT THE RED CROSS CHILDREN'S HOSPITAL.

INFORMATION CHART FOR DATA COLLECTION FROM THE PRIMARY CAREGIVER

REHABILITATION OUTCOME

Please use the following key to choose answers to the following questions

4 =Able to do this independently

3 =With some difficulty

2 =With a lot of difficulty

1 =Not able to do this at all

After the burn, was your child able to

42. Play with other children again

43. Play alone with his toys

44. Return to crèche / preschool/ school

45. Interact with other people?

46. Eat with cutlery/ eat with their hands?

47. Drink from a cup/ drink from a bottle?

48. Use the toilet

49. Write /draw holding a pen or pencil

50. Play his/her favourite game

51. Catch a ball?

52. Kick a ball

53. Play with his/her friends

54. Dress themselves

55. Answer questions about his /her burn

56. Climb stairs

57. Walk in a public place

58. Put their own shoes / sandals on

59. Assist with application of their pressure garments

60. Run on grass/ on sand / on a tarred surface

61. . Maintain basic hygiene- (brush their hair, teeth)

62. Assist with/ independently wash themselves

63. Interact with you as a caregiver / parent on a one to one basis

64. Play with you as the primary caregiver / parent on a one to one basis