

**CAREGIVER FACTORS THAT CONTRIBUTE TO DEVELOPMENT OF
COMPLICATIONS IN DISABLED CHILDREN IN ELIM HOSPITAL, VHEMBE
DISTRICT OF LIMPOPO PROVINCE IN SOUTH AFRICA.**

by

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DECLARATION

I declare that the mini-dissertation hereby submitted to the University of Limpopo, for the degree of Master of Public Health on **Caregiver factors that contribute to development of complications in disabled children in Elim Hospital, Vhembe District of Limpopo Province in South Africa** has not previously been submitted by me for a degree at this university or any other university, that it is my work in design and in execution, and that all the material contained herein has been duly acknowledged.

Mulugo N.R

Date: 11 May 2016

DEDICATION

I dedicate this work to:

- The God of heaven who makes the impossible to be possible. I managed to do it through Christ who gives me strength. I thank you, Lord.
- My husband Mr T.B. Mpilo and my three daughters (Mpho, Thendo and Tshilidzi) who were really supportive throughout the conduct of this study. God has plans for us. I do love you all.
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- My younger sisters: Itani and Muofhe. You are the best!
- My brothers Jeffrey, Mbulaheni and Duncan. I love you.

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ABSTRACT

Background: Disabled children with different conditions such as cerebral palsy, traumatic brain injuries, developmental delays, severe orthopaedic impairment, hydro and micro-cephalous are brought to Elim Hospital for rehabilitation therapy. Most of these disabled children stay with caregivers who are responsible for their care including rehabilitation therapy at home to avoid complications. The aim of the study was to establish factors that contribute to development of complications in disabled children.

Methods: The quantitative descriptive study design was used and convenience sampling method was used to select 52 caregivers out of the population of 60. Questionnaires and observation checklist were used for data collection at the rehabilitation therapy clinic during their rehabilitation therapy visit. Data were analysed using SPSS version 22.

Results: The results show that there is no association between diagnosis and the development of complications. There was an association between availability of resources which is one of the caregiver factors and the development of complications.

Conclusion: The study concludes that, availability of resources to provide the rehabilitation therapy on the disabled children is the contributing caregiver factors on the development of complications in disabled children at Elim Hospital.

DEFINITION OF TERMS

- **Caregivers:** In the context of this study *caregivers* refers to an individual who take care of the disabled children (WHO, 2011).
- **Cerebral Palsy:** a brain disorder that affects movements and posture (Willard, 1998).
- **Complications:** In this study complication is when a child's disability becomes worse in its severity or shows a higher number of signs, symptoms or new pathological changes become widespread throughout the body or affects other systems, the ability and life of the child (Calarke, 2003).
- **Disabled child:** a person who has a physical, cognitive, mental, sensory, emotional and developmental disability or a combination of disabilities (Werner, 1999).
- **Dietitian:** a person responsible for evaluating, developing and implementing a plan to meet one's nutritional needs. Nutrition is a very important part of a disabled child's recovery process (WHO, 2011).
- **Developmental delays:** a delay in mental and physical development e.g. gross motor, fine motor, thought processes and language (Werner, 1999).
- **Factors:** according to this study factors are circumstances, facts or influence that contribute to the results or the outcome (Oxford Dictionary, 2000).
- **Hydrocephalus:** is when the child is born with too much fluid in the brain (Werner, 1999).
- **Micro cephalus:** is the impairment of growth and development of the brain (Werner, 1999).
- **Occupational therapy:** Occupational therapy (OT) focuses on helping an individual to achieve independence in all areas of their lives. OT helps children with various needs improve their cognitive, physical, and motor skills to enhance their self-esteem and a sense of accomplishment (Willard, 1998).

- **Physiotherapist:** The physiotherapist (PT) helps the disabled child to develop strength, endurance and coordination to improve function and become more independent in all spheres of life (Werner, 1999).
- **Rehabilitation team:** a wide range of professionals specializing in rehabilitation medicine. In this study each member of the team is trained to work closely with the disabled child and family or caregivers to further recovery process at the rehabilitation therapy sessions (Werner, 1999).
- **Speech and hearing therapist:** an individual who teaches the disabled child communication, swallowing, and other skills to stimulate muscle of the mouth to be able to function properly (Werner, 1999).
- **Traumatic brain injury:** injury to the brain caused by the head being hit by something or shaken violently (Werner, 1999).
- **Catchment area:** In this study it is an area served by Elim Hospital (Werner, 1999).
- **Care Dependency Grant:** is a non-contributory monthly cash transfer to caregivers of children with severe disabilities who require permanent care or support services (Budlender and Woolard, 2006).

LIST OF ABBREVIATIONS

- **CG:** Caregivers.
- **CDG:** Care Dependency Grant.
- **CDC:** Centre for Diseases Control
- **CBO's:** Community Based Organizations
- **CP:** Cerebral Palsy.
- **DG:** Disabled child.
- **DCC:** Day Care Centre
- **DPO's:** Disabled People Organizations.
- **HPCSA:** Health Professional Council of South Africa.
- **NDT:** Neuro Developmental Technique.
- **PT:** Physiotherapist
- **OT:** Occupational Therapist.
- **SA:** South Africa.
- **SPSS:** Statistical Packages for Social Sciences
- **WHO:** World Health Organisation

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CHAPTER 1

1.1 Introduction and background

A disability in this study may be generally defined as a condition which may restrict a child's mental, sensory, or mobility functions to undertake or perform a task in the same way as a child who does not have a disability (WHO, 2012). It does not mean that a child with a disability is unable to perform all the important requirements of her daily life expectations. Werner (1999) points out that disabilities affect children in different ways. According to WHO (2008), the only thing that separates the children with a disability is that, for one reason or another, they are unable to do certain things in the same way as the normal children. They may require some form of adaptation or alteration to assist them to overcome the effect of their disability. Living with a disabled child can have profound effects on the entire family (caregivers, siblings, and extended family members). It is a unique shared experience for families and can affect all aspects of family functioning (Werner, 1999).

On the positive side, disability of a child can increase family members' awareness of their inner strength, enhance family cohesion, and encourage connections to community groups or religious institutions. On the negative side, the time and financial costs, physical and emotional demands, and logistical complexities associated with raising a disabled child. The impact will likely depend on the type of condition and severity, as well as the physical, emotional, and financial wherewithal of the family and the resources that are available (Willard and Sparkman, 1998).

The study done by 2007 Sadiki, on the experience of parenting a physically disabled child in the Thohoyandou Vhembe District of Limpopo Province, from the perspective of mothers. The objectives of the study were to investigate feelings linked to parenting a physically disabled child in the community within which the parents find themselves, to explore the impact of raising a physically disabled child, as well as strategies that parents employ in coping with raising a physically disabled child.

A disabled child with neurological condition in this study is a person who has a physical, cognitive, mental, sensory, and emotional and developmental disability or a combination of disabilities mentioned (WHO, 2011). The age ranges from 6 months to 18 years old. The degree of functional limitations varies greatly from one disabled child to another and ranges from no limitations to severe limitations. Clinical manifestations of disabled children start from mild to severe; some causes are before, during or after birth. A disabled child needs a caregiver who takes care by providing physical and

emotional support because of the total dependence (Willard and Sparkman, 1998). A disabled child needs constant assistance or supervision by the caregiver.

A caregiver plays a very important role in providing quality of life for the child. At Elim Hospital most of the disabled children had neurological and physical conditions like Cerebral Palsy (CP), traumatic brain injury, severe orthopaedic impairment that are caused by congenital anomalies like amputations, tuberculosis of the bones, fractures, burns, clubfoot, hydrocephalus, micro cephalous, and other neurological conditions. The interdisciplinary rehabilitation treatment included caregivers and focused on preventing long-term complications like contractures, malnourishment, pressure sores and other physical deformities that limit physical function.

Caregivers face many challenges. These range from financial, emotional and other resources such as transport. Caring for a child with special needs due to neurological disability could be financially demanding, not only because institutionalization could be expensive, but the caregivers depend on grants as it is the main source of income (Willard and Sparkman, 1998). It is emotionally distressing for the caregiver who has no skills to take care of disabled children to fulfill all special needs such as providing nutritious food, special care, adapted suitable chairs, buggy, nappies, taking the child to special schools and other special hospital or clinical consultation. A disabled child needs responsible caregiver to bring him/her to the hospital. A disabled child needs assistive devices such as wheelchair, buggy and splints. Assistive devices are not always available in the hospitals and are very expensive and the waiting list is long. In some hospitals when assistive devices are needed the family are advised to buy these from private companies (Werner, 1999).

Rehabilitation is very important to disabled children because the more the rehabilitation therapy the less the complications. Disabled children need a lot of interventions such as physiotherapy, occupational therapy, speech and hearing, a dietician and assistive devices, depending on the individual disability. Disabled children need physiotherapy, occupational therapy to facilitate normal development of head control, sitting, crawling, walking, expressing their needs and using their hands. In order to obtain these skills, disabled children should be brought to the hospital more often or on a monthly basis. Speech and hearing therapist and dietitians assist with rehabilitation by facilitating swallowing and communication skills. The assistive devices used by disabled children such as buggies, wheelchairs, rollator and others are subsidized by the provincial budget and distributed to public hospitals.

The caregivers benefit by obtaining better understanding on why their disabled child's functioning is improving or deteriorating. Observations made at Elim Hospital, Vhembe District, during disabled children's consultation was that the caregivers brought their disabled children with complications and in spite having been provided with different skills from the rehabilitation team. This research aimed at establishing factors that contribute to the development of complications in disabled children.

1.2. Statement of the problem

At Elim Hospital there are disabled children with neurological and physical conditions who are receiving rehabilitation therapy as out patients. Most of the disabled children stay with caregivers who are responsible for their care including rehabilitation at home to prevent complications. The caregivers are offered skills and knowledge training from the rehabilitation team of professionals registered with the Health Professional Counsel of Southern Africa (HPCSA). The training includes physiotherapy, occupational therapy and speech and hearing therapy. This training equips caregivers with the skills they need to take care of their disabled children. The disabled children are offered rehabilitation therapy and each disabled child is seen once a month. The assumption is that the more the caregivers are receiving training of skills and knowledge from the rehabilitation team the lesser the chances of the disabled child being totally dependent in any activity of daily living (feeding, bathing, dressing and others) and the development of complications.

Problems arise when the same group of caregivers come to the rehabilitation with complications whereas they receive training from the rehabilitation team. Out of twenty disabled children that attend the Rehabilitation therapy on monthly basis quarter will present with complications more especially the children with Cerebral palsy condition. Home programme of the disabled children are monitored by follow up dates, home and clinic visits but still the disabled children are brought to the Rehabilitation therapy clinic with complications.

Ellen et al. (2003) points out that the ability of caregivers of the disabled children to provide quality care and contribute to the management of their children's condition is a vital health care resource. He further indicates that rehabilitative care must be aimed at helping caregivers of disabled children to develop problem-solving, organizational, planning and communication skills to enable them to take care of their children more efficiently. Some caregivers are able to carry out care giving tasks better than others because of their knowledge, experience, level of engagement and skills (Ellen et al., 2003). The problem under investigation is that caregivers are offered training by the health care professionals, yet their disabled children are still

presenting with different complications such as contractures, different physical deformities, malnourishment and pressure sores. For the most part, these complications can be prevented by implementing the learnt skills.

The study will solve the problem because the researcher will find out the caregiver factors that contribute to the development of complications in disabled children at Elim Hospital. And the researcher will advise the rehabilitation team to prevent the development and further development of those noticed factors.

1.3 The purpose of the study

The purpose of this study was to establish the factors that contributed to the development of complications in disabled children at Elim Hospital.

1.3.1 The aim of the study was:

To establish the factors that contribute to the development of complications in disabled children at Elim Hospital, Vhembe District.

1.3.2 Objectives of the study were:

- To determine factors related to caregivers that contribute to the development of complications.
- To establish the complications that the disabled children present with.
- To establish the level of skill of caregivers in executing the rehabilitation home programme.
- To determine the association between caregivers factors and the development of complications in the disabled.

1.4. Research question

What are the factors related to caregivers that contribute to the development of complications in disabled children at Elim Hospital?

1.5 Conclusion

This chapter explained the background to the study, defined the problem, motivated the research and explained the significance of the study. The next chapter reviews the literature that pertains to the caregiver factors that contribute to complications in disabled children.

CHAPTER 2

Literature review

2.1 Introduction

The literature was reviewed under the following categories: children and disability, caring for children living with disability, complications on children with disability, rehabilitation therapy and caregiver training, the triadic model of caregiving and problems experienced by the caregivers. Most of the literature reviewed about children with disability was done in South Africa between 2000 and 2012 by different authors including the World Health Organisation (WHO). In Malamulele Hospital, which is in Vhembe District, a study related to the caregivers and the rehabilitation team was conducted by Saloojee (2007), actively involving the rehabilitation team on the intervention of the disabled children, who were provided and fitted with the assistive devices they needed. The aim was for the caregivers to take care of their disabled children.

2.2 Children and disability

Children's disability was influenced by a wide range of biological and environmental factors, some of which protect and enhance their development while others compromise their developmental outcomes (WHO, 2012). Children who are diagnosed with disability early in life can be disproportionately exposed to risk factors such as poverty, stigma or discrimination, poor caregiver interaction, institutionalization, violence, abuse or neglect, limited access to programmes and services, all of which can have a significant effect on their survival and development (WHO, 2011).

The Canadian Institute of Child Health (2003) notes that promoting development in young children with disabilities requires a twin track approach. This approach recognises that children with disability and their caregivers have basic and ordinary needs and must have access to rehabilitation programmes and good care by the caregivers. Some health conditions associated with disability may be detected during pregnancy where there is access to prenatal screening while other impairments may be identified during and after birth (WHO, 2012). Caregivers are needed to take care of the children that are diagnosed with disability in order to improve the level of functioning and independence in all spheres of life.

2.3 Caring for children living with disability

Caregiving is a crucial service in societies, often offered without pay, and it preserves the health of the disabled child (Singer et al., 2009). Health systems would be unable to provide adequate coverage to the disabled without the caregivers' contributions (Talley and Crews, 2007).

Singer et al. (2009) notes that caregivers support family members who experience disabilities related to physical and cognitive impairments that restrict normal functioning. These disabilities can first become evident at any time, ranging from birth, in the case of children born with some developmental disabilities to advanced old age. As in most countries, the care of seriously disabled children most often falls to the parents or family of the child and reduces the use of institutional care for the child (Freedman et al., 2007).

However, Cummins (2001) alludes to the complexity of the caregiving that is done at home. This complexity is brought about by competing needs of the child, the state and the family. Moreover caring for children with severe disabilities within the family has never been a social policy based on what is best for caregivers, but based on the philosophy of “normalization” as being in the best interests of the child (Cummins, 2001). Given the fact that individuals living with many different kinds of disabilities are living longer and better, this means that caregivers are attending to the needs of the disabled children for a growing portion of their lives (Mac-Donald et al., 2007).

Cummins (2001) states that the challenge with caregiving at home for a seriously disabled child is complex because of the competing needs: those of the child, the State and the family. A child diagnosed with an illness, disability or sensory impairment that needs a lot of additional support for them to live day to day, might be described as having “complex needs”. A child might have complex needs from birth, or following an illness (Talley and Crews, 2007). Having a disabled child may also affect parents' allocation of time and financial resources to their healthy and unhealthy children, their parenting practices, their expectations of healthy siblings in terms of achievement, responsibility, and short and long-term contributions to the household, and the siblings' health and development.

2.4 Complications on children disability

There are many complications in children's disability. The more the complications to the disabled children, the more the rehabilitation therapy by the caregivers and the rehabilitation team. Most of the complications are seen when proper rehabilitation therapy is not done by the rehabilitation team and the caregiver. However, although the rehabilitation team provides therapy and trains the caregivers, some children still present with complications. Ingrid Soderback (2009), indicate that common types of complications in children with neurological and physical conditions are contractures (inability to perform a full range of motion). These result from factors such as limb positioning, duration of immobilization, muscle, soft tissue and bone pathology. Contractures place the child at risk of secondary medical and functional deficits.

Pressure sores result from the death (necrosis) of tissues due to local deprivation of blood supply, and thus of oxygen (ischemic necrosis) (Soderback, 2009). This is why tissue compression is the first clinical sign of pressure sores; it blocks the small blood vessels supplying tissues. According to Werner (1999), pressure sores are also complications suffered by disabled children, a result of different causes (often combined):

- **Physical factors:** these are simple pressure points in parts of the body located between bones and hard surfaces, but also cause friction (for instance induced contractures) leading to degeneration of different skin planes and accentuating pressure. Repeated friction on the skin also leads to chafing (sliding down or being pulled up the bed, involuntary movements).
- **Factors disturbing sensitivity or source of immobilization:** immobilization causes prolonged pressure to the weight bearing part, loss of sensitivity, paralysis and all other conditions requiring immobilization, or present with sensitivity disorder, factors that may contribute to ulcerations. Pressure sores therefore affect particularly individuals with sensitivity-related conditions: vascular hemiplegia, spina bifida, peripheral neuropathies etc. (WHO, 2011).
- **Other extrinsic factors** (external): moisture, maceration, or foreign bodies, such as connectors of *urinary catheterization*, bread crumbs, medical adhesives and bandages, can increase the incidence of pressure sores (Soderback, 2009).
- **Intrinsic factors** (inherent to the person): everything that might contribute to aggravating the oxygen deprivation in tissues and affect their ability to heal, dehydration, cardiac, respiratory or renal failure; anaemia; vascular conditions and poor general health status (under nutrition, weight loss, significant physical fatigue) (WHO, 2012).
- The **negligence** of the disabled child or their carer for prevention.

Complications of immobilization (beyond pressure sores), sometimes referred to as “decubitus complications” (in lying position), these complications are more specifically linked to immobilization: loss of vertical position and a lack of exercise are combined in this complication (Trombly, 2008). Trombly further mentions that prolonged immobility can cause serious complications if no preventive measures are taken. Complications like loss of muscle mass or increase in the muscle atrophy caused by neurological conditions; muscle contractures, and abnormal postures imposed by the muscles, at the same time, immobilized tendons become weaker. These complications affect nerves located near the osseous structures (radial nerve for the arm, ulnar nerve for the elbow).

Risk factor for contractures is any condition that may prevent a joint going through its full ROM can result in contractures. Joints must periodically be put through their full ROM to prevent a tightening of the surrounding soft tissues and muscles. This is one of the home programmes given to the caregivers to prevent contractures of the joints in a disabled child (Werner, 1999). Any neurological condition that may increase muscle tone or cause muscle weakness can also result in impaired mobility of the joint, resulting in contracture. Disabled children with lengthy illnesses and chronic conditions are at the highest risk of developing contractures, by virtue of immobility (Braddom et al., 2007). According to the 2005 Online Survey, Certification And Reporting (OSCAR) database, 28.9% of approximately 386,000 nursing homes residents across the United States have contractures as a complication. This study reports a higher prevalence of contractures among nursing homes residents than was previously reported in the OSCAR 2005 data.

Because of the epidemiological transition, the global burden of illness has changed. Several factors have contributed to this change, including improvements in maternal and child health, increasing age of populations, and newly recognized disorders of the nervous system. It is now evident that neurologic disorders have emerged as priority health problems worldwide. This is reflected in the Global Burden of Disease Study, jointly published by the World Health Organization and other groups in 2012. They further mentioned that the proportionate share of the total global burden of disease resulting from neuropsychiatric disorders is projected to rise to 14.7% by 2020.

The prevention measures of complications are a series of simple and repeated actions performed in a logical, rigorous and persevering fashion by the caregivers and the rehabilitation team, at best through systematic procedures or protocols in collaboration with other rehabilitation team members involved (Werner,1999). According to Trombly (2008), the goal of preventing complications in neurological conditions are to prevent the development and further development complications by:

- Daily monitoring areas at risk.
- Changing positioning (lying, sitting, standing).
- Performing massages on the affected muscles.
- Doing active and passive movement of all the joints.
- Using prescribed assistive devices.
- Eating healthy food.

- Follow prescribed home programme.

2.5 Rehabilitation therapy and caregiver training

Clark and Pasacreta cited in Trombly (2008) mention that the rehabilitation team and other professionals can contribute to the client's quality of life by providing education and training to their caregivers. They suggest the following strategies and considerations:

- Make sure that rehabilitation therapy intervention plans incorporate specific goals, strategies and timeline for caregiver training.
- Incorporate caregiver education and training in your intervention from day one by involving family members on how to participate in providing care.
- Ask other family members to attend therapy sessions and include them as active participants, this will help the disabled child to continue with treatment when the caregiver is not around.
- Set up caregiver education plan that extends beyond the duration of rehabilitation intervention. Identify possible resources for continued caregiver education and support in the future.
- Take responsibility for helping caregiver to transfer what they have learned in the hospital setting to their home and family contexts.
- Collaborate with other health care professional to ensure that caregiver education and training is multifaceted and ongoing.

Facilitation of training for caregivers, family members and health workers regarding the care and rehabilitation of children with disabilities is to ensure the prevention of secondary health complications (WHO, 2008). According to research done at Uhambo Foundation in Mfuleni (2012), to establish a skills training programme for children with disabilities, caregivers confidently used stimulation kit which assists them to interact and stimulate children with disabilities, allowing them to play and participate more in daily activities. The disabled children were independent in playing, interacting, manipulating toys, and most complications were reduced. Schumacher et al. (2000) maintains that the basic knowledge that caregivers use to make decisions and solve problems provides the foundation for developing and improving skills. In turn, most of the caregivers learn skills to prevent complications. They are given guidance and counselling and they rehearse what they learn to their family members. Schumacher et al. (2000) further note that the requisite caregivers need include monitoring, interpreting, making decisions, taking action, adjusting to changing needs, comforting with hands-on care (direct care), accessing resources, working with the disabled child, and negotiating the health care system.

Saloojee (2005) conducted a study at Malamulele Hospital and its local clinics in Vhembe District. The study yielded outstanding results from twelve Neuro Developmental Technique (NDT) trained therapists delivering an intensive five (5) day block of treatment intervention, including daily hands-on therapy and training of the disabled children's caregivers in how to continue with the programme of treatment skills at home. At the end of the study each child was provided and fitted with the assistive devices and splints they needed. Rehabilitative staff members were closely involved in all aspects of the intervention. The overall aim was for the caregivers to be able to take care of their disabled children using the skills and knowledge from the therapists, in order for their children to develop to their fullest, experience independence and have opportunity to attend special school focusing on their special needs.

Training caregivers by including family members or caregivers into rehabilitation therapy of the children with disability is of crucial importance. Talley and Crews (2007) mention that all the professionals, family, immediate and extended caregivers and the disabled child as a care recipient are acknowledged and valued in terms of associated responsibilities and needs in the triadic model.

2.6 The triadic model of caregiving

In 2001, the California Department of Aging in the US released a report that summarized the findings from more than 180 journal articles into a systems-based framework. This model shaped caregiving into a life-course perspective of a family system for the benefit of a local planning programme. It treated caregiving as an interactional process marked by changes in social involvement, familial support, and wellbeing.

The model recognized many aspects of access to care as challenges that caregivers could face. It took into account not only the physical and financial barriers, but also the less-well researched areas influencing the perception of access such as having knowledge about available services or working with clinicians who might not be able to build a therapeutic alliance with certain clients. The last domain within this model recognized inter- and intrapersonal resources of caregivers and the influences of caregivers' values and beliefs, such as expectations about caregiving on the basis of gender, generational values, and ethnic or cultural background.

According to Talley and Crews (2007) relationships among family caregivers, professional caregivers, and the care recipients are embedded in the triad's framework of prominent forces affecting health and well-being (Figure: 1) These forces can include societal, political, and scientific issues that shape the context of care, such as global disease burden, demographic changes,

health insurance coverage, and scientific discoveries. Within this framework, the care triad deals with a variety of internal as well as external variables that facilitate or inhibit the care situation, enhancing the chances for success or hindering them. The triadic model of caregiving allows for recognition of current and potential care partners and their resources in planning for care provision. Talley and Crews (2007) point out further that this model takes into account the strengths and needs of all care partners and features a triadic relationship among the family, immediate and extended caregiver, the care recipient (disabled child), and the professional caregiver (rehabilitation team members).

According to the triadic model, caregiving is a life span experience. Although there is, of course, great variability in caregiving experiences, many parents provide care to their children with disabilities, and child caregivers may provide assistance to their siblings, parents, or grandparents. Thus, caregiving can take a lateral, upward, or downward form. Each experience involves multiple health professionals. If the caregiver is healthy, the quality of life of the disabled child will be substantially improved. Conversely, a failure in the health of the caregiver may mean that fragile support systems collapse. In many respects, physical and mental health may be at the core of successful caregiving.

Relationships among family caregivers, professional caregivers, and the care recipients are embedded in the triad's framework of prominent forces affecting health and well-being. These forces can include societal, political, and scientific issues that shape the context of care, such as global disease burden, demographic changes, health insurance coverage, and scientific discoveries. Within this framework, the care triad deals with a variety of internal as well as external variables that facilitate or inhibit the care situation, enhancing the chances for success or hindering them.

It is the responsibility of all parties (caregivers, rehabilitation team of professionals and the disabled child) to work together in preventing the development of complications. Prevention is not only the responsibility of the rehabilitation team of professionals, but also all the individuals surrounding the children with disability, starting with his or her own self. Some of the complications like pressure sores and malnourishment are the signs of a lack of concern in daily life care (Soderback, 2009). The triadic model emphasizes that family, immediate and external caregivers, the rehabilitation team of professionals and the disabled child should use all the resources such as political forces, advocacy organizations, society and other healthcare systems to take care of disabled children.

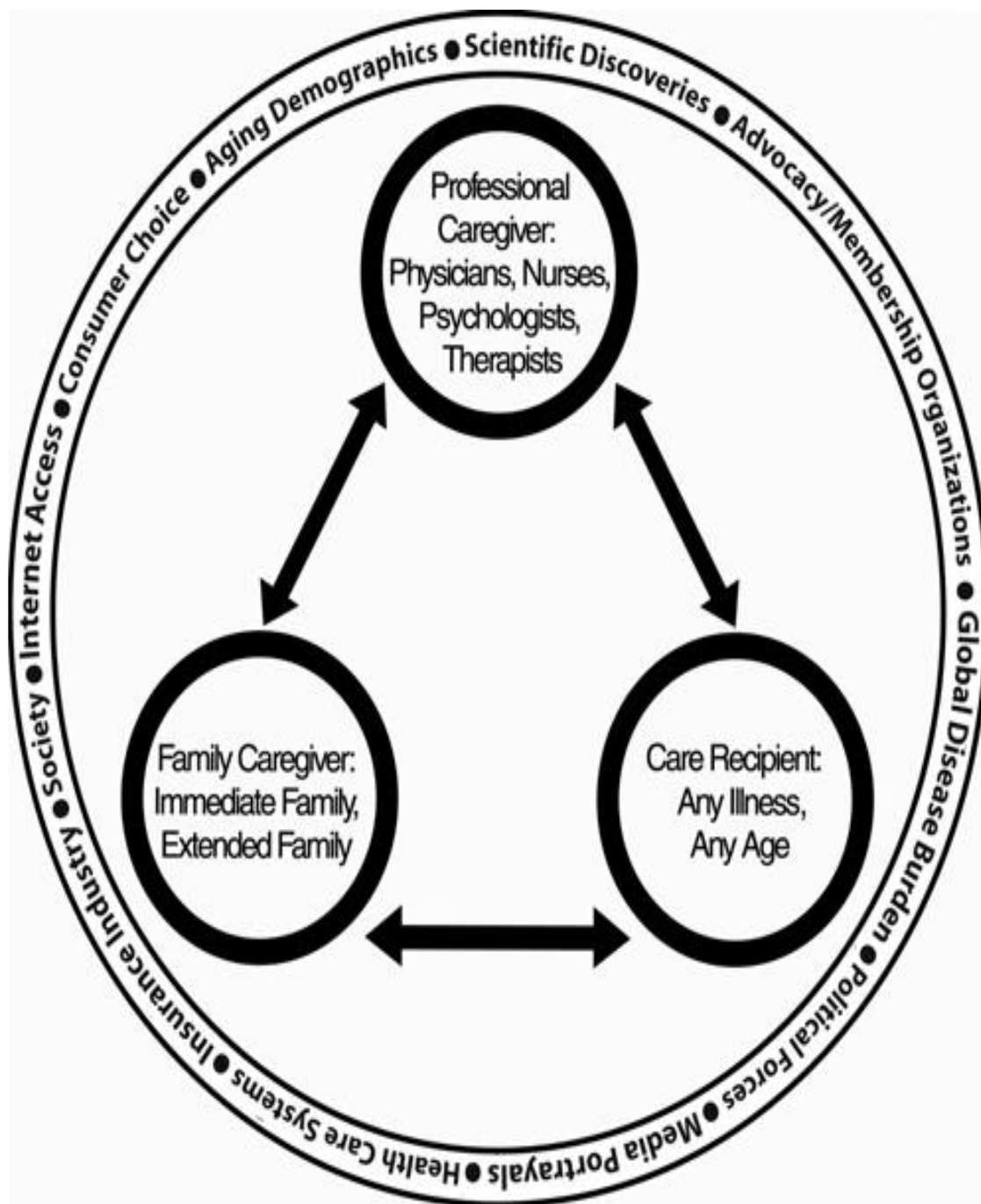


Figure 1: A triadic model of caregiving: factors influencing the care recipient, family caregiver and professional caregiver team (American Journal Public Health, 2007).

The use of health care systems in the model needs policies on disability that aim to facilitate the achievement of priorities of the South African Department of Social Development through the development of integrated developmental services to parents or caregiver of children with disabilities.

It further sheds light on the rights of children with disabilities by analyzing all the relevant disability instruments, supporting equality and accessibility as a coherent whole. Sekweyiya (2007), former Minister of Social development mentions in the policy on disability that it is important to note that the principles are often inter-related and that one cannot apply one of the principles in the absence of the other principles (South African Integrated National Disability, 1997). Principles on disability are as follows:

2.6.1 Right to self-representation

Children with disabilities have the right to self-representation in processes and structures of decision-making on issues that affect them. This emphasizes that a caregivers are important in taking care of the disabled children and their special needs.

2.6.2 Support system

The caregiver is promoted as a significant support system in meeting the needs of children with disabilities. Other support systems include Disabled People's Organisations (DPO's), Non-Governmental Organizations that work with issues of disability and social services, Community Based Organizations (CBO's) and rehabilitation therapy team. Elements of a support system vary from counselling to assistance with use of assistive devices like wheelchairs, buggy, rollator and others to dealing with prejudices and social stigma associated with disability.

2.6.3 Access to appropriate services

There are various types or categories of disability, each of which results in special needs. For example, a child who uses a wheelchair needs a ramp and wider door space to gain access to buildings; a child who is deaf/ or living with a hearing impairment needs sign language interpreters or hearing devices to hear/listen. A quadriplegic would have additional and different needs from a paraplegic although both may use a wheelchair; all wheelchair users are not necessarily paraplegics or quadriplegics, the needs of a deaf-blind person are different from that of a deaf or a blind person. This principle speaks to the need for services to be appropriate and relevant to the type or category of disability that one is addressing. It also speaks to the need for the services that are provided to be accessible to the intended target group or beneficiary (see principle of accessibility above). Thus, social services interventions for children with disabilities must be specific and responsive to all types and categories of disability.

2.6.4 Social Integration

The social model to addressing disability reflects social integration as one of its pillars. The model is based on an understanding that a focus on the abilities of the children with disabilities and on the “environmental” barriers that they experience will provide a more comprehensive and appropriate response to facilitating full inclusion and integration into society. Social integration is the key measure by which one can assess whether children with disabilities are being accorded all their full rights and treated with the same equality accorded to all other citizens. The principle speaks to the need for integration of children with disabilities into mainstream society as well as the need for an integrated package of services that facilitate full social inclusion. For example, the provision of a social grant to a child who uses a wheelchair, may be responsive to some of the disabled child’s needs, but the grant does not in any way provide the disabled child with access to a school in the community that he/she lives in, especially if the school has not been equipped with a ramp or accessible ablution facilities.

Many of the factors contributing to the high levels of impairment are potentially preventable, and include congenital defects, malnutrition, childhood illnesses, and lack of education, poverty, lack of sanitation, poor shelter, clean water and accidents. According to children’s Act (2007), not only facilities need to be accessible, but programmes also need to be appropriate (home programmes, rehabilitation therapy) and inclusive of children with disabilities. Opportunities exist around amending the regulations on current grants to prioritise children with disabilities. In addition, opportunities to design conditional grants for the specific needs of children with disabilities, such as for rehabilitation and the provision of assistive devices, should be explored (Strategic Plan of the Department to find appropriate and affordable child care, and affect decisions about work, education/training, having additional children, and relying on public support (Singer et al.,2009). It may be associated with guilt, blame, or reduced self-esteem. It may divert attention from other aspects of family functioning (WHO, 2008). The out-of-pocket costs of medical care and other services may be enormous. All of these potential effects could have repercussions for the quality of the relationship between the parents, their living arrangements, and future relationships and family structure.

2.7 Problems experienced by care givers

Raina et al. (2005) did a study on the psychological and physical health of caregivers of the children with CP. In this study the caregivers were primarily mothers of disabled children.

The findings were strongly influenced by child behaviour and caregiving demands. Child behaviour problems were an important predictor of caregiver psychological well-being, both directly and indirectly, through their effect on self-perception and family function.

The other findings were caregiving demands which contributed directly to both the psychological and the physical health of the caregivers. The practical day-to-day needs of the child created challenges for parents. The influence of social support provided by extended family, friends, and neighbours on health outcomes was secondary to that of the immediate family working closely together. Family function affected health directly and also mediated the effects of self-perception, social support, and stress management. The findings revealed that strategies for optimizing caregiver physical and psychological health include supports for behavioural management and daily functional activities as well as stress management and self-efficacy techniques. These data support clinical pathways that require biopsychosocial frameworks that are family centered, not simply technical and short-term rehabilitation interventions that are focused primarily on the child. In terms of prevention, providing parents with cognitive and behavioural strategies to manage their child's behaviours may have the potential to change caregiver health outcomes.

Brehaut et al.(2004) did a study on the health of primary caregivers of children with cerebral palsy. Although many families cope well despite the added challenges of caring for a child with a disability, their findings recommended that the demands of their children's disabilities can explain differences in the health status of parents, and that parents of children with CP are more likely to have a variety of physical and psychological health problems.

However, Raina et al. (2005)'s findings were consistent with stress from caregiving, further noting that stress can directly or indirectly affect a variety of measures of health, although some of the findings were asthma and arthritis. Alternate interpretations of these findings include the possibility that caregivers who are in regular contact with the health care system may have more opportunities to discuss and receive attention for their own health concerns than do comparison adults; or that the greater number of health issues reported by caregivers are related to the psychological and physical health, perhaps leading these caregivers to focus on their health and well-being in more depth than is usually feasible in a population survey.

2.8 Conclusion

Caregivers enjoyed healthy children with little need for specialized health care services. However, some disabled children experience difficulties in early childhood and require access to and utilization of considerable health care resources over time. Although impaired motor function is the hallmark of neurological conditions of children, many disabled children with this development disorder also experience sensory, communicative, and intellectual impairments and may have complex limitations in self-care functions or activity of daily living. Although care giving is a normal part of being the caregivers of a child, this role takes on an entirely different significance when a child experiences functional limitations and possible long-term dependence. One of the main challenges for caregivers was to manage their child's chronic health problems effectively and juggle this role with the requirements of everyday living such as nutritious food, special care, special chairs, buggy, nappies and special schools.

Next chapter outline the research methodology used in this study.

CHAPTER 3

3.1 Introduction

This chapter provides a detailed outline of the research design, study site, study population, sampling procedures, data collection instruments, collection method, data analysis procedures and ethical procedures.

3.2 Research design

Mouton (2001) indicates that a research design is a plan or blueprint of how you intend conducting the research, in such a manner that the eventual validity of the research findings is maximized. A good research design, therefore, gives direction to the envisaged research study. Tustin, Ligthelm, Martins and Van Wyk (2005) describe a research design as the master plan that specifies the methods and procedures for collecting and analyzing the required information.

In this study the quantitative method was used to collect numerical data so as to establish the association of the dependent variables with complications experienced by the disabled children. Mouton cited in Brynard and Hanekom (1997) indicate that the quantitative methodology is associated with analytical research, and its purpose is to arrive at a universal statement. In this type of methodology the researcher assigns numbers to observations.

The naturalistic observational and descriptive research design was used because one of the factors contributing to the success of a rehabilitation programme is the ability of the caregiver to execute the home programme effectively and be able to handle daily activities of the child. It was important therefore to observe the caregivers as they interact with the children. Descriptive statistics were used to describe and synthesize the data, in terms of tables, charts, graphs and percentages to present the findings.

3.3 Study site

The study was conducted at Elim Hospital, which is a district hospital under the jurisdiction of Vhembe District in Limpopo Province. The hospital is located in Makhado Municipality. It has 316 beds, serving 20 clinics and 2 health centres. It serves 20 clinics which render day service starting from 07h30 to 16h30 and 2 health centres which provide 24-hour service in the community.



Figure 2: The Map of Vhembe District showing Hospital, Community Health Centers and Clinics (Limpopo Provincial Health Department, 2011).

3.4 Study population.

The population consisted of 60 caregivers whose disabled children were offered rehabilitation therapy at Elim Hospital. These are the caregivers that are offered rehabilitation therapy at the hospital on monthly basis they bring their disabled children. Most of the caregivers ages range from 20 to above 50 years and mostly females.

3.5 Sampling method and procedure

Convenient sampling is a non-probability sampling technique where subjects are selected because of their convenient accessibility. Van der Walt and Van Rensburg (2006) point out that convenience sampling is also referred to as accidental or availability sampling and it involves the choice of readily available subjects or objects for the study. Convenience sampling was used to select 52 caregivers because of their availability and easy to access. It includes whoever is available and meets the criteria.

Advantages of convenience sampling:

- Simplicity of sampling and ease of research.
- Helpful for pilot studies and for hypothesis generation.
- Data collection can be facilitated in short duration of time.
- Cost effectiveness.

Disadvantages of Convenience Sampling

- The risk that the sample might not represent the population as a whole.
- Generally unclear.
- High level of sampling error.

3.6 Inclusion criteria

Inclusion criteria were as follows:

- Caregivers who reside in Elim Hospital catchment area.
- Caregivers whose children are disabled and attending rehabilitation therapy at Elim hospital, and
- Caregivers between the ages of 20 and 60 years.

3.7 Data collection

Two methods of data collection were used. The caregivers were directly approached during their visit at the rehabilitation therapy clinic area at Elim Hospital to be part of the research. Information was explained to the caregivers and those who consented signed the informed consent form (Appendix: 2). Codes were assigned to each questionnaire for tracking responses. The collection of data took six weeks to complete.

3.7.1 Detailed questionnaire with closed-ended questions

The questionnaire (Appendix: 1) had 3 sections. Section A: Demographic information of the caregiver. Section B: Aspects that established the reasons for disabled children presenting with complications. Section C: Aspects that were used on screening the disabled children. The researcher interviewed the caregivers in Tsonga and Venda language using close-ended questions and administered the questionnaire.

The caregivers were asked questions directly from the questionnaire using their preferred language and it was administered by the researcher. Responses were recorded on the questionnaire by the researcher. It took the researcher 20 minutes to complete one questionnaire.

3.7.2 Observation of the skills using self-constructed checklist

Observation was done only once during the rehabilitation session and the observed skills from the caregiver were recorded by the researcher on the checklist which was also coded (Section D).

3.8 Data analysis

Once the data were loaded onto the computer, quantitative data were summarised using Statistical Package for Social Sciences (SPSS) Version 22. Quantitative data were subjected to deductive analysis (Leedy and Ormrod, 2010). Results were then presented using frequency tables and chi-square tests. Analysis techniques conducted in this study included descriptive and inferential statistics.

The researcher also calculated chi-square test to look at significant difference, where the p value was greater than 0.05, the findings showed that there was no association between gender and caregiver factors. Where the p value was less than 0.05, the findings showed that there was an association between age and the caregiver factors.

Psychological aspects on the disability of their disabled children ,P value of 0.031 is less than 0.05. Also there was an association on the disability screening P value of 0.009 which is less than 0.05. Data were summarized and presented by making use of descriptive and inferential statistics. Tables, graphs were used in the presentation of the findings. The mean, standard deviation, minimum and maximum values for all scaled questions were also computed and used in the explanation of the findings.

3.9 Reliability and validity

The pilot study was done to test the reliability and validity of the questionnaire. Polit, Beck and Hungler (2001) define validity as “the degree to which an instrument measures what it is supposed to measure”. Therefore, it is important that the validity of the measuring instrument was done to avoid questionable results.

In the current study, the research instrument was developed with the assistance of a statistician. Content validity of the questionnaire was done by asking a therapist with experience in working with disabled children, on whether it reflects the skills that they are providing to the caregivers. Furthermore, a pilot study was done at Louis Trichardt Memorial Hospital, Five caregivers whom are attending rehabilitation therapy were interviewed using a structured questionnaire and the researcher administered the questionnaire. The findings showed there was no association between gender and caregiver factors, the P value was greater than 0.05. There was an association between age and the caregiver factors; the P value was less than 0.05. Those interviewed caregivers were not included in the actual study.

During the pilot study, the caregivers evaluated if there were no elements of ambiguity in the questions presented in the research instrument and whether all caregivers' understanding of the elements of the instrument was consistent. Comments and suggestions from the pilot study were utilized to refine the questionnaire, for example in the responses from the questionnaire, the caregiver could not fully distinguish the terms: “strongly agree” and “strongly disagree”, those terms were removed because they were causing confusion. And “agree”, “disagree” and “not sure” were used for the questionnaire that was used to collect the data, so that the questions have one response that she or he is sure of. The question of asking the age was changed to the specific “How old are you?”

3.10 Ethical considerations

The study took the following ethical aspects into considerations:

- The researcher requested a clearance certificate from Turfloop Research Ethical Committee (TREC) and Medunsa Research Ethical Committee (MREC).
- The researcher requested the approval from ethics committee in the provincial Department of Health as well as from the Chief Executive Officer of Elim Hospital.
- No study was conducted prior to approval being granted.
- Caregivers volunteered to take part in the research and were given an opportunity that, even when they had agreed to participate they were free to withdraw at any time they wished during the study.
- The caregivers were fully informed of the procedures, expectations in research and they gave the consent to participate.
- The participation in the research guaranteed confidentiality to all the caregivers.
- The caregivers were assured that no identifying information would be made available to anyone not directly involved in the study.
- The findings were reported in a complete and honest manner.

3.11 Significance of the study

The study was important to the caregivers in Elim Hospital, Vhembe District because they needed to take care of disabled children with a variety of conditions such as CP, traumatic brain injuries, developmental delays, severe orthopaedic impairment, hydro and micro-cephalus and they had unique problems that needed special care in order for them to be independent in all spheres of life (social, leisure, play, school, and personal management).

3.12 Conclusion

This chapter described the research methodology and the issues regarding ethical considerations. The next chapter presents the data analysis procedures and interpretation of the findings.

CHAPTER 4

RESULTS

4.1 Introduction

The purpose of this chapter is to present and interpret the empirical findings of this research.

4.2 Results

Data obtained from the questionnaires were analyzed and interpreted. The results are illustrated using tables and bar charts. This chapter illustrates the responses on a question-by-question basis.

4.3 Demographic data

The profiles of the caregivers were analyzed in terms of their gender, age, relationship with the disabled children, economic status and qualification.

4.3.1 Profile of the caregivers by gender

There was a need to determine the gender of the caregivers in order to enable the researcher to make demographic inferences concerning the caregivers.

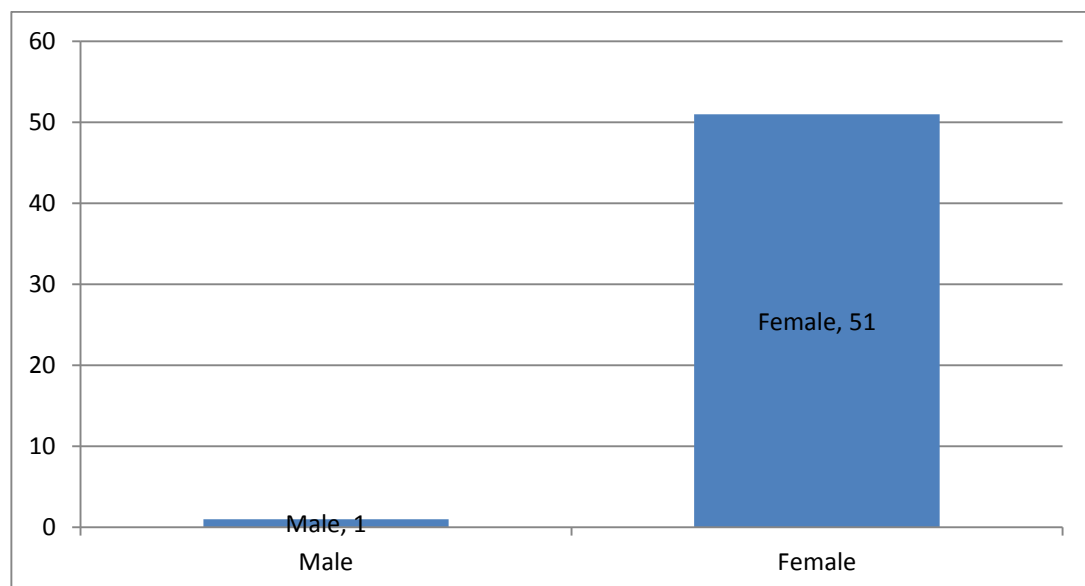


Figure 3: Profile of caregivers by gender

The bar chart above shows that male caregivers constitute (2%) 1 of the caregivers while their female counterparts constitute the remaining (98 %) 51. The results indicate female are more involved in taking care of disabled children than males.

4.3.2 Age of the caregivers

Table 1: Age of the caregivers

Age	Frequency distributions (n)	Percent (%)
20 - 30 years	17	32.69
31 - 40 years	21	40.38
41 - 50 years	7	13.46
>50 years	7	13.46
Total	52	100.00

The table above shows that the majority of caregivers were at 31-40 years, which constitutes (40.38 %).

4.3.3 Economic status of the caregivers

The economic status of the caregivers was established to determine if the caregivers could afford some of the special needs of the disabled children, for example special schools and assistive devices. The economic status was grouped as follows: (1) Self-employed, (2) Pensioner, (3) Social grant recipient and (4) earning a salary. The table below illustrates the profile of the caregivers.

Table 2: Profile of the caregivers by economic status.

Economic status	Frequency	Percent
Self-employed	2	3.8
Pensioner	1	1.9
Social grant	43	82.7
Earning a salary	6	11.5
Total	52	100.0

The results show that those who are self-employed represented 3.8%, pensioner represented by 1, 9% of the caregivers. Most of the caregivers depend on the social grant and they constitute 82.7%, and those earning a salary are 11.5%.

4.3.4. Qualification of the caregivers

Table 3: Profile of the caregivers by qualification

Qualification	Frequency	Percent
Grade 11 or lower	38	73.1
Grade 12	10	19.2
Diploma/ Degree or Certificates	4	7.7
Total	52	100.0

The results show that 73.1% of the caregivers have grade 11 and lower qualifications.

4.3.5 Relationship of the caregiver and the disabled children

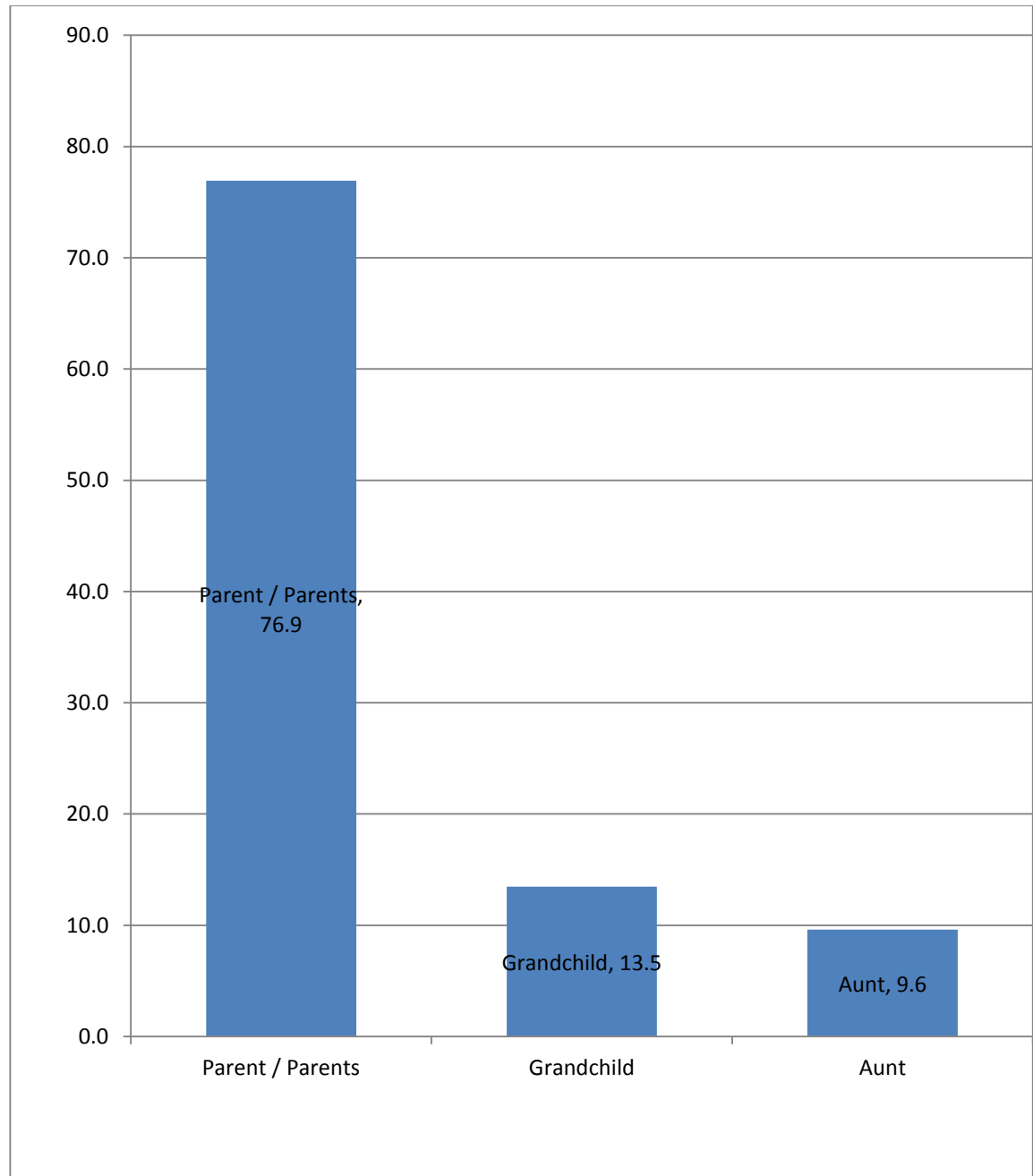


Figure 4: Relationship of the caregivers and the disabled child.

The results show the relationship between the disabled children and caregivers, who bring the disabled children to the rehabilitation therapy. The results show that 77% of the caregivers are parents of the disabled children, 13 % grannies of the disabled children and (10%) are aunts of the disabled children.

4.3.6 The person who first discovered that the disabled child has medical problems

Table 4: The person who first discovered that the disabled child has medical problems

Person who saw medical problems	Frequency	Percent
Doctor	16	30.8
Nurse	8	15.4
Rehabilitation team member	1	1.9
Caregiver	27	51.9
Total	52	100.0

The results show that the medical condition of the children was mostly 51.9% and first seen by the caregiver. The rehabilitation team members were the least people to see the condition of the children first.

4.3.7 Place where medical problems were seen

These also determine where, how and when rehabilitation therapy was done after seeing medical problems. If medical problems are seen at home, some caregivers tend to take their disabled children to the rehabilitation therapy team after they see the complications.

Table 5: Places where medical problems were seen

Places where medical problems seen	Frequency	Percent
Hospital	16	30.8
Clinic	9	17.3
Home	27	51.9
Total	52	100.0

The figure above shows that the medical problem of the disabled child was mostly seen in the homes of the caregivers; the figure below shows 51.9% home, 30.8% in the hospital and 17.3% at the clinic.

4.3.8 Age range at which the medical problems were found.

There was a need to determine at what age the caregivers detected the medical problems.

Table 6: Age range at which the medical problems were found.

Age	Frequency	Percent
0 - 5 years	52	100.0

The Table above indicates that all the children's medical problems were detected at age ranging from 0-5 years

4.3.9 Rehabilitation team's visits to disabled children

The frequency of visits by the rehabilitation team was established from the caregivers. The outcome of this investigation is illustrated in Table 7 below.

Table 7: Rehabilitation team's visits to the disabled child.

Visits by rehabilitation team	Frequency	Percent
Daily	1	1.9
Monthly	9	17.3
Yearly	42	80.8
Total	52	100.0

The Table above shows how often the rehabilitation team visits the disabled child. Most of the disabled children (80.8%) are visited on a yearly basis.

4.4 Factors related to caregivers that contribute to the development of complications in disabled children

A number of factors that can contribute to the development of complications in disabled children were investigated.

4.4.1 Home programme done by the caregiver

There was a need to determine the understanding of home programme by the caregiver and the demonstration of home programme by the rehabilitation team.

Table 8: Questions on home programme done by the caregiver

Q	Questions on offered home programme	A	D	N S
Q12	The caregivers understand the role of rehabilitation team members.	46 (88.5 %)	6 (11.5%)	0
Q13	The rehabilitation team clearly explains their role to the caregivers.	51(98 .1%)	1 (1.9%)	0
Q14	The rehabilitation team explains the importance of doing home programme.	50(96 .2%)	2(3.8%)	0
Q15	The home programme is clearly demonstrated to you each time you come for the visit.	51(98 .1%)	1 (1.9%)	0
Q16	The rehabilitation team gives you the chance as caregivers to demonstrate the home programme as well so that the caregivers will leave the treatment room knowing what to do at home.	40(76 .9%)	12(23. 1%)	0
Q17	The rehabilitation team present themselves in such a way that the caregivers feel free or comfortable to ask questions for clarity.	52 (100 %)	0	0

TheTable above shows that 46 (88.5%) of the caregivers agreed that they understood the role of the rehabilitation team. Fifty-one (98.1%) further agreed that the role was clearly explained to them and 50 (96.2%) agreed that they understood the importance of doing a home programme, 51 (98.1%) agreed that it was clearly demonstrated in such a way that there were given a chance to demonstrate to the rehabilitation team. Forty (76.9%) confirmed that they got a chance to demonstrate and all the caregivers said that they were very comfortable in working with the rehabilitation team.

4.4.2 Psychological aspects of the disability of the caregivers' children

There was a need to determine the psychological aspects of the disability of the caregivers' children. The caregivers must understand the condition of their children in order to provide good care.

Table 9: Psychological aspects of the disability of the caregivers's children.

Q	Questions on psychological aspects of the disability of the caregivers 's children	A	D	NS
Q18	The caregiver understands the disability of the child.	44 (84.6%)	8 (15.4%)	0
Q19	It took some time for the caregiver to understand condition or the disability of the child.	2(3.8%)	23 (44.2%)	27 (51.9%)
Q20	The caregiver feels that this child is a burden to you and others in the family.	17(32.7%)	35(67.3%)	0
Q21	The caregiver has many people to socialize with.	37(71.2%)	15(28.8%)	0
Q22	The caregiver has time to attend community meetings, imbizo and other gatherings.	1(1.9%)	39(75.0%)	12(23.1%)

The table above indicates that 44(84.6%) agreed that they had understanding of disability of their children, 23 (44.2%) said that it took sometime for them to understand the disability of their disabled children and 35 (67.3%) of the caregivers disagreed that the disabled children were a burden to them and the family. Thirty-seven (71.2%) agreed that they had people to socialize with and 35 (75%) disagreed that they had time to attend community gatherings.

4.4.3 Traditional belief of the caregiver towards the disability of their children

There was a need to determine the traditional belief of the caregivers towards the disability of their children and what they believe in.

Table 10: Traditional belief of the caregivers towards the disability of their children.

Q	Questions on traditional belief	A	D	NS
Q23	The caregiver takes your child to the traditional healer.	23 (44.2%)	29 (55.8%)	0
Q24	The caregiver believes that the child has been bewitched.	17(32.7 %)	35 (67.7%)	0
Q25	The caregiver feels that the child is a symbol of a curse.	10(19.2 %)	42(80.8%)	0
Q26	The child is protected by super natural forces.	5(9.6%)	47 (90.4%)	0

Table above shows that 29 (55.8 %) of the caregiver disagreed that they take their children to the traditional healers. 35(67.7%) disagreed that their children are bewitched. 42 (80.8%) disagreed that their children is a symbol of a curse and 47 (90.4%) disagreed that their children are protected by super natural forces.

4.4.4 Disability screening done by the rehabilitation team.

Rehabilitation team does the screening by visiting the disabled child's home and the villages.

Table 11: Disability screening done by the rehabilitation team.

Q	Questions on disability screening done by rehabilitation team.	A	D	NS
Q27	Rehabilitation team visit the home of the disabled child.	1 (1.9 %)	15(28.8%)	36 (69.2%)
Q28	The caregivers followed the entire immunisation programme.	1 (1.9%)	48 (92.3%)	3 (5.8%)
Q29	The disabled child cried immediately after birth.	8(15.4%)	18(34.6%)	26 (50%)

The Table above shows that 36 (69.2%) of the caregivers were not sure if the disabled children were visited by the rehabilitation team, 48 (92.3%) disagreed that the disabled children followed the entire immunization programme and 26 (50%) of the caregivers were not sure if the disabled child cried immediately after birth.

4.4.5 Availability of the resources to do a proper rehabilitation therapy

There was a need to determine availability of resources; resources include the rehabilitation team, assistive devices and the caregivers in the study.

Table 12: Availability of the resources

Q	Questions on availability of the resources	A	D	NS
Q30	The caregiver receives assistive devices during your rehabilitation therapy.	22 (42.3%)	30 (57.7%)	0
Q31	The Rehabilitation team members always available on your appointment date.	46(88.5%)	6 (11.5%)	0
Q32	The caregiver receives disability grant.	40(76.9%)	12(23.1%)	0
Q33	The is enough space to do rehabilitation therapy.	51(98.1%)	1 (1.9%)	0
Q34	The child has activities made by low cost materials.	10(19.2%)	42 (80.8%)	0

The Table above shows that 30 (57, 7%) disagreed that their disabled children received assistive devices during the rehabilitation therapy, 46 (88.5%) agreed that rehabilitation team members always available on appointment date, 40 (76.9%) agreed that their disabled children received disability grant, 51(98.1%) agreed that there was enough space for rehabilitation therapy and 42 (80.8%) disagreed that their disabled children had activities made by low cost materials.

4.4.6 Support to caregivers

There was a need to determine the support given to the caregivers. Support is expected to be from the family, the rehabilitation team, and other stakeholders.

Table 13: Support to caregivers.

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Q	Questions on availability of the resources	A	D	NS
Q35	The rehabilitation therapy team members assisted you to belong in a support group.	10 (19.2%)	42 (80.8%)	0
Q36	The caregiver thinks that you are benefiting from the rehabilitation therapy.	1(1.9%)	44 (84.6%)	7(13.5%)
Q37	The caregiver sometimes fails to comply with the home programme due to lack of support.	28(53.8%)	24(46.2%)	0
Q38	Family members give you enough support with regard to your disabled child.	33(63.5%)	19(36.5%)	0
Q39	If the child is attending a special school, are the rehabilitation team available in that special school?	1(1.9%)	2(3.8%)	49(94.2%)

4

The table above shows that 42 (80.8%) of the caregiver disagreed that the rehabilitation therapy team members assisted them to belong in a support group, 44 (84.6%) of the caregivers disagreed that they benefited from the rehabilitation therapy and 28 (53.8%) of the caregivers agreed that sometimes they failed to comply with the home programmes. Thirty-three (63.5%) agreed that family members gave them enough support with regard to their disabled child and 49 (94.2%) of the caregivers were not sure if the rehabilitation team were available in the special school.

4.5 Diagnosis of the disabled children of the caregivers

There was a need to determine the diagnosis of the disabled children of the caregivers. This helped the researcher to be able to know what conditions the children in the rehabilitation therapy were in so that complications could be prevented.

4.5.1 Diagnosis of the disabled children of the caregivers and complications cross tabulation

Caregivers learnt skills in order to prevent complications of their disabled children.

Table 14: Profile of the disabled children by diagnosis

Diagnosis	Frequ ency	Perc ent
Cerebral palsy	32	61.5
Hydro/micro-cephalous	3	5.8
Developmental delay	10	19.2
Congenital deformity of lower limbs	4	7.7
Other neurological conditions	3	5.8
Total	52	100.0

Most of the diagnoses are cerebral palsy (61.5%). The least common is other neurological deformity conditions and hydro/micro cephalous which showed 5.8%, developmental delays showed (19.2 %), congenital deformity of the lower limbs showed 7.7%.

Table 15: Profile of the disabled children by diagnosis and complications.

Diagnosis	The child has bedsores, physical deformity, Malnourishment, Contractures(Complications).		Total
	Complications	Non - Complications	
Cerebral palsy	10 (19.2%)	22 (42.3%)	32 (61.5%)
Hydro/micro- cephalous	1 (1.9%)	2 (3.8%)	3 (5.8%)
Developmental delay	1 (1.9%)	9 (17.3%)	10 (19.2%)
Congenital deformity of lower limbs	3 (5.8%)	1 (1.9%)	4 (5.8%)
Other neurological conditions	1 (1.9%)	2 (3.8%)	3 (5.8%)
Total	16 (30.8%)	36 (69.2%)	52 (100.0%)

The results show that in each diagnosis there are complications that the disabled children brought with at the rehabilitation therapy: 16 (30.8%) of the disabled child brought by the caregivers had complications and 36 (69.2%) of the disabled children brought by the caregivers had no complications.

Table 16: Diagnosis and the development of complications Chi-Square Tests.

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	5.721 ^a	4	.221
Likelihood Ratio	5.805	4	.214
Linear-by-Linear Association	.129	1	.720
N of Valid Cases	52		

Using chi-squared test $P = 0.221$ greater than required P value of 0.05 (5%), this implies that there is no association between diagnosis and complications.

4.6 Association between caregiver factors and the development of complications

There was a need for the researcher to determine the association between caregiver factors and the development of complications in disabled children.

4.6.1 Home programme and the development of complications

There was a need to determine the association between home programme and the development of complications. The researcher wanted to find out if the understanding of home programme had an impact on the development of complications.

Table 17: Home programme and development of complications.

Home Programme	The child has bedsores, physical deformity, Malnourishment, Contractures(Complications)		Total
	Complications	Non-Complications	
Not sure	10	25	35
	19.2%	48.1%	67.3%
Not Clearly Demonstrated	6	11	17
	11.5%	21.2%	32.7%
Total	16	36	52
	30.8%	69.2%	100%

Table 18: Home programme and the development of complications Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)	Exact Sig. (2- sided)	Exact Sig. (1- sided)
Pearson Chi-Square	.243 ^a	1	.622		
Continuity Correction ^b	.030	1	.863		
Likelihood Ratio	.240	1	.624		
Fisher's Exact Test				.751	.426
Linear-by-Linear Association	.238	1	.626		
N of Valid Cases	52				

Using chi-squared test $P = 0.622$ greater than required P value of 0.05 (5%), this implies that there is no association between home programme given by the rehabilitation therapy and the development of complications.

4.6.2 Psychological aspects of the children's disability and the development of complications

There was a need to determine the association between psychological aspects and the development of complications. The researcher wanted to find out if the caregivers had understanding of psychological aspects of their children's disability and if this had an impact on the development of complications.

Table 19: Psychological aspects of the children's disability and the development of complications.

Psychological aspects	The child has bedsores, physical deformity, malnourishment, contractures. (Complications)		Total
	Complications	Non-Complications	
Understand psychological aspects	7 13.5%	16 30.8%	23 44.2%
Not sure	5 9.6%	11 21.2%	16 30.8%
Do not understand psychological aspects	4 7.7%	9 17.3%	13 25.0%
Total	16 30.8%	36 69.2%	52 100.0%

Twenty-three (44.2%) of the caregivers understood the psychological aspects of the disabled children and 7 (13.5%) had complications, 16 (30.8%) caregivers were not sure of their disabled children psychological aspects and 5 (9.6%) had complications, and 13 (25%) of the caregivers did not understand the psychological aspects of their disabled children and 4 had complications.

Table 20: Psychological aspects of the disabled children and the development of complications Chi-Square test.

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	.003 ^a	2	.999
Likelihood Ratio	.003	2	.999
Linear-by-Linear Association	.001	1	.977
N of Valid Cases	52		

Using chi-squared test $P = 0.999$ greater than required P value of 0.05 (5%), this implies that there is no association between psychological aspects of the children disability and the development of complications.

4.6.3 Traditional belief and the development of complications

There was a need to determine the association between the development of complications and traditional belief. The researcher wanted to find out if the caregivers had traditional belief on their children's disability and if it had an impact on the development of complications.

Table 21: Traditional belief and the development of complications

Traditional belief	The child has bedsores, physical deformity, malnourishment, contractures. (Complications)		Total
	Complications	Non-Complications	
Traditional belief	7 13.5%	9 17.3%	16 30.8%
Not sure	1 1.9%	11 21.2%	12 23.1%
Not traditional belief	8 15.4%	16 30.8%	24 46.2%
Total	16 30.8%	36 69.2%	52 100.0%

Sixteen (30.8%) of the caregivers believed in their traditions and 7 (13.5%) had complications, 12(23.1%) caregivers were not sure of what to believe in and 1 (1.9%) had complications, 24 (46.25%) caregivers did not believe in their traditions and 8 (15.4%) had complications.

Table 22: Traditional belief and the development of complications Chi-Square test.

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	4.175 ^a	2	.124
Likelihood Ratio	4.826	2	.090
Linear-by-Linear Association	.254	1	.614
N of Valid Cases	52		

Using chi-squared test $P = 0.124$ greater than required P value of 0.05 (5%), this implies that there is no association between traditional belief and the development of complications.

4.6.4 Disability screening and the development of complications

There was a need to determine the association between the development of complications and disability screening. The researcher wanted to find out if the caregivers had understanding on disability screening that was done by the rehabilitation team and if this had an impact on the development of complications.

Table 23: Disability screening and the development of complications

Disability screening	The child has bedsores, physical deformity, Malnourishment, contractures. (Complications)		Total
	Complications	Non-Complications	
Not sure	7 13.5%	12 23.1%	19 36.5%
Adequate disability screening	6 11.5%	8 15.4%	14 26.9%
Inadequate disability screening	3 5.8%	16 30.8%	19 36.5%
Total	16 30.8%	36 69.2%	52 100.0%

Nineteen (36.5%) of the caregivers said that they were not sure if the disability screening was done and 7 (13.5%) had complications, 19(36.5%) of other caregivers said inadequate disability screening was done and 3 (5.8%) had complications and 14 (26.9%) of the caregivers said adequate disability screening was done and 6 (11.5%) had complications.

Table 24: Disability screening and the development of complications Chi-Square test.

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	3.291 ^a	2	.193
Likelihood Ratio	3.489	2	.175
Linear-by-Linear Association	2.451	1	.117
N of Valid Cases	52		

Using chi-squared test $P = 0.193$ greater than required P value of 0.05 (5%), this implies that there is no association between disability screening and complications.

4.6.5 Availability of resources and the development of complications

There was a need to determine the association between the development of complications and availability of resources. The researcher wanted to find out if the caregivers had an understanding on the availability of resources during the rehabilitation therapy of their children's disability and if this had an impact on the development of complications.

Table 25: Availability of resources and the development of complications.

Availability of resources	The child has bedsores, physical deformity, malnourishment, contractures. (Complications)		Total
	Complications	Non-Complications	
Availability of resources	11 21.2%	11 21.2%	22 42.3%
Not sure	5 9.6%	14 26.9%	19 36.5%
Not available resource	0 0.0%	11 21.2%	11 21.2%
Total	16 30.8%	36 69.2%	52 100.0%

Twenty-two (42.3%) of the caregivers said there were available resources and 11(21.2%) had complications, 19 (36.5%) of the caregivers were not sure if the resources were available and 5 (9.6%) had complications, and 11(21.2%) of the caregivers said there were no available resources and nobody had complications.

Table 26: Availability of resources and the development of complications Chi-Square test.

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	8.885 ^a	2	.012
Likelihood Ratio	11.794	2	.003
Linear-by-Linear Association	8.705	1	.003
N of Valid Cases	52		

Using chi-squared test $P = 0.012$ greater than required P value of 0.05 (5%), this implies that there is association between availability of resources and the development of complications

4.6.6 Support to caregivers and the development of complications

There was a need to determine the association between development of complications and support to caregivers. The researcher wanted to find out if the caregivers received adequate support from their family and the rehabilitation team in order to take care of their children's disability and if it had an impact on the development of complications.

Table 27: Support to caregivers and the development of complications.

Support to caregivers	The child has bedsores, physical deformity, malnourishment, contractures. (Complications)		Total
	Complications	Non-Complications	
Adequate support	8 15.4%	12 23.1%	20 38.5%
Not sure	7 13.5%	17 32.7%	24 46.2%
Inadequate support	1 1.9%	7 13.5%	8 15.4%
Total	16 30.8%	36 69.2%	52 100.0%

Twenty (38.5%) of the caregivers indicated that they got adequate support from the family and rehabilitation therapy team and 8 (15.4%) presented with complications, 24 (46.2%) of the caregivers were not sure of the support they received and 7(13.5%) had complications and 8 (15.4%) of the caregivers said they got inadequate support to take care of their disabled children and 1 (1.9%) had complications.

**Table 28: Support to caregivers and the development of complications
Chi-Square Test**

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	2.082^a	2	.353
Likelihood Ratio	2.270	2	.321
Linear-by-Linear Association	1.997	1	.158
N of Valid Cases	52		

Using chi-squared test $P = 0.353$ greater than required P value of 0.05 (5%), this implies that there is no association between support to caregivers and development of complications.

4.7 Rehabilitation therapy training by the rehabilitation team

There was a need to determine rehabilitation therapy training by the rehabilitation team. Training is needed to improve function and safety for the disabled children .

Table 29: Rehabilitation therapy training by the rehabilitation team

Rehabilitation therapy training	Frequency	Percent
Proper therapy training	24	46.2
Not sure	10	19.2
Improper therapy training	18	34.6
Total	52	100.0

The Table above shows that the majority 24 (46.2%) got proper rehabilitation therapy, 10 (19.2%) were not sure if they got the rehabilitation therapy training and 18 (34.6%) got improper rehabilitation therapy training.

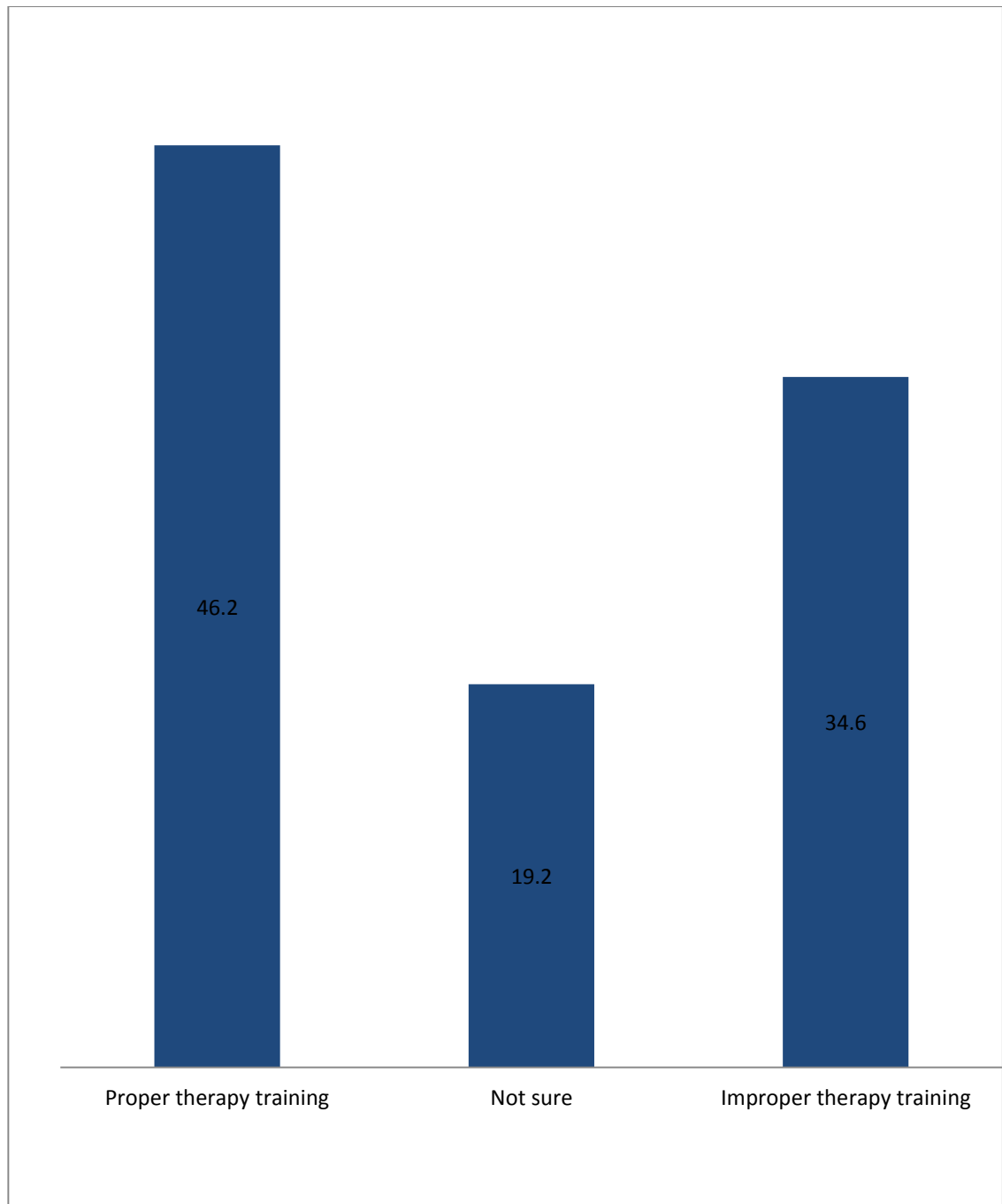


Figure 5: Rehabilitation therapy training by the rehabilitation team.

4.8 Observed skills.

In this study these are the observed skills by the researcher during the rehabilitation therapy.

Table 30: Observed skills of caregivers in executing the rehabilitation home programme.

Item No	Items	Not applicable	Yes	No
D52	The caregiver can correctly position the child while playing/during therapy.	0	46(88.5%)	6(11.5%)
D53	Executes exercises correctly (Stretching, facilitation head control, facilitation of sitting).	0	42(80.8%)	10(19.2%)
D54	The caregiver can correctly position the child on an assistive device.	34(65.4%)	12(23.1%)	6(11.5%)
D55	The child can sit.	0	27(51.9%)	25(48.1%)
D56	The child can crawl.	0	11(21.2%)	41(78.8%)
D57	The child can walk.	0	8(15.4%)	44(84.6%)
D58	The caregiver can carry the disabled child appropriately on her back.	0	50(96.2%)	2(3.8%)
D59	The caregiver communicates appropriately with the disabled child.	0	44(84.6%)	8(15.4%)
D60	The caregiver can make eye contact and understand the child.	0	48(92.3%)	4(7.7%)

D61	The child uses assistive devices.	1(1.9%)	17(32.7%)	34(65.4%)
D62	The child looks clean.	0	51(98.1%)	1(1.9%)
D63	The child has bedsores, physical deformity, contractures.	0	16(30.8%)	36(69.2%)
D64	The caregiver was patient or not in a hurry during the session.	0	49(94.2%)	3(5.8%)
D65	The caregiver looks sad/unhappy during the session.	0	4(7.7%)	48(92.3%)

The Table above shows the level of observed skill of caregivers in executing the rehabilitation home programme.

Table 31 : Checklist of the observed skills

Score	Frequency	Percent
Poor	3	5.8
Satisfactory	1	1.9
Good	48	92.3
Total	52	100.0

The Table above shows that 92.3% of the observed skills were good, 5.8% poor and 1.9% satisfactory. The majority of the caregivers' observed skills during the rehabilitation therapy was good.

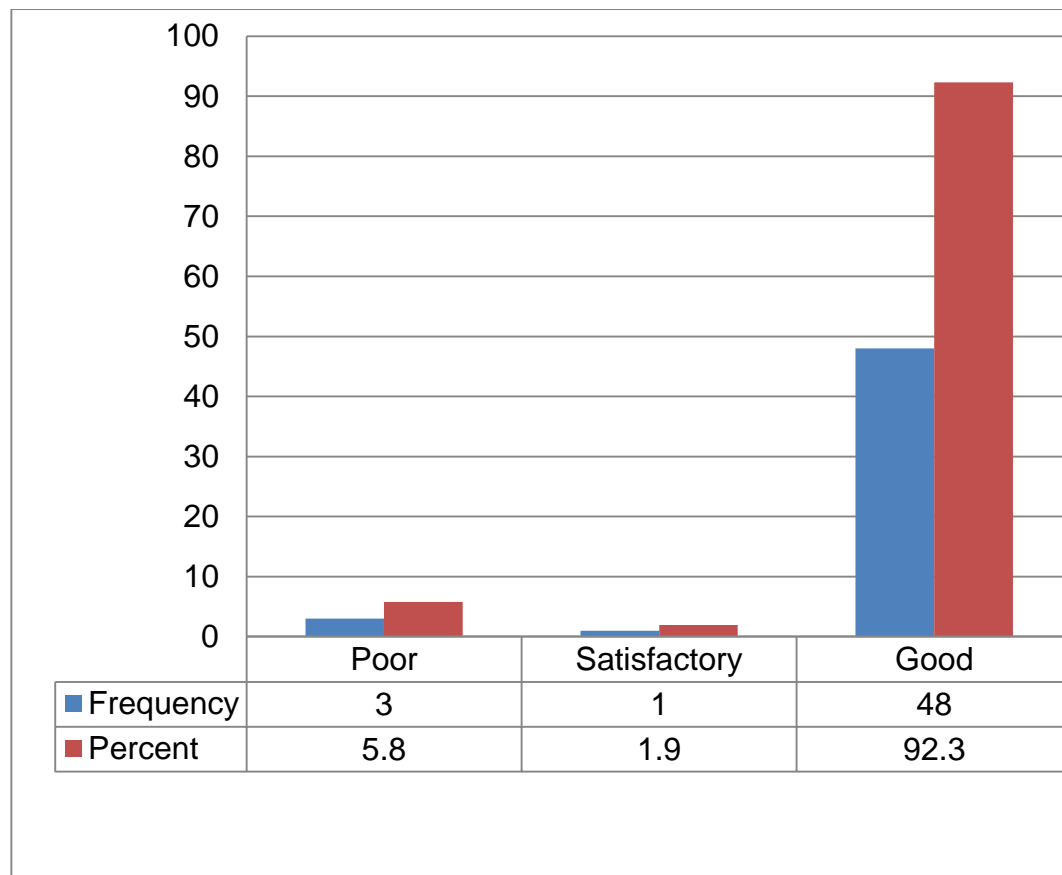


Figure 6: Observed skills from caregivers.

The above figure shows:

- Poor = 3 caregivers scored 30% and less.
- Satisfactory = 1 caregiver scored from 30% to 49%
- Good = 48 caregivers scored 50% and above.

4.8 Conclusion

This chapter focused on analysing and interpreting the data gathered through questionnaires. Tables and bar graphs were utilized to represent the findings and thereby aiding the interpretation of the findings. It is clear from the above mentioned findings that some factors related to caregivers that contribute to the development of complications in disabled children at Elim Hospital are home programme given to caregivers, psychological aspects to the disability of the children, traditional beliefs, support to caregivers by family, community and rehabilitation therapy. There was an association $P = 0.012$ greater than required P value of 0.05 (5%), this implies that there is association between availability of resources and the development of complications. In the following chapter a summary of results, conclusions and recommendations will be presented

CHAPTER 5

DISCUSSION OF THE MAJOR FINDINGS

5.1 Introduction

The caregivers of the disabled children with neurological conditions are offered rehabilitation therapy skills by the rehabilitation therapy team of professionals (physiotherapist, occupational therapist, speech and hearing therapists and dietitians) in order to take care of their disabled children and to prevent development and further development of complications. There are 60 caregivers that receive rehabilitation therapy at Elim Hospital on a weekly basis, each caregivers comes once a month and 52 were the target population of the study. And if they are not getting those rehabilitation therapy from the rehabilitation team their disabled children will be totally dependent on them in all spheres of their lives (personal management, play, social and leisure), because they will have to do everything for them, and it will be difficult to the disabled child to get special school placement or Day Care Centre.

This research intended to investigate caregiver's factors that contribute to development of complications in disabled children at Elim Hospital. In order for the caregivers to understand the conditions of their disabled children they must also understand the role of the rehabilitation team in the life of their disabled children. The Rehabilitation therapy team are monitoring the rendered services by visits to their homes and provide follow up dates. There should be coordination of the services rendered in the clinic, hospital and all health workers should understand each other's roles. Chapter one discussed the problem statement, objectives and aims of the study, the significance of the study, definition of terms and the outline of the study. Chapter two presented the literature review. Chapter three provided an outline of the research methodology and design. Chapter four presented the results of the study.

This chapter will discuss the outcomes of the study with cross reference to other literature studies. It also presents conclusions from the study as well as recommendations for future studies.

5.2 Summary of the results

There were a higher percentage of female caregivers than males. The majority of the caregivers were parents of the disabled children. There was a need to determine the qualification of the caregivers as there might have been a possibility that the caregivers were having difficulty in continuing with schooling when there was a disabled child at home (Livestrong.com, 2015). Most of the caregivers had Grade 11 and below, few of them had below grade 11. Chauke, (2013) found that teenage mothers found it difficulty to

balance between school and caring for the disabled child, hence they drop out of school.

In some cases, support for teen mothers lacks from school teachers and fellow learners, as a result, these teen mothers drop out of school (Chigona and Chetty, 2008). The results also indicate that the majority of caregivers depended on the social grant. Elim is a rural area, with very high unemployment status, as a result most of unemployed caregivers rely on the disability grant, which is earmarked for caring for the disabled child. Also, these children and their caregivers rely on this grant to take the child for rehabilitation, hence, they sometimes delay on bringing them for consultation.

The results show that most of the disabled children that are brought for the rehabilitation therapy were diagnosed with cerebral palsy (CP). According to National council for Persons with physical Disabilities, SA (2014), CP is more prevalent in rural areas than urban areas in SA. According to Center for Disease Control, (CDC), cerebral Palsy is the most common childhood disability (CDC,2015). It is also reported that most CPs are boys compared to girls (CDC, 2015).

The results further revealed that most of the caregivers that brought the disabled children at the rehabilitation therapy clinic were the parents of the disabled children. This is probably because they needed to be part of treatment of their children and to pay close attention in their children's condition so that they facilitate functional independency faster.

The results revealed that the rehabilitative team conducted home visits, mainly once in a while, some even saying they do so once a year. Home visits form a significant part of rehabilitation, and therefore, needs to be frequent in order to curb the complications such as contractures and facilitate function within the child's environment. Home visits ensure that the therapist is able to determine how the disabled child relates to his environment and this relationship influences the care of the disabled child (Cummins, 2001). According to Crews and Talley (2007), relationship among the caregivers, professionals and the disabled child is acknowledged and valued in terms of associated responsibility of the caregivers and needs.

Therefore, the rehabilitation therapy team need to do more home visits and assist in the adjustment of the homes when they visit the disabled children in order for the assistive devices to be propelled or used properly without any limitation by uneven area (Werner, 1999).

The results further revealed that caregivers noticed medical problems of their disabled children whilst at home than at the hospital.

The reasons can be:

- The caregivers are the ones that spent most of the time with their children and see all the developmental stages of the child.
- Average length of stay in the hospital is 3 to 4 days and it is an acute hospital.

5.2.1 Factors related to caregivers that contribute to the development of complications

According to WHO (2012) there are wide range of biological and environmental factors that can contribute to the development of complications on the children's disability. The study revealed that home programme done by the caregivers, psychological aspects of the disability of the caregivers's disabled children, traditional beliefs of the caregiver towards the disability of their disabled children, disability screening done by the rehabilitation team on the disabled children, availability of resources to participate in rehabilitation therapy and support to caregivers all contribute to the development of complications, even though the children are brought for rehabilitation therapy and caregivers are trained on how to take care of their children at home.

- **Home programme done by the caregiver**

The study showed that most caregivers were not sure about the home programme given to them by the rehabilitation team and few presented with different complications. Few of the caregivers indicated that the home programme was not clearly demonstrated to them and only a quarter presented with complications. May be more workshops should be provided to the caregivers. The importance of home programme is emphasized by Cullen and Barlow (2004) when they point out that doing home programme every day as prescribed can limit the development of complications. Access to different home programme from health care services such as health care and rehabilitations therapy plays a significant role in determining child health, development and basic treatment for common childhood illness (Richman et al, 2008).

The current study indicated that there is no association between prescribed home programme and development of complications.

- **Psychological aspects of the disability of the caregivers' disabled children**

The results indicated that just under half of the caregivers reported that they understood the psychological aspects of the disabled children. According to Finkelstein (1990), understanding the psychological aspect of the disabled

child will benefit the caregiver so that they can motivate the child to reach their utmost best in their rehabilitation. Reichman et al., (2008) suggested that living with a disabled child can have a devastating effect to the entire family, which implies financial costs and emotional demands. Therefore, understanding the psychological aspect of the child assists with how families cope with the child's disability. In some instances, parents blame themselves for the disability, and view disability as a curse and tragic; therefore family members feel guilty and ashamed with their disabled children (Supple, 2005). In most instances, such children are left or hidden at home to avoid community backlash and therefore missing the opportunity for the child to interact with other people and stimulate the child's mental capacity. Hommel et al., (2000) further suggest that psychological factors should be incorporated into the overall rehabilitation of the disabled child in order to facilitate cognitive acumen of the child. The results of the study show that there is no association between psychological aspects of the children disability and the development of complications.

- **Traditional belief**

The results showed that less than half of the caregivers believed in their traditions. Some community members do not draw a clear line between their culture and religion. According to Salmons (2007) rehabilitation therapy team and hospitals face challenges and great opportunities as they work with caregivers of the disabled children from diverse and complex traditional belief backgrounds. Caregivers do not perform given home programmes because they believe that their childr are a curse and failing to perform home programmes lead to complications such as contractures , malnourishment and even death.

According to Laird (2006) there is nothing about evolutionary theory which encourages or discourages belief in the supernatural, there is also nothing about it which deals with prayer. Whether a person prays or not is as irrelevant in evolution as it is in other fields of the natural sciences. This can be because they focus on traditional belief and not on rehabilitation therapy as required by the hospital staff; a quarter of caregivers were not sure of what to believe in because according to the caregivers their disabled children are cursed and very few presented complications, most caregivers did not believe in their traditions and few of those that did not believe in traditions had complications.

In the current study it is indicated that there is no association between traditional belief and the development of complications.

- **Disability screening by the rehabilitation team**

The results of the study illustrated that a third of the caregivers were not sure of the disability screening done by the rehabilitation team and only few of the ones that indicated they were not sure presented children with complications. A third of the caregivers also reported inadequate disability screening was done to them because they were visited once a year instead of on a monthly basis. Few from those that they were visited presented children with complications and a quarter of the caregivers reported adequate disability screening was done and from those that reported adequate screening was done few of them had children with complications. Some children's disability could be detected during pregnancy as there was access to prenatal screening, while other impairments could be identified during and after birth (WHO, 2012). Most of the medical problems were found by the caregivers at home, before the screening can be done by the rehabilitation therapy.

Many children with disabilities are unable to express themselves when feeling the pain, meaning that there is no warning sign. It is only through daily rigorous prevention that complications like pressure sores can be screened at an early stage (WHO, 2008). Complications can be prevented by screening and monitoring home programme of the disabled child (Richman et al, 2008). The current study indicated that there is no association between disability screening and the development of complications

- **Availability of resources**

The study indicated that just less than half of the caregivers who participated in the study reported that there were available resources. Almost half of them had developed complications, one third of the caregivers were not sure if the resources were available for the proper rehabilitation therapy and few of those were not sure if the resources were available. This could be because they were not sure of the available resources for rehabilitation therapy, just under a quarter of the caregivers said there were no available resources and nobody from those reported children with complications.

Philpott and McLaren (2011) mention that in order for caregivers to care for and support their disabled children, parents need to know their rights and responsibilities and what resources are available to them. In the current study the caregivers are visited once a year. According to WHO (2012) involvement of caregivers and their disabled children in all early childhood development activities is needed in the community including policy development, health services design, and home programme monitoring.

According to WHO (2011) resources such as staff, transport, equipments, assistive devices and other consumables are needed to provide rehabilitation to the community. This encourages and build strong partnership between caregivers and rehabilitation therapy to ensure early child development services relevent to children with. The current study revealed that there is association between availability of available resources and the development of complications.

- **Support to caregivers**

The study indicated that more than a third of the caregivers got adequate support to take care of their disabled children and few of those who got adequate support presented children with complications. According to CDC (2015) children with disabilities should be supported by the rehabilitation team and the community support services who work together to help the disabled child and the caregivers to reach their goals of caring. Almost half of the caregivers were not sure of the support they received, possibly because they were not sure of what to expect and few of those who were not sure of the support they received had children with complications and less than a quarter of the caregivers reportedly got inadequate support with just one case reporting children with complications. Singer et al. (2009) noted that caregivers with disabled children need support from family members. This collective support will help in providing proper care to the disabled child.

The current study indicated that there is no association between support to caregivers and development of complications. According to WHO, (2011) support to caregiver of the disabled child is very important in the rehabilitation therapy.

5.2.2 Complications that the disabled children present with.

The results of this study indicated that most of the disabled children are diagnosed with cerebral palsy, as it was a common condition that was seen by the rehabilitation team during the study period, and few of those CP had contractures, malnourishment and other physical complications. In Hydro/micro-cephalous diagnose one of them had contractures complications; in developmental delay diagnose one of them had contractures complications; in congenital deformity diagnose of the lower limbs , few of them had contractures complications; in neurological diagnose one of them had contracture complications.

The results indicated that in each diagnosis there were complications that the disabled children were brought with at the rehabilitation therapy. One third of the disabled children brought by the caregivers had contractures, malnourishment and other physical complications. Most of the disabled children brought by the caregivers had no complications.

Rehabilitation therapy offered at Elim Hospital aims at preventing the development and further development of complications as Cullen and Barlow (2004) emphasize that the rehabilitation therapy of neurological conditions focus on preventing long-term complications like pressure sores, contractures, and other physical deformities that limit the expected daily physical function.

The above mentioned diagnoses are brought to the rehabilitation therapy so that complications such as pressure sores, contractures, malnourishment, and other physical deformities can be monitored and prevented.

The study revealed that home programmes carried out by the caregivers, psychological aspects of the disability of the caregivers' disabled children, traditional beliefs of the caregivers towards the disability of their disabled children, disability screening done by the rehabilitation team on the disabled children and support to caregivers are not caregiver factors that contributed to the development of complications. There was no association between caregiver factors and the development of complications. Availability of resources was the only factor that contributed to the development of complications as has been indicated earlier that there is an association between availability of resources and the development of complications.

5.2.3 To establish the level of skill of caregivers in executing the rehabilitation home programme

The result showed that observed skills presented as follows:

- Poor = 3 caregivers scored 30% and less.
- Satisfactory = 1 caregiver scored from 31% to 49%
- Good = 48 caregivers scored 50% and above.

This can be because the majority of the caregivers perform well when they see the rehabilitation therapy team, the result indicated a score of more than 50%, which shows that the performance of the rehabilitation therapy skill was good. Disabled children succeed best in the rehabilitation therapy when caregivers are actively engaged in performing rehabilitation therapy skill and involved in enjoyable "hands-on" experiences (Werner, 1999). WHO (2008) further add that rehabilitation therapy sessions are designed to be play-based, interactive and fun for the disabled child. WHO (2008) further mention that rehabilitation therapy sessions include coaching on techniques and methods that caregivers can use at home, during daily routines activities to promote, improve, maintain and support disabled children's optimal development.

5.3 Limitation of the study

The study focused on caregivers of disabled children whose disabled children are attending rehabilitation therapy at Elim Hospital. The research was only valid for the context within the Elim Hospital and may not be generalized although congruence with secondary data may indicate wider generalization.

5.4 Conclusion

The study aimed to investigate factors that contribute to the development of complications in disabled children at Elim Hospital in Limpopo Province. The researcher identified the following research question:

What are the factors that are related to caregivers which contribute to the development of complications in disabled children at Elim Hospital?

The rehabilitation therapy team of professionals and caregivers of the disabled children can play an extremely important role in “community-directed rehabilitation” (WHO 2012). By simplifying and sharing knowledge and skills, they can reach many more disabled children, but to do this home visits are needed. Rehabilitation therapy teams need to meet and work with caregivers on their terms, as learners, teachers and information providers. They can also help caregivers, parents, and other concerned individuals to organize small rehabilitation centres in the community.

If caregivers had skills in taking care of the disabled children, they can teach those who have interest to take care of the disabled children in their family so that they can continue with the rehabilitation therapy. Werner (2009) notes that caregivers can teach other caregivers to improve low-cost designs for rehabilitation aids and toys. He further states that this can encourage village leaders to improve paths and entrances to schools and public places for the disabled children. Rehabilitation therapy training is important and that those who received proper training can help the ones that reportedly received improper training, thus avoiding common complications.

5.5 RECOMMENDATIONS

Based on the results of the study the following are recommended:

- Home visits by the rehabilitation therapy team are needed every month to transfer the skills and for disability screening. This helps in identifying the need for assistive devices, thus helping the caregiver on improving skills and knowledge.

- Monitoring of children with disability should be done in the clinics. Nurses and rehabilitation staff should be identified so that they monitor the home programme. This will help the caregivers get proper support needed in care giving.
- Nurses and doctors should do a thorough assessment when discharging mothers of the new born babies after delivery, because according to the study findings most of the medical problems were identified by the caregivers at home.
- Frequent workshops are needed for caregivers to be able to run proper home programmes and to understand what resources are needed on the conditions of their children.
- Insight or support groups by the caregivers should be formed so that the caregivers of the disabled children have knowledge on how to start support groups in the community.
- Information on different diagnosis should be given during community meetings; imbizo and others community gatherings , this increase skills and knowledge and reduce the confusion on the prognosis of the diagnosis.
- Information on special schools and Day Care Centres should also be provided to caregivers so that they are able to go and work for their children.
- Caregiver should be encouraged to perform rehabilitation therapy of their disabled children, so that when school placement time arrives there are no complications and the child can be independent in all spheres of life (personal management, social, leisure and play).
- The Department of Health should have enough budget to provide the needed assistive devices to cater for the special needs of the disabled children. According to the findings of the study most of the disabled children do not have assistive devices.
- Rehabilitation team members, nurses, doctors should do a proper referral system to avoid some medical problems being identified at home by the caregivers. Collaboration is needed to avoid development of complications.
- Studies on how taxi drivers feel about transporting a caregiver with disabled children while carrying assistive devices should be made.
- Children with disabilities should be able to attend special schools and Day Care Centres which are closer to their homes for the caregiver to be able to look after them daily.

- Clinics, hospitals, villages and disabled child 's home should be accessible, especially for the caregivers and their disabled children that are using buggies, rollator, walking devices and wheelchair..
- There should be community awareness programmes so that people from the community are able to collaborate with caregivers of the disabled children, to show community support.
- Community income generating projects should be initiated by the caregivers of the disabled children to prevent them from being totally dependent on social grants.
- Day Care Centres for the disabled children should be initiated by the caregivers of the disabled children. This effort will benefit the caregivers themselves as well as the disabled children. Out of this exercise, strong support groups can emerge.
- Hospital and provincial budgets should be revised so that it can be enough to purchase suitable resources to render rehabilitation therapy.
- Dedicated transport as part of the resources is needed for the rehabilitation therapy.

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APPENDICES

APPENDIX: 1 QUESTIONNAIRE.

SECTION A

(i) DEMOGRAPHIC INFORMATION OF THE CAREGIVER

Your responses will be used for statistical purposes only. Confidentiality is guaranteed. Please answer the following questions by putting a cross (X) in the relevant block or by writing down your answer in the space provided. Please mark only one item per question.

1. Gender

Male	1
Female	2

2. How old are you?

	1
--	---

3. How would you describe your economic status?

Self-employed	1
Pensioner	2
Social grant	3
Granting aid	4
Earning a salary	5

4. Your highest educational qualification

Grade 11 or lower	1
Grade 12	2
Diploma/Degree or Certificates	3
Postgraduate degree	4

5. Diagnosis of the child

Cerebral palsy	1
Hydro/micro-cephalous	2
Developmental delay	3
Congenital deformity of lower limbs	4
Other neurological conditions	5

6. Relationship with the disabled child

Parent/Parents	1
Grandchild	2
Sibling	3
Aunt	4
Cousin	5

(ii) DETAILS OF THE DISABLED CHILDREN**7. The disabled child's medical problems was first seen by**

Doctor	1
Nurse	2
Rehabilitation team member	3
Caregiver	4

8. The disabled child's medical problems was seen in the

Hospital	1
Clinic	2
Home	3
School	4

9. At what age was the child when you discovered that he or she has a disability?

0-5 years	1
6-10 years	2
11-15 years	3
16-18 Years	4

10. How often does the Rehabilitation Team visit your disabled child?

Daily	1
Weekly	2
Monthly	3
Yearly	4
Not visited	5

SECTION B

Please answer the following questions by putting a cross (X) in the relevant block. This section of questionnaire determines caregiver's factors that contribute to the development of complications.

11. How often does the Rehabilitation Team visit your village?

Daily	1
Weekly	2
Monthly	3
Yearly	4
Not visited	5

Below is the continuation of the questions of the above objective. Please mark only one item per question.

A=Agree, D=Disagree, NS=Not sure

	Home programme	A	D	NS
12.	The caregivers understand the role of rehabilitation team members.	1	2	0
13.	The rehabilitation team clearly explain their role to the caregivers.	1	2	0
14.	The rehabilitation team explain the importance of having home programme.	1	2	0
15.	The home programme is clearly demonstrated to you each time you come for the visit	1	2	0
16.	The rehabilitation team gives you the chance as the caregivers to demonstrate the home programme as well so that the caregivers will leave the treatment room knowing what to do at home.	1	2	0
17.	The rehabilitation team present themselves in such a way that the caregivers feel free or comfortable to ask questions for clarity.	1	2	0
	Psychological aspects			
18.	The caregiver understands the disability of the child.	1	2	0
19.	It took sometime for the caregiver to understand the condition or the disability of the child.	1	2	0
20.	The caregiver feels that this child is a burden to you and others in the family.	1	2	0
21.	The caregiver has many people to socialize with.	1	2	0
22.	The caregiver has time to attend community meetings, imbizo and other gatherings.	1	2	0
	Traditional belief			
23.	The caregiver takes your child to the traditional healer.	1	2	0

24.	The caregiver believes that the child has been bewitched.	1	2	0
25.	The caregiver feels that the child is a symbol of a curse.	1	2	0
26	The child is protected by supernatural forces.	1	2	0
	Disability screening			
27.	Rehabilitation team visit the home of the disabled child.	1	2	0
28.	The caregivers followed the entire immunization programme.	1	2	0
29.	The disabled child cried immediately after birth.	1	2	0
	Availability of resources			
30.	The caregiver receives assistive devices during your rehabilitation therapy.	1	2	0
31.	The rehabilitation team members are always available on your appointment date.	1	2	0
32.	The caregiver receives a disability grant.	1	2	0
33.	There is enough space to do rehabilitation therapy.	1	2	0
34.	The child has activities made by low cost materials.	1	2	0
	Support to caregivers			
35.	The rehabilitation therapy team members assisted you to belong in a support group.	1	2	0
36.	The caregiver thinks that you are benefiting from the rehabilitation therapy.	1	2	0
37.	The caregiver sometimes fails to comply with the home programme due to lack of support.	1	2	0
38.	Family members give you enough support with regard to your disabled child.	1	2	0
39.	If the child is attending a special school, are the rehabilitation team available in that special school?	1	2	0

SECTION C

This questionnaire is asked to screen all the disabled children for complications.

	Rehabilitation therapy training by the rehabilitation team.	A	D	NS
40.	The caregiver receives stimulation therapy training.	1	2	0
41.	The caregiver receives muscle strengthening therapy training.	1	2	0
42.	The caregiver receives perceptual therapy training.	1	2	0
43.	The caregiver receives feeding therapy training.	1	2	0
44.	The caregiver receives play therapy training.	1	2	0
45.	The caregiver receives hearing and auditory therapy training.	1	2	0
46.	Training for using wheelchair was done after issuing.	1	2	0
47.	Training for using buggy was done after issuing.	1	2	0
48.	Disabled children handling was shown to the caregiver.	1	2	0
49.	Attending of support day care centre and special school has more training on handling a child.	1	2	0
50.	Every family member can continue with the rehabilitation therapy training.	1	2	0
51.	Rehabilitation therapy training by the rehabilitation therapy team is available in the village or local clinic.	1	2	0

SECTION D

This observation checklist is used to establish the level of skill in executing the rehabilitation home programme.

	Knowledge and practice			
	Observation checklist	Yes	No	N/A
52.	The caregiver can correctly position the child while playing/during therapy.	1	2	0
53.	Executes exercises correctly (Stretching, facilitation head control, facilitation of sitting).	1	2	0
54.	The caregiver can correctly position the child on an assistive device.	1	2	0
55.	The child can sit.	1	2	0
56.	The child can crawl.	1	2	0
57.	The child can walk.	1	2	0
58.	The caregiver can carry the disabled child appropriately on her back.	1	2	0
59.	The caregiver communicates appropriately with the disabled child.	1	2	0
60.	The caregiver can make eye contact and understand the child.	1	2	0
61.	The child uses assistive devices.	1	2	0
62.	The child looks clean.	1	2	0
63.	The child has bedsores, physical deformity, contractures.	1	2	0
64.	The caregiver was patient or not in a hurry during the session.	1	2	0
65.	The caregiver looks sad/ unhappy during the session.	1	2	0

APPENDIX: 2 INFORMED CONSENT

I hereby confirm that I have been informed by the investigator, Naledzani Rosemary Mulugo about the nature, conduct, benefits and risks of this study. I have also read the above information regarding this study.

I may withdraw my consent as well as my participation in the study and declare that I had sufficient opportunity to ask questions and therefore declare myself prepared to participate in the study.

Parent/guardian's Name _____

Parent/guardian's signature _____

Date _____

Investigator's name

Investigator's signature _____ **Date**

I, Naledzani Rosemary Mulugo herewith confirm that the above patient has been informed fully about the nature of the study.

Witness name _____

Witness signature _____ **Date** _____

UNIVERSITY OF LIMPOPO
Medunsa Campus



MEDUNSA RESEARCH & ETHICS COMMITTEE

CLEARANCE CERTIFICATE

MEETING: 07/2014
PROJECT NUMBER: MREC/HS/271/2014: PG

PROJECT:

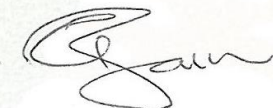
Title: Caregiver factors that contribute to development of complications in disabled children in Elim hospital, Vhembe district of Limpopo Province

Researcher: Ms NR Mulugo
Supervisor: Prof NP Mbambo - Kekana
Co-supervisor: Mr MP Kekana
Department: Medical Science, Public Health & Health Promotion
School: Health Sciences
Degree: MPH

DECISION OF THE COMMITTEE:

MREC approved the project.

DATE: 04 September 2014

pp. 

PROF GA OGUNBANJO
CHAIRPERSON MREC



The Medunsa Research Ethics Committee (MREC) for Health Research is registered with the US Department of Health and Human Services as an International Organisation (IORG0004319), as an Institutional Review Board (IRB00005122), and functions under a Federal Wide Assurance (FWA00009419)
Expiry date: 11 October 2016

Note:

- i) Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee.
- ii) The budget for the research will be considered separately from the protocol. PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.



LIMPOPO
 PROVINCIAL GOVERNMENT
 REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Latif Shamila

Ref:4/2/2

Mulugo NR

University of Limpopo
 Medunsa

Greetings,

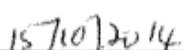
Caregiver factors that contribute to development of complications in disabled children in Elim Hospital, Vhembe District of Limpopo Province.

The above matter refers.

1. Permission to conduct the above mentioned study is hereby granted.
2. Kindly be informed that:-
 - Further arrangement should be made with the targeted institutions.
 - In the course of your study there should be no action that disrupts the services.
 - After completion of the study, a copy should be submitted to the Department to serve as a resource.
 - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
 - The above approval is valid for a 3 year period.
 - If the proposal has been amended, a new approval should be sought from the Department of Health.

Your cooperation will be highly appreciated.


 Head of Department


 Date



LIMPOPO
 PROVINCIAL GOVERNMENT
 REPUBLIC OF SOUTH AFRICA

**DEPARTMENT OF HEALTH
 ELIM HOSPITAL**

Ref: S5/2/5/1
 Enq: Chauke N.E.
 Date: 28.10.2014

LIMPOPO PROVINCE
HUMAN RESOURCES MANAGEMENT
2014 -10- 28
P/BAG X312, ELIM HOSPITAL, 0960 DEPT. OF HEALTH & SOCIAL DEVELOPMENT

To: Mrs Mulugo (Mpilo) N.R.
 CC: Senior Clinical Manager.
 CC: Deputy Director: Allied Health Services.
 CC: Acting Deputy Manager: Nursing Services.

**RE: PERMISSION TO CONDUCT A RESEARCH OF CAREGIVERS
 FACTORS THAT CONTRIBUTE TO DEVELOPMENT OF
 COMPLICATION IN DISABLED CHILDREN AT ELIM HOSPITAL.
 MPH: UNIVERSITY OF LIMPOPO: YOURSELF.**

1. The above matters refers.
2. Request of your receipt for permission to conduct a research study is hereby acknowledged.
3. Kindly be advised that there is no objection as the Head of the Department has granted you the opportunity to conduct your study research.
4. The research will commence as soon as the permission has been granted.
5. Thank you.


 CHIEF EXECUTIVE OFFICER

29/10/2014
 DATE



University of Limpopo
Department of Languages
Private Bag X1106, Sovenga, 0727, South Africa
Tel: (015) 268 3069, Fax: (015) 268 2868, Email:
lukas.mkuti@ul.ac.za

29 October 2015

TO WHOM IT MAY CONCERN

**Subject: EDITORIAL WORK FOR MULOGO, N.R. (19761284)
RESEARCH PROPOSAL**

This letter serves as proof that I edited Ms N.R. Mulugo's research proposal entitled "CAREGIVER FACTORS THAT CONTRIBUTE TO DEVELOPMENT OF COMPLICATIONS IN DISABLED CHILDREN IN ELIM HOSPITAL, VHEMBE DISTRICT OF LIMPOPO PROVINCE IN SOUTH AFRICA".

Yours faithfully

DR L.D. MKUTI
HOD: DEPARTMENT OF LANGUAGES