THE IMPACT OF THE REHABILITATION PROGRAMME FORCEREBRAL PALSYPATIENTS ADMITTED INTO A CARE CENTRE, MOPANI, SOUTH AFRICA.

BY

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A mini-dissertation submitted in partial fulfilment of the requirements for the degree of Master of Public Health (MPH) at the University of Venda, Thohoyandou 0950, Limpopo province, South Africa.

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DECLARATION

I, Jamela Ngoveni hereby declare the dissertation titled **"The impact of rehabilitation programme for cerebral palsy patients admitted into care centre, Mopani, South Africa"** has not previously been submitted for a degree at this university or any other university and this is my own work in design and execution. All references materials contained therein have been duly acknowledged.

Ngoveni J

Signature _____Date _____

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DEDICATION

This work is dedicated to God Almighty who against all odds gave me courage, wisdom and strength to pursue this degree. To my best friend who gave me support in all aspects during the period of my studies and to my two sons Hlonipho and Khanimamba for understanding and encouraged me to work hard in my studies.

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ABSTRACT

Worldwide there are millions of children and adolescents with adisability. The United Nations Children's Fund estimates the worldwide prevalence to be 150 million children under 18 years older, the World Health Organization also estimates that there are 93 million children with impairment.

This study focused at describing the impact of rehabilitation programme for the young adult living with cerebral palsy admitted in a care centre Mopani District, South Africa.

The study utilized a quantitative, descriptive cross-sectional survey method. Data was collected using an observational check list. The target population is young adults' aged 18-35 yearswith cerebral palsy in a Care Centre. Sampling was not necessary in this study since the targeted population was small in number. Confidentiality of respondents' information was maintained where study subjects wereidentifiedusing codes. Data were analysed using descriptive statistics and the results of the analysis are presented in the form of tables and charts to enhance clarity. The results are presented according to the objectives. The conclusion and recommendationswere made based on the findings.

Key words: care centre, cerebral palsy, impact, programme, rehabilitation, young adult.

The study results show that there were more females than males (ratio 3:1) and the range of age distribution was 20 to 37 years. The study also finds out that cerebral palsy condition was accompanied by other complications such as blindness, mental retardation, epilepsy and hydrocephalus. The study indicated that rehabilitation can only have minimal effects but it can improve the quality of life of the patient. With regard to communication outcome of the rehabilitation programme it indicates progress following rehabilitation between 57% and 80% could use expressive language and follow basic instructions. The study also observed that patients made a steady improvement right through from those who spent 4 to 8 years to those who had been there for long, 15 years and above. Since cerebral palsy can affect motor development as well as social development, the rehabilitation seems beneficial to focus on intervention programme on the cognitive stimulation of children and young adults with cerebral palsy.

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ACRONYMS

ACRWC------ African Charter on the rights and welfare of the child

ADL ---------- Activities of daily living

CBR --- -------- Community based rehabilitation

CP--- ---------- Cerebral palsy

ICF--- ---------- International classification of functioning

KZN ----------Kwazulu- Natal

QOL ----------Quality of Life

UN ------ ------United Nations

UNICEF ----------United Nations of Children's Fund

UNCRC----------United Nations Convention on the Right of the Child

UNCRPD----------United Nation's convention on the Rights of Persons with Disabilities

WHO------- ------World Health Organisations

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INTRODUCTION

1.1. Background of the Study

Worldwide there are millions of children and adolescents with a disability. The United Nations Children's Fund (UNICEF, 2005) estimates the world prevalence to be 150 million children under 18 years and older. The WHO (2011) states that in these countries particularly, having a disability hinders access to education, health care and special care. The International Classification of Functioning disability and health (ICF) defined disability as an umbrella term encompassing the outcome of the interaction between a person's impairments, activity limitations or participation restrictions and environmental factors that affect these domains (WHO,2012).These statistics also include cerebral palsy.

The global prevalence of cerebral palsy is between 0.2 and 0.3 percent (McLaren, et al, 2004).In Australia the crude prevalence of CP is 2 to 2, 5 per 1000 live births; in Sweden it is 2.18 per 1000 live births. Unfortunately very little is known regarding the prevalence of cerebral palsy in developing countries. The cerebral palsy Association of Eastern Cape, based in Port Elizabeth (2013, estimates that one in 400 babies born each year present with cerebral palsy (giving an estimate of 2 200 children diagnosed with cerebral palsy annually in South Africa). There is evidence that the occurrence of cerebral palsy is increasing due to the survival of low birth weight and vulnerable premature babies (before 40 weeks), linked with the goal of reducing infant mortality rates (Maulik and Darmstadt, 2007).

The UN Convention on the Rights of Persons with Disabilities has stated that comprehensive rehabilitation services involving different types of interventions, including medical and social, are needed to ensure the equal rights and participation of people with disabilities in the society. WHO (1997) have defined quality of life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationships to salient features of their environment. The impact and outcomes of rehabilitation on quality of life varies worldwide. A person's ability to transcend his or her physical limits is in no small part due to the kinds of therapies that are used to fine-tune his or her abilities. Rehabilitation fosters functionality, mobility, fitness and independence. The types of therapies vary, based on a person's unique needs, type of cerebral palsy, extent of impairment and associative conditions. Therapy is identified as one of the aspects that can assist parents and care-givers of children with

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disabilities. Rehabilitation for children with cerebral palsy should be appropriate for the age and functional condition of the patients. The aim of cerebral palsy rehabilitation should minimize disability and promote independence and social participation. The management of cerebral palsy (CP) is dependent on the child's specific symptoms. Children with cerebral palsy are at high risk of peer rejection and social isolation. The main goal of rehabilitation of CP is therefore to maximise active participation of young adult in the society (Sorsdahlet al, 2010).

In Alabama a quasi-experiment study was conducted where-by twenty-six participants were categorized as follows: twelve ambulatory and fourteen non-ambulatory, ten were males and sixteen were females, with the mean age of 42.3+11.2 years. The participants enrolled in a study using a repeated measures design, including baseline. Intervention and follow-up phases of twelve weeks each were provided and, twenty participants completed all the phases. The primary outcome measures used were pain scale, which refers to the count of body parts with pain. The purpose of this exploratory pilot study was to examine the effect of exercise on pain and fatigue of adults with CP. Significant beneficial changes were found in the pain and fatigue scales amongst the ambulatory participants during the intervention phase. However, the beneficial changes diminished during the follow-up phase. Secondary outcomes examined included, pain interference, daily physical activity and health-related quality of life. Therefore, study outcomes suggested that that exercises may provide some benefit for ambulatory adults with CP. Implications for rehabilitation pain and fatigue are secondary conditions experienced by many adults with cerebral palsy. These have a significant impact on function and quality of life. Physical activity is an intervention which has been demonstrated to decrease both pain and fatigue in other health conditions .In a relatively small sample this study demonstrated decreased pain and fatigue after an exercise intervention in ambulatory adults with cerebral palsy (Vogtle et al, 2014).

In a study done on the impact of rehabilitation on the quality of life in Posio Finland using an experimental design, it was found that the self- perceived health of the elderly and disabled persons improved for the experimental group. No changes were found for functional capacity, independence in household tasks, social participation and leisure activities. The primary costs of rehabilitation were lower for the experimental group, but secondary costs were the same. The researcher recommended better training of community rehabilitation (CBR) functionaries in evaluation as well as Involvement of outside experts, planning for evaluation at the beginning and having an interdisciplinary supervisory team (Mannan, 2007).

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Another study in a Vietnamese city looked at the effectiveness of home-based intervention based on the portage curriculum for pre-schoolers. The intervention involved eleven teachers from primary special education schools receiving training to enable them to train parents to work with their children with intellectual disabilities. A total of thirty children aged three to six years participated in the study with random allocation to the intervention. The Vineland adaptive behaviour scale parent survey form (VABS) was used to assess development over a one year intervention period with testing at 0.6 and twelve months. Repeated measures MANOVAs motor skills (F=3.9 p greater than 0.5) and daily living skills (F=2.7,p greater than 0.5)over a year. Further, the programme could not meet the needs of all children and one child was excluded from the study as his physical disability was too severe for him to receive the intervention service (Shin et al, 2009).

An evaluation study was done in Philippines and Zimbabwe to assess the impact of rehabilitation using a post –test only design. It was found that a large number of persons with disability(41%) was undiagnosed, based upon the coordinators rating of a client's progress it was noted that 16% demonstrated outstanding progress,79% steady progress and 5% showed little or no progress. Except for one, all the 136 participants found the program to be helpful. The study used a pre-test post-test design and found that ability scores after CBR training increased by 78% inthePhilippines and 93% in Zimbabwe. Likewise, about 26% of children with disabilities in the Philippines and 69% in Zimbabwe started school. In addition 61% of persons with disabilities were employed in the Philippines and 50% in Zimbabwe (Lagerkvist, 1992).

Another study was done in a slum near Lahore in Pakistan where-by a questionnaire from the WHO manual in a house–to-house survey was used to gauge the prevalence of disability and identify persons in need of intervention. Eighty- two persons were trained and revaluated after one to two years using the WHO questionnaire. It was found that 80% had made improvement in one or more areas of the program such as looking after self, moving around the house and attending school. Recently Dambi and Jelsma (2014) evaluated the impact of hospital-based and community- based models of cerebral palsy rehabilitation using a quasi-experimental study in Harare Zimbabwe. It was found that children receiving outreach –based treatment were significantly older than children in the institution-based group. Regression analysis revealed that once age and level of severity were controlled, children in the outreach based-treatment group improved their motor function by6% more than children receiving institution based services.

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A study on the unmet rehabilitation needs of children with disabilities in South Africa was conducted a decade ago. In a study of 156 disabled children conducted inaperi-urban township in Orange Farm, Gauteng a quarter (26%) of the 156 of children in need of rehabilitation had received such services in addition, of the 233 assistive devices required, only 64 (28%) had been issued. Children with motor impairments were found to be significantly more likely to receive rehabilitation than those with intellectual disability. Furthermore a study conducted in Manguzi in KZN found that the rehabilitation staff at the local hospital interacted with just 35 percent of the children requiring rehabilitation services. In addition 112 studies coordinated by the Department of Social Development in Mpumalanga in deep rural areas of Ehlanzeni.Nkangala and GertSibande Districts found that only 42 percent of the children with disabilities identified were receiving rehabilitation and 33 percent had the assistive devices they required. The other 59 percent reported that the caregiver did not know how to apply for an assistive device (Department of Social Development, 2012).

Zweigenthal et al (2014) asserts that rehabilitation is concerned with the prevention, reduction and elimination of impairments, activity limitations and participation restrictions and with helping to create a society that is accepting and accommodating towards disabled people. It further indicated that rehabilitation focuses on helping people help themselves to lead healthy lives, develop the abilities and skills they need to participate fully in their physical and social environments, regardless of their impairments that limit their functional ability and perform daily activities.

The Western Cape Provinceconducted a study to examine health conditions and support needs of persons living in residential facilities for adults aged 18 years with intellectual disability. It was suggested that such persons experience a wide range of health conditions (notably mental health and behavioural issues). Despite access to general health care, rehabilitation services in their adult years is neglected subject in the African context, despite international evidence that these individuals are at greater risk of poor physical and mental health than the general population. Furthermore, it was outlined that the wellbeing of people with disabilities is diminished by isolation, stigma and limited support provision, particularly on the African continent. (McKenzie, 2013).

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1.2. Problem Statement.

The researcher is a social worker who works in a study setting. During the course of her duty, she has observed with concern that within the community there are still young adults with intellectual disabilities (CP included) who are locked behind doors due to stigmatization. Their disability grant is used as a source of family income. In some cases, the familiesare not knowledgeable about the services available at the centre. As a result these disabled persons do not have access to proper care. The monthly and quarterly admission reports ofthe rehabilitation Centreshows that about 90% of young adults are still experiencing the same preadmission problemsinto the Centre. Hence In a bid to assess the care of the young adult with cerebral palsy in this Centre, the researcher saw it fit to assess the impact of the rehabilitation programme provided to the young adults with cerebral palsy. Therefore this study describes the impact of the rehabilitationprogrammeonthe quality of life of young adults living with cerebral palsy in the Care Centre.

1.3. Rationale of the study

Based on literature review, to the best of the researcher's knowledge, no study has been done which assessed the impact of rehabilitation services for cerebral palsy young adults in a Care Centre. Although cerebral palsy (CP) is a lifelong disability, the researcher has mainly focused on young children with cerebral palsy (Sandstrom, 2009). The use of community-based rehabilitation may be associated with positive and negative effects. The purpose of this impact assessment in the field of disability and rehabilitation is to create a critical mass of data to evidence the effectiveness of rehabilitative services in improving the lives of people living with disabilities in real terms. Thereis lack of evidence for the impact of interventions across development programmes and those studies that were conducted frequently failed to yield useful information because they did not use rigorous methods or data (Finkenflugel et al, 2008). Currently there is no known supporting evidence to justify community-based rehabilitation for cerebral palsy rehabilitation in Sub-Saharan Africa and South Africa. Therefore stronger-evidence based data is required to adequately inform health policy decisions and guide methods of service delivery to effectively improve cerebral palsy outcomes. It is clear that there is a need to improve the models of service delivery regarding the rehabilitation of adults with cerebral palsy.

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1.4. Significance of the study

The findings of this study may assist allied rehabilitation team about the importance of providing support to the young adult who is placed at the centre and the team's role in re-uniting the young adult and their family and implementing the care plan about the young adult. Furthermore, the study may help to improve theguidelines on the quality of life of young adults living with cerebral palsy. This information may be used to inform rehabilitation policy and practice, and set benchmarks for rehabilitation services that are comparable across programmes and interventions.

1.5. Aim

Is to assess the impactof rehabilitation programme on the quality of life of young adults living with cerebral palsy admitted into Shiluvana Care Centre, Mopani, South Africa

1.5.1. Objectives

The objectives of the study are as follows:

- To assessthe performance of basic activities of daily living by the young adults living with cerebral palsy who live in a Care Centre.
- To assess the level of communication of the young adults living with cerebral palsy in the care centre.
- To observe and record the level of participation of the study group regarding the physical and social skills being taught by the occupational therapist (ability to acquire simple physical & social skills).
- To assess the health-related quality of life of the young adults living in the Care Centre.

1.6. Definition of Key Concepts

Impact

Impact is defined as the positive and negative, primary and secondary long-term effects produced by a development intervention, directly or indirectly, intended or unintended.(KabzemandChimedza 2002).Thus impact assessments aim to assess the following questions:

- Has a programme/service/intervention achieved its basic aim?

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- What real difference did this programme/service/intervention make?
- Are observed changes a result of the programme? that is establishing causality, attribution

For the purpose of the study impact refers to observed and perceived changes in the quality of life of the young adult as a result of the rehabilitation services being offered by the Care Centre.

Cerebral palsy

Parkes and Hill (2010) explain that cerebral palsy is a group of motor impairment that affects voluntary movement and posture that has different causes, clinical presentations and implications for the child and family. In this study cerebral palsy refers to young adults diagnosed with cerebral palsy.

Rehabilitation

Rehabilitation is a process aimed at enabling people with disability to reach and maintain their optimal physical, sensory, intellectual, psychological and social functioning levels. Rehabilitation provides persons with disability with the tools they need to attain independence and self-determination (WHO 2013).In this study rehabilitation refers to the ability of young adults with CP since admission to a care Centre.

Young adult

In this study a young adult will be a patient admitted in a Care Centre between 18 and 35 years of age, who is living with cerebral palsy.

Quality of life

It focuses on aspects of life quality that are influenced by or that can influence one's health status directly. These aspects include symptoms of disease and treatment, side effects, treatment satisfaction, physical functioning and well-being, social functioning and life satisfaction and mental health including emotional well-being and cognitive functioning (Amy et al, 2016).

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2. LITERATURE REVIEW

2.1. Introduction

This chapter presents a review of literature related to this research. The literature review was done under the following sub-headings:

2.1.1. Cerebral palsy

It has been a challenge to define cerebral palsy, as noted by the different definitions that several authors have come up with. The executive committee for the definition of cerebral palsy describes it as follows: cerebral palsy describes as a group of permanent disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, by epilepsy and secondary musculoskeletal problems (Rosenbaum et al, 2007). According to Parkes and Hill (2010) cerebral palsy refers to a group of motor impairments that affect voluntary movement and posture, that have different causes, clinical presentations and implications for the child and family. Cerebral palsy is a disability that affects movement and body position of children, the part of the brain that controls movement is damaged and the damage does not get better. Cerebral palsy can be caused before birth through the mother's infection or illness, it can also be caused at birth if it occurred early or not getting enough air or sustained head injury during birth. Lastly it can also be caused after birth due to high fevers, brain infection, head injury, lack of oxygen, bleeding in the brain or brain tumours.

2.1.2. Global prevalence of cerebral palsy

World-wide it has been estimated that the incidence of individuals with cerebral palsy ranges between 2.0 and 2.5 per 1000 live births in developed countries (Hagberg and Hagberg, 2001). It is fair to assume that this data is not different from findings in other parts of the world; for instance, the prevalence of cerebral palsy in China is reported to be 1.6 per 1000 children under the age of seven. In the USA the prevalence stands at 2.12 per 1000 inhabitants with higher prevalence of males and non-significant higher prevalence in black people (Dolk, Patternden and Johnson,2001). It was also found that the prevalence in Australia stands at 2.0 and 2.5 per 1000 live births (Redibough and Collins, 2003), whilst in the United Kingdom the prevalence of CP is 3.3 per 1000 live births in the most deprived

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quartiles and 2.08 per 1000 live births in the most affluent. This is seen especially in African countries even though not much is known about the prevalence of CP in these countries (Shawky,Abakhali and Soliman, 2002).The prevalence of cerebral palsy in South Africa is not known, though a study on the incidence of cerebral palsy in rural South Africa estimated the incidence to be 2 and 3 per 1000 live births (Kromburg et al, 1997). Research has shown that potentially braindamaging illnesses are more prevalent amongst the poorer communities of developing countries (Kibel and Wagstaff, 1995).

2.1.3. Prevalence of cerebral Palsy in South Africa

Very little is currently known about the prevalence of childhood disability in developing countries (Couper, 2002). This lack of information has implications for health, rehabilitation, welfare, and educational services. These implications need to be researched and addressed appropriately in order develop suitable rehabilitation services within the South African context. Schleichkorn (1993) provides the following reasons for our limited knowledge regarding incidence and prevalence of cerebral palsy. Many children are only diagnosed with cerebral palsy in childhood and are therefore exempt from being accounted for in the health statistics of newborn infants. The incidence of cerebral palsy is likely to vary according to geographical areas as a function of the quality of pre-, peri-, and post-natal care.

There are several conditions present at birth, of which abnormal tone is a component, but for which another diagnostic classification is felt to be more appropriate for care and treatment purposes. While these are common areas of concern in compiling accurate and representative healthcare statistics, Schleichkorn (1993) fails to acknowledge the number of children born at home in rural areas, which may contribute to the inaccuracy of statistics, as well as the level of stigma attached to disability. Disabled People of South Africa (2002) reports that currently there are still many households who hide disabled family members in their homes, out of sight of the community as a means of escaping the stigma associated with disability. This is a harsh reminder of the level of shame associated with disability in South Africa, and is likely to be a factor associated with inaccurate statistics related to disability. Children with cerebral palsy living in poor and poor areas in South Africa are particularly neglected and underserved group. Although they qualify for government assistance in the form of care dependency grant, this money is usually the family's only source of income and not all the money is spent on the child. Caring for a child with cerebral palsy involves many additional costs not associated with non-disabled children trips to clinics and hospitals, special diet and disposable nappies

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In the rural district of Limpopo Province of South Africa, a poorer province with worse medical care compared to the province Mpumalanga, a prevalence of 35.6 per 1000 children with developmental disabilities in this population has been reported. Epilepsy (15.5%) and cerebral palsy (8.4%) were the most common associated disabilities in this group. The prevalence of cerebral palsy in rural South Africa has been set at 3 per 1000 children (Christianson et al., 2002).

Recently two South African studies (2002) indicated high prevalence rates for CP, 1.0 percent and 8.0 percent, but there is no recent data. The CP Association of Eastern Cape, based in Port Elizabeth, estimates that one in every 400 babies born each year present with CP (giving an estimate of 2 200 children diagnosed with CP annually in South Africa). There is evidence that the occurrence of CP is increasing due to the survival of low birth weight and vulnerable premature babies (before 40 weeks), linked with the goal of reducing infant mortality rates.

2.2. Impact of rehabilitation on people living with cerebral palsy

2.2.1 Impact of rehabilitation on quality of life among people living with cerebral palsy

Quality of life is used to describe a patient's condition at a level other than diagnosis (Colver et al 2003). The term quality of life has been defined as a subject centred or individually appraised perspective on health (Bullinger et al, 2005). Health-related quality of life is a multi-dimensional concept that includes a domain related to physical, mental, emotional and social functioning. It goes beyond direct measures of population health, life expectancy and causes of death and focuses on the impact of health status on quality of life. Health related quality of life was seen as an important outcome in the delivery of health care. Quality of life usually describes an overall assessment of well-being across various domains. Examples of domains that are covered when exploring quality of life are physical well-being, social well-being, emotional well-being, school, access to services and acceptance by other people (Waters et al 2005).

Cerebral palsy has a significant impact on one's quality of life .It affects all parts of daily life, from walking, to eating and sleeping. Overall cerebral palsy limits the independence of people diagnosed with it, making it almost impossible for them to live without help. Many people with cerebral palsy have problems in communicating, more especially problems with their speech not clearly understood by others or totally no speech at all. It compounds the challenges they face in terms of movement. Furthermore many people with CP experienced

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accompanying health issues, such as pain, scoliosis, joint dislocations and nutritional problems. This is empirically confirmed by the various studies:

Mc Manus et al (2008), in a study among children with cerebral palsy in South West Ireland, concluded that increased severity of impairment was associated with significantly diminished quality of life but only in relation to two domains; namely, physical well-being, which was 0.05 and social support and peers of 0.01. Respectively, children with mild, moderate and severe impairment had median scores of 65.0, 45.0 for physical well-being and 62.5, 50.0 and 40.0 for social support and peers. Independent of gender, age and level of impairment, overall participation in everyday activities had a significant effect on three quality of life domains. A one-unit increase in participation was associated with increases of 7.8, 4.5 and 13.9 in quality of life related to physical well-being, moods and emotions and social support and peers, respectively.

Two studies have been published so far by Gaskin and Morris (2010)of health-related quality of life in relation to physical activity in an Australian CP population. The two studies demonstrated that in general the patients had low levels of physical functioning and vitality. Jahnsen et al (2004) reported that their results in most domains of health-related quality of life were significantly lower in adults with CP than those in a Norwegian reference sample.

2.2.2. Impact of rehabilitation on social and physical participation of young adults living with cerebral palsy.

A growing interest has emerged to move beyond the improvement of body functions, capabilities and functional abilities of children with disabilities to include the prioritization of social participation as one of the major issue for rehabilitation services
(King et al, 2002). This may require identifying measures that can efficiently document the potential impact of rehabilitation interventions on social participation. The World Health Organization (WHO) defined participation as the nature and extent of a person's involvement in life situations and categorizes participation in terms of personal maintenance, mobility, information exchange, social relationships, home life, education, work and employment, economic life and community social and civic life (WHO,2001). According to the international classification of functioning, disability and health (ICF), participation is the involvement of a person in life-situations and is determined by impairment or limitations of activity, as well as by environmental and contextual factors (Morris et al, 2005). Articles 23-30 of the 2006 UN convention on the right of persons with disabilities, so far ratified by 34 nations has stated that people with disabilities should be able to participate on an equal basis with others in family life, health maintenance, education, public life and recreational, leisure and sporting

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activities. Participation leads to life satisfaction as well as a sense of competence and is essential for psychological and emotional well-being and skill development (King et al., 2006).

Few studies have been published on physical activity levels of adults with cerebral palsy. Turk et al (1997) has found that the health status of adult females with CP had a negative effect on exercise participation. Participants who have reported pain range at 84%; musculoskeletal conditions range at 59%; for bowel and bladder problems ,56% limited their participation in exercise in spite of these health problems, 83% of the 63 community-dwelling women with CP in the study engaged in at least one physical activity, including swimming, walking, weight-lifting and using exercise equipment. This scale includes activities such as writing letters and reading, both activities are more readily available for people with CP because of environmental modifications.

Stevenson, Pharaoh and Stevenson (2001) found that young adults with cerebral palsy were less socially active, participated in few leisure activities, and were more socially isolated than typically developing peers.Margalit (2011) studiedthe leisure activities of 51 children with cerebral palsy in comparison to children with no disability and found that the activities of children with cerebral palsy were mostly at home and dependent on adults. Their activities were limited and were suitable for younger children and encouraged a passive life style. The Researchers also have reported that children with physical impairment tend to engage in less varied leisure activities than children without disabilities. It was further argued that their participation is characterized by a greater frequency of quiet recreation activities and fewer social activities, especially social activities of a spontaneous nature. King et al (2006) reported that adults with disabilities participated more in self-improvement activities and showed a higher enjoyment level on this scale than boys with physical disabilities.

In a study six children with disabilities were interviewed in Canada to gain a better understanding of how they view their participation in out -of -school time activities in a range of environmental settings. The children identified aspects of their environments and activities that acted as supports or barriers to their participation. Environmental accessibility and physical comfort were noted as supports, social support alluded in the form of friends, friendly helpers, pets and neighbours. Finally participants, health statuses were recognised as a barrier to their participation in some of the settings (Harding et al, 2009).

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2.2.3. Performance of basic daily activities

Activities of daily living, in short ‘daily activities, is used as an umbrella term comprising those activities or tasks that people undertake in their everyday life.With respect to contents, daily activities are historically subdivided into personal care (for example, feeding, toileting, bathing, dressing), functional mobility (for example, ambulation, wheelchair mobility, bed mobility, transfers), and domestic and community tasks (for example, housekeeping, cooking, managing money, using the telephone.

In a study conducted by Van der Dussen et al (2011) at rehabilitation centre in The Hague in the Netherlands among 134 young adults a large percentages of young adults with CP indicated that there is no independence or difficulty in performing activities such as self-care activities, mobility and communication. In this study sample 75% of the participants were mainly independent with regard to activities of daily living. These percentages are comparable or higher than those who found in the literature. Again in a study of Turk et al (1997) among a group of community living women with CP aged 20-74 years, 50 percent were independent in self-care activities. In a study undertaken by O’Grady et al (1995), 71 patients with CP aged 17-51 years were interviewed. It was found that 79% of the group were able to use their hands adequately.

2.2.3.1. Importance of activities with people living with cerebral palsy.

Daily each one of us engages in activities of daily living (ADL). As adults we do activities on our daily living independently so, people with cerebral palsy or with impairment should be assisted to be independent in order to make their lives and family members easier. In the past years methods for independence have been involved universally to assist the person become as independent as possible in ADL.Assistive devices have been developed. Some of them are available but are expensive, yet families cannot afford to have them at home. However, they are found in occupational therapy departments at hospitals. Assistive devices must fulfil a purpose, be accepted and used otherwise. There are different types of assistive devices which assist people with disabilities CP.These assist with activities of daily living which include devices for dressing, bathing, grooming, and toileting, eating and cooking (Margaret et al, 2000).

Activities of daily living encourage the child or person with cerebral palsy to move differently so that they do not get stiff. These activities also encourage better way of moving to change muscle tone, help to control movements, help everyday activities like dressing and feeding.

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People with cerebral palsy feel better if they move and blood circulation moves effectively and the people will breathe more easily.

2.2.4. Communication of people with cerebral palsy

Regarding communication three quarters of the people in most studies have indicated that they had no difficulty in making themselves understood by means of speech. Children with CP are at risk of communication difficulties due to motor, language, cognitive and sensory perceptual impairments (Light and Drager, 2007)). These communication difficulties influence the child's ability to interact and engage with their environment. Children with CP and complex communication difficulties demonstrate reduced participation in social activities compared to their non-disabled peers (Thirumanickam et al, 2011).

Children with cerebral palsy may have difficulties in acting as a sender and or a receiver of messages in communication. Motor impairments can limit the intelligibility of speech and gesture and the ability to write using either a pen or a computer. Cognitive impairments can cause delayed spoken and written language development. Visual impairment can affect language development and interpersonal interaction. Hearing impairments impact on speech perception, development, spoken and written language. Epilepsy can affect cognitive and language processing. Communication development may also be affected by reduced experience of the world and limitations in activity imposed by the impairments above (Pennington et al 2008).

2.3. Professional rehabilitation services provided to cerebral palsy adults

There are many specialities in rehabilitation. Ideally team members work alongside one another so that they can support and promote each other's work for the maximum benefit of their clients. The following table summarizes rehabilitation professionals and their main focus and all professionals must be registered with the South African health professional council before they interact with the public.

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Table 1. Rehabilitation professions and service focus

Rehabilitation Profession	service focus
1.Hearing therapy or Audiology	Health promotion and prevention of hearing loss and balance disorders. Assessment and management of hearing balance, function and communication of individuals with hearing impairment.
2.Occupational therapy	Enabling occupation: this means finding practical solutions to the challenges that people face in doing the familiar, ordinary things that they need and want to do.
3.Physiotherapy	The skilled use of movement techniques and other physical means for the prevention and treatment of injury and disease as well as the rehabilitation of function.
4. Speech therapy	Assessment and management of speech, language,non-verbal communication and swallowing disorders.

The above professionals are specifically meant to provide rehabilitation services. However nurses, doctors, social workers and psychologists are also very significant members of the multi-displilinary team (Zweigenthal et al, 2014).

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Hence the department of adult rehabilitation has limited experience in treating adults with cerebral palsy. A decline in the utilisation of health care between 18 years and adulthood shows a decrease in visits to allied health discipline of adult with cerebral palsy indicated that 32% visited their rehabilitation physician during the past year and 15% had seen a neurologist in that period. On average adults with cerebral palsy consulted a mean of 12 in the services of the allied health care and 1.1 for the services of medical specialists and physicians treating a large number of adults with cerebral palsy appear to be more sensitive to relate to some impairment to cerebral palsy. This suggests that the majority of rehabilitation physicians have limited knowledge about these adults and their needs (Sander et al, 2007).

People with cerebral palsy can be stimulated with conducive education and cognitive stimulation during the rehabilitation process and can be identified as follows: understanding complex relationship between young adults with cerebral palsy and personal and environmental contextual factors which either constrain or enhance their functional abilities, participation and quality of life. Most cerebral palsy does not adhere to a regular exercise programme of stretching and strengthening, and aerobics leads to further decline in functional (Sienko, 2014).

2.3.1. Conductive Education

Conductive education seeks to instil in the child both a desire and an expectation to exert independence. In practice, the day is carefully structured for young children by a conductor, who tailors a programme of activities that enable children to experience the learning and enjoyment that come from being "active, upright and interested in the world" (Rozsaheygi, 2006).

It is an effective way to stimulate children with cerebral palsy in their motor functioning and to teach them skills that are necessary in everyday activities. Dr Andreas Peto conceived the concept, conducive education (CE), in Hungary in the 1950’s in order to assist children with motor dysfunction to attain “orthofunction” which can enable them to attend school with maximum independence (Coles andZsargo, 1998). Hari and Akos (1988) described 'orthofunction'as that protean capacity involving the entire personality enabling the individual to satisfy the biological (and social) demands made upon him”.

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Conductive Education is based on an educational rather than a medical model of intervention and it integrates education and rehabilitation goals into one programme. The four main elements of conducive education are task-orientated learning within highly structured programme, facilitating motor actions by the structured use of rhythmic singing, integration, of manual abilities into context of activities of daily life and child-orientated group settings to facilitate psychosocial learning to increase the level of participation. According to the study by Blank et al. (2008), conductive education improves especially coordinative hand functions and activities in daily life in children with cerebral palsy. Hand functions play a key role in self-care and independence in self-care is a major goal of conducive education.

2.3.2. Cognitive Stimulation

Since cerebral palsy not only affects motor development but also the cognitive and social development. It seems beneficial to focus an intervention program also on the cognitive stimulation of children and young adults with cerebral palsy because one of the most important ways through which children learn and explore actively is play. Therefore, one could gain much insight into a child's cognitive development by observing play performance (Messier et al, 2008). Playing with toys helps children to master developmental and cognitive tasks (Hsieh-Chun, 2008).

2.4. Rehabilitation Strategies in South Africa

2.4.1. Community- Based vs. Institutional rehabilitation.

Community- Based Rehabilitation (CBR) has been promoted internationally for more than 30 years as a core strategy for improvement in the quality of life and services for people with disabilities: "Community Based Rehabilitation is a strategy within community development for the rehabilitation, equalisation of opportunities and social inclusion of all adults and children with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities and the appropriate health, education, vocational and social services." (UNESCO, 2004).

Community-based rehabilitation (CBR) is the strategy endorsed by WHO and other international organisations (ILO, IDCC and others) for general community development for the rehabilitation, poverty reduction, equalisation of opportunities, and social inclusion of people with disabilities, particularly in low- and middle-income countries (WHO, 2010). The

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concept was first introduced in the late 1970s (WHO, 1976; Finkenflugel, 2004) as a promising strategy to provide rehabilitation for people with disabilities in developing countries and as part of the broader goal of reaching 'Health for All by the Year 2000' (WHO, 1978).

Rehabilitation services have been traditionally provided through institutions. Institutions range from hospitals to specialized rehabilitation centres and homes for the disabled. IBR services further are divided into inpatient and outpatient services. Institution-based rehabilitation and outpatient services are models recognizable to most health professionals and the ones that have historically influenced education provision. These services have been driven and developed by health care professionals. Health care reforms are seeing an increasing emphasis on service user involvement in shaping future models of health service delivery (Stubbs 2002).

2.4.2. Educational rehabilitation

This rehabilitation provides learners with special needs with the best possible environment to learn develop and reach their potential. The special needs may include learning difficulties, emotional and behavioural problems and birth conditions such as cerebral palsy. Some children have special educational needs like poor vision or poor hearing and it cannot be met in mainstream schools some dedicated facilities exists for example in Limpopo we have Rivoni School for the Blind ,Yingisani and Letaba School for the Disabled.

2.4.3. Vocational rehabilitation

This type of rehabilitation aims to match the abilities of an impaired worker to the requirements of his or her jobs or to find a job that best matches what the worker can offer. The process includes the assessment of abilities some of which may need to be developed or re-developed and preparation for a return to full or part time work. Vocational skills training aimed at promoting general work skills, punctuality of patients, perseverance, responsibility, productivity and production speed. Vocational skills rehabilitation practitioners are being challenged by the trends and demand of poverty to think more about job creation.

2.4.4. Psychosocial rehabilitation

People with mental and emotional problems are helped through psycho-social rehabilitation to manage their thinking, feelings and behaviour. They are supported in their effort to live independently to build stable and healthy relationships. Psycho-social rehabilitation is offered in psychiatric hospitals, mental health clinics and centres at primary level public health care services and specialised mental health care centres. This rehabilitation is also provided by non-governmental organisations concerned with the needs of specific groups of

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people such as abused women, drug addicts, homeless people and people subjected to trauma and human rights abuse (Zweigenthalet al.2014)

2.5. Legal context

2.5.1. South African Constitution

The South African Constitution provides the framework for democracy in the country; it has been central to the transformation of society, away from one of racial segregation towards one in which the human rights of all citizens are recognised and protected. The Preamble states that its intention is to “heal the divisions of the past and establish a society based on democratic values, social justice and fundamental human rights … improve the quality of life of all citizens and free the potential of each person”. The Bill of Rights in the Constitution sets out the rights of all citizens, as well as the specific additional rights of children. The latter includes the right to family or parental care, or to alternative care when removed from the family environment, as well as to basic nutrition, health care services, social services and protection. According to the Bill of Rights, everyone has the right to basic education. Significantly, the Bill of Rights specifies the right to dignity, freedom and equality. It recognises that everyone is equal before the law and has equal protection and benefit of the law. Discrimination on a number of grounds, including disability, is prohibited under Section 9(3). Section 6(5) (a) (iii) also provides for the development and use of sign language. Furthermore, the South African government has expressed its commitment to realising the rights of children with disabilities through ratification of international treaties, including the UN Convention on the Rights of the Child (UNCRC), the African Charter on the Rights and Welfare of the Child (ACRWC or the African Charter), and the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

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2.5.2. UN Convention on the Rights of the person with disabilities

The UN Convention on the Rights of the people (1989) is a universally agreed-upon set of non-negotiable standards and obligations to protect the full range of human rights for all children that is civil, cultural, economic, political and social rights. The UNCRC acknowledges children as subjects of rights and participants in all matters affecting them. Although all the rights contained in the UNCRC apply to all children, the Convention also introduced specific rights for children with disabilities for the first time in international human rights law. Provisions included in Article 2 (non-discrimination) prohibit discrimination on a number of grounds including disability, while Article 23 specifically obliges State Parties to recognise and fulfil the rights of children with disabilities.

2.5.3. African Charter on the Rights and Welfare of the person with disability

The African Charter on the Rights and Welfare of the person (ACRWC) set out the rights that African states must ensure for person living in their jurisdiction.46 The Charter provides a uniquely African framework for the protection and promotion of children's rights. While acknowledging the dire situation of persons on the continent, the Charter recognises the child as occupying "a unique and privileged position in the African society and that for the full and harmonious development of their personality, the disabled person should grow up in a family environment in an atmosphere of happiness, love and understanding." In particular, Article 13 of the ACRWC makes provision for rights of persons with mental and physical disabilities as follows:

1. Every person who is mentally or physically disabled shall have the right to special measures of protection in keeping with his physical and moral needs and under conditions which ensure his dignity, promote his self-reliance and active participation in the community.

2. States Parties to the present Charter shall ensure, subject to available resources, to a disabled child and to those responsible for his care, of assistance for which application is made and which is appropriate to the child's condition and in particular shall ensure that the disabled child has effective access to training, preparation for employment and recreation opportunities in a manner conducive to the child achieving the fullest possible social integration, individual development and his cultural and moral development.

3. The States Parties to the present Charter shall use their available resources with a view to achieving progressively the full convenience of the mentally and physically disabled person to movement and access to public highway buildings and other places to which the disabled may legitimately want to have access to. South Africa ratified the ACRWC in 2000, but its

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initial report (due in 2002) has not yet been submitted to the African Committee of Experts on the Rights and Welfare of the Child, which reports to the African Union.

2.6. Theoretical framework

The study will be guided by the following theoretical framework:

2.6.1. ICF-framework

Several studies (McConachie, 2003) conclude that the ICF is a good framework for determining the functioning of children and adolescents with impairment. The WHO (2002) developed the ICF-framework for describing and organizing information on functioning of persons with impairment. The domains of the ICF are based on functioning and contextual factors. This study focuses on two domains of functioning: activities and participation. The ICF published a list of topics that should be investigated to determine the activities and participation of a person with impairment. For this study the present researcher used the topics that cover the domains daily life activities, communicative activities and social participation. This implies that for children with cerebral palsy, the following daily life activities will be included: mobility, self-care and domestic life. The topic 'methods of communication' will be used to investigate communicative activities for adolescents with a hearing impairment. Topics related to social participation the following are: relationship with family, relationship with friends, school, work, leisure time, relationship with community and attending religious places.

2.7. Summary

The chapter reviewed information on the global prevalence of cerebral palsy and in south Africa to outline the overview of cerebral palsy, it also explained the impact of rehabilitation on people living with cerebral palsy, impact of cerebral palsy on social and physical participation of young adults living with cerebral palsy, performance of basic daily activities, importance of activities with people living with cerebral palsy, communication of people with cerebral palsy, professional rehabilitation services provided to cerebral palsy, rehabilitation strategies in south Africa, legal context and theoretical framework.

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3. RESEARCH METHODOLOGY

3.1. Study design

The design of the study is quantitative using a descriptive cross-sectional survey method. This method was best for this study because data was collected at a point in time.

3.2. Study setting

The study was conducted in Shiluvana Care Centre which is situated in Mopani District, the Centre is managed by a private non-governmental organisation (Life Health Care). The Life Health Care supports organizations that provide interventions for children and adolescents with cerebral palsy in South Africa. This Care Centre is a residential facility in rural South Africa for children and young adult with neurological disorders, situated in Mopani, Limpopo Province.

The Centre opened in March 1985 and currently accommodates 160 people with different disabilities categorised as follows: 56 mental retardation, 74 physical disabilities mostly due to stroke and 30 with cerebral palsy. Their ages range from 18 years and above. The centre has five wards which serve as accommodation and patients are placed according to their functional level. The home employs approximately 116 workers including nurses, physiotherapist, occupational therapists, pharmacist, doctor, social worker, and porter, driver, cleaning and cooking staffs that take care of the daily needs of the young adults.

3.3. Study /target Population

Polit and Beck (2012) defined population as “the totality of all subjects that conform to a set of specifications, comprising the entire group of persons that is of interest to the researcher and to whom the research results can be generalized”. It can also be referred to as a target population. The targeted population for this study are all the young adults with cerebral palsy receiving rehabilitation services in the Care Centre. Considering the fact that there are only thirty young adults that are living with cerebral palsy in the center, a total population study was done. This implies that all the thirty patients were included in the study and there was no need for sampling.

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Table 2: Distribution of young adults living with cerebral palsy in a Care Centre.

AGE DISTRIBUTION	SEX DISTRIBUTION				TOTAL	%
	Male		Female			
	no		no			
18-24 years	01		03		04	13
25-29 years	02		02		04	13
30-35 years	07		15		22	73
TOTAL NUMBER	**10**		**20**		**30**	**100**

3.4. Data collection instrument.

The researcher used an observational checklist or structured observation which entails specifying in advance precisely the behavior or events that are to be observed and how they will be recorded and preparing forms for record keeping (Brink, 2006). The researcher used anobservational checklist to observe and record precisely and objectively the behavior of the population being studied. The researcher developed the observational checklist based on the specific objectives of the study. The checklist was divided into five sections as follows:

Section 1: Demographic of respondent'se.g. age, gender, date of admission, diagnosis.
Section 2: performance on activities of daily living e.g.can't he patient care for own Personal hygiene, use toilet appropriately, make own bed, dress appropriately, etc.
Section 3: communication abilities e.g. can the patient follow basic instruction, basic conversation, make sounds to make needs known, gesture to make self-understood, speak clearly and be understood by others.
Section 4: social participatione.g. goes to different places unaided, interact socially appropriately with people within and outside the Centre according to age and gender, etc.
Section 5: Health related quality of lifee.g. Can report illness or discomfort, take own medication, show initiative on time for medicine, leisure activities involved , management of personal relationships and emotional adaptation to anxiety or stress of the surrounding environment.

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The checklist was based on the standards that are set or expected by the Department of Social Development on the outcomes of activities by the rehabilitation centre. The scores for assessing the impact of rehabilitation programme on the centre were derived from a scale of 0-1 and scale of 2.

0-1 Will mean that the standard is not met (i.e. patient cannot perform task at all)

0r the standard is partially met (i.e. patient can do task under supervision)

2-Will mean the standard is met (i.e. Patient can perform task independently)

3.5. Validity and reliability of the data collection instrument.

3.5.1. Validity

Babbie (2010), defined validity as the extent to which an empirical measure adequately reflects the real meaning of the concept under consideration. In this study validity was ensured through face and content validity.

Face validity – refers to the extent to which an instrument "looks" valid (Creswell, 2009). In this study the instrument was scrutinized based on the standards set by the Department of Social Development on the rehabilitation outcome. The instrument was submitted to the Higher Degrees Committee of the School of Health sciences for scrutiny.

Content validity – refers to the extent to which an instrument covers the complete content of the particular construct that it is set out to measure. To ensure content validity of the instrument a provisional version of the instrument was presented to the experts in the field for comments and the inputs was taken into consideration before finalizing the instrument.

3.5.2. Reliability

Bryman (2012) defined reliability as the consistency of a measure concept and that there are three prominent factors involved when considering whether a measure is reliable. These factors are stability, internal reliability and inter-observed consistency.

Test –retest method wasapplied in this study to test the reliability of the observational checklist. The process involved observing one patient (with the assistance of the occupational therapist) on one occasion and re-observation was done to the same patient in another day or occasion (Bryman, 2012). The same procedurewas done to at least 10% of the study population. It was found that the co-relation coefficient is above 0,7 therefore the checklist was used because it indicated reliability.

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3.6. Data collection methods

3.6.1. Observation

According to De Vos et al (2012) observation is a systematic data collection approach and researchers use all of their senses to examine people in a natural setting or naturally-occurring situations. Observational studies involve the systematic detailed observation of behaviour and talk, watching and recording what people say and act. They are sometimes referred to as field research. In this study data was collected with the use of observational checklist. The target group observation was used, the procedure for data collection involved dividing the patients into five, whereby every week five patients were observed by working with the occupational therapist. Each patient was observed and was recorded using a copy of the checklist.

During the process the patient was seated comfortably in a wheelchair and the occupational therapist evaluated the performance of the patient on the checklist items. The researcher was working as a team member with the occupational therapist. The information gathered through the help of occupational therapist and observation by the researcher was supplemented by the information gathered from the patients' case notes and recorded appropriately. This implies that data collection process took six weeks, five patients per week.

3.7. Data analysis

Data analysis refers to the techniques used to reduce, organize and give meaning to data, (Burns and Groove, 2009). Polit and Becker (2009) described data analysis as a process of organizing data in order to provide structure and elicit meaning. In this study data was coded, summarized in a data master sheet. Then data was entered in statistical package for social sciences (SPSS) version 23.0 programme and analyzed. Frequency of data was generated according to the objectives of the study. Descriptive statistics was applied to analyze data and results of analysis are presented in the form of tables and charts to enhance clarity.

3.8. Ethical consideration

The proposal was submitted to the University of Venda Higher Degree Committee for Ethical approval, Ethical clearance was obtained from the University of Venda Research Ethics Committee. Permission to enter the centre was obtained from the Department of Social Development in Polokwane.

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3.8.1. Confidentiality and Anonymity

Refers to the researchers upholding with respect and integrity the respondents information gathered during the interview (De Vos 2012). Confidentiality also implies that all information collected from participants will be strictly treated in a confidential manner (Akinsola: 2005). The information gained during observation from the participants was not discussed to a third party other than the supervisor of the study and research assistance and the occupational therapist of the care centre. In this study the researcher maintained anonymity by using codes instead of the participants' names or identity.

3.8.2. Informed consent

For the young adults with cerebral palsy who are 18 years and above, who are unable to communicate, permission to carry out the study was requested from the parent or grandparents responsible for the young adults. The mental capacity of respondents was not stable therefore the researcher identified the parents or family members of the participants to give consent on their behalf.Consent was requested by the researcher from the participants' family before conducting the study. The purpose of the study was explained to the participants family, the procedures to be undergone through during the observation was also explained where each patient was observed while completing the checklist. The participant's family were informed that patients (participants) are not going to be remunerated for participating in the study. Each patient will be observed for 15 minutes and all the 30 family members of the participants have signed the consent forms.

3.8.3. Principle of respect for human dignity.

Participants have the right to self-determination and full disclosure. The researcher disclosed all information pertaining the study before commencement with the study. All participants were treated equally with respect and dignity at all times irrespective of their mental abilities.

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CHAPTER FOUR: THE RESULTS

Introduction

In this chapter the results of the study are presented under five sections namely, social demographic and clinical characteristics, performance of activities of daily living, communication abilities, social participation and health quality of life.

- **Section 4.1: Demographic characteristics of the respondents.**

The results of the study shows that out of the 30 patients, 20 (66.7%) werefemales,the age distribution shows that majority (83.4%) were above the age of 26 years. The age ranges between 20 and 37 years. With regards to the diagnosis, 53.3% have cerebral palsy and other complications including hydrocephalus, mental retardation, blindness and epilepsy. On the average, each patient had stayed for about 12 years (Table 1).

- **Table 4.1: social demographic and clinical characteristics**

Demographic and clinical characteristics (No = 30)		
Characteristics	**No**	**Percentage**
Gender distribution		
Male	10	33.3
Female	20	66.7
Age distribution (Years).		
20 – 25	5	16.7
26 – 31	11	36.7
32 – 37	14	46.7
Diagnosis		
cerebral palsy	14	46.7
cerebral palsy + epilepsy	10	33.3
cerebral palsy+ Blindness	2	6.6
cerebral palsy and MR	3	10
cerebral palsy + hydrocephalus	1	3.3
Duration of stay (Years).		
Mean duration of stay	12	
Range duration of stay	15 (4-19 yrs.)	
The median duration of stay	13	

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The mode duration of stay	19

- **Section 4. 2: Perfomance of activities of daily living.**

As shown on Table 2, on admission, none of the patients could bath independently, dress half body, use toilet appropriately or demonstrate good personal hygiene. With regards to these 4 indicators, even following rehabilitation for a period of about 12 years on the average, only between 4 and 5 (13.3 – 16.7%) of them could bath independently, dress half body, and display good personal hygiene habits respectively. However, 13 (43%) were able to use toilet appropriately. On admission only between 6 and 8 (20 – 26.6%) of the patients could wake up independently or identify personal belongings. Following rehabilitation, over 53% can wake up independently while about 37% can identify personal belongings.

Fig. 4.2 (a-c) shows the observed impact of the rehabilitation programme being run in the center according to duration stay in the center. For those who had stayed for between 4 and 8 years, none of them could wake up independentl at the time of data collection while only 20% could bath independently and dress indeindependently. However, 60% could use toilet appropriately and identify personal belongings (Fig. 4.2a). For those who had stayed for between 9 and 14 years, none of them could either bath or dress independently. Furthermore, only 10% of them could use toilet appropriately or display good toilet hygiene habits. However, over 36% could wake up independently or identify personal belongings (Fig. 4.2 b). For those who had stayed in the center for between 15 and 19 years, between 36-50% could either wake up independently, identify personal belongings or use the toilet appropriately (Fig. 4.2 c).

- **Table 4.2:Distribution of the patients according to their ability to perform activities of daily living: comparison between condition on admission and period following rehabilitation (N=30).**

Indicators	On admission		Following Rehabilitation	
	Number	Percentage	Number	Percentage
Can Bath Independently	Yes: 0	0%	Yes : 04	13.3%
	No: 30	100 %	No : 26	86.6%
Can Dress Half Body	Yes: 0	0%	Yes : 5	16.7%
	No : 30	100%	No : 25	83.3%
Can Wake-Up Independently	Yes : 8	26.6%	Yes : 16	53.3%
	No : 22	73.3%	No : 14	46.7%

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Can use Toilet Appropriately	Yes : 0	0	Yes :13	43.3%
	No : 30	100%	No :17	56.7%
Has good Personal Hygiene	Yes: 0	0	Yes :5	16.7%
	No :30	100%	No : 25	83.3%
Can identify Personal Belongings	Yes :6	20%	Yes :11	36.7%
	No :24	80%	No :19	63.3%

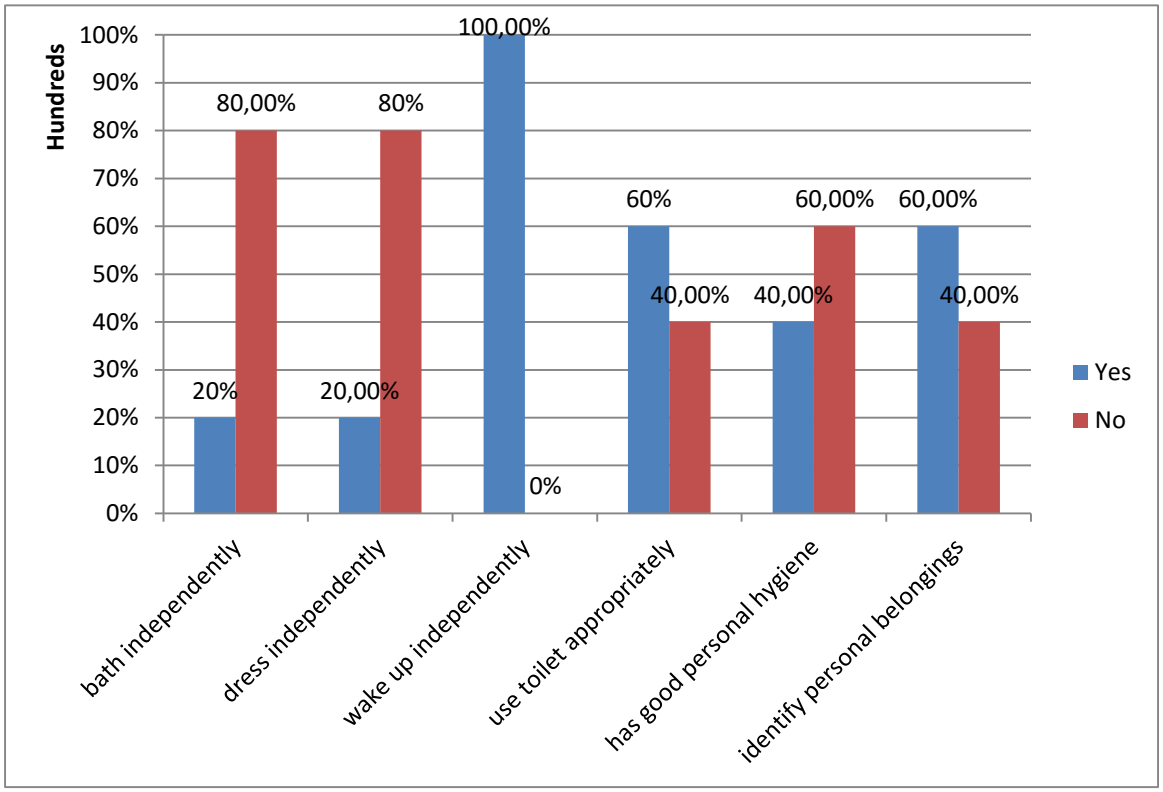

Figure 4 .2 (a) duration of stay for 4-8 years and perfomance on daily activities.

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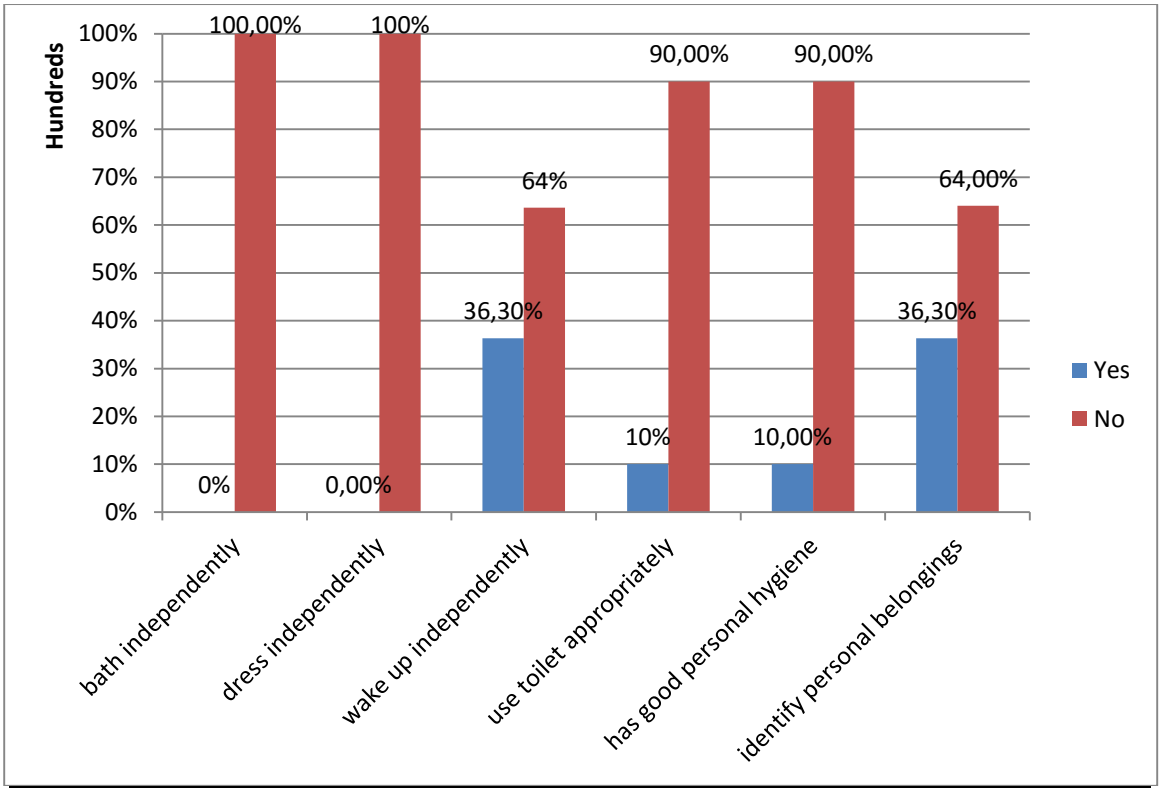

Figure 4.2 (b) duration of stay for perfomance on daily activities between 9-14 years

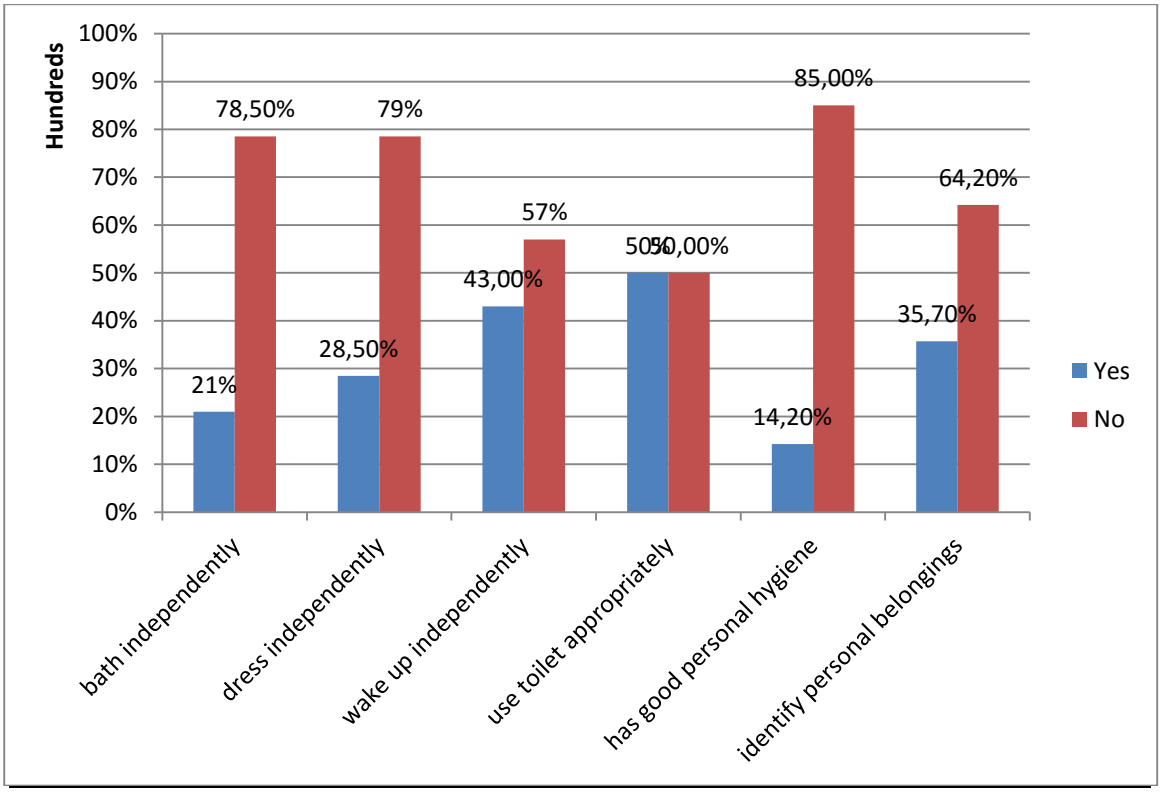

Figure 4.2 (c) duration of stay for perfomance on daily activities between 15-19 years

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- **Section 3: Communication abilities**

The communication abilities of the patients are as shown on Table 4.3 and they were assessed using 5 indicators. On admission, only between 4 and 7 (13.3 – 23.3%) could use expressive language, speak clearly, follow basic instructions or follow basic conversations. However, 17 (about 57%) could make meaningful gestures. Following rehabilitation, between 57 and 80% could use expressive language, follow basic instructions, follow basic conversations and make meaningful gestures. However, only 9 (30%) could speak clearly.

The patients communication ability was also assessed according to their duration of stay in the center (Fig. 4.3 (a-c). For those who had stayed in the center for between 4 and 8 years, 80% were able to follow basic conversation and make meaningful gestures respectively. Sixty percent were also able to use expressive language, speak clearly and follow basic instructions
(Fig. 4.3 a) . For those who had been through the rehabilitation programme for 9 to 14 years, between 81 to 91% could follow basic instructions, make meaningful gestures and follow basic instructions respectifully. However, only 18% could either use expressive language or speak clearly.

- **Table 4.3: Distribution of the patients according to their communication ability: comparison between condition on admission and period following rehabilitation(N=30).**

Indicators	On admission		Following rehabilitation	
	Number	Percentage	Number	Percentage
Can Use expressive Language	No :26	86.7%	No :13	43.3%
	Yes :4	13.3%	Yes :17	56.7%
Can speak clearly (can be understood)	No :26	86.7%	No :21	70%
	Yes :4	13.3%	Yes :9	30%
Can Follow Basic Instructions	No :23	76.7%	No :6	20%
	Yes :7	23.3%	Yes :24	80%
Can Follow Basic Conversation	No :23	76.7%	No :13	43.3%
	Yes :7	23.3%	Yes :17	56.7%
Can make meaningful Gestures.	No :13	43.3%	No : 7	23.3%
	Yes :17	56.7%	Yes :23	76.7%

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(Fig. 4.3 b). Fig. 2c shows the communication ability of the patients for those who had spent between 15 and 19 years in the rehabilitation center. Of this group, over 85% could make meaningful gestures, use expressive language and follow basic instructions respectifully. However, only about 36% of the patients could speak clearly after spending 15-19 years in the center.

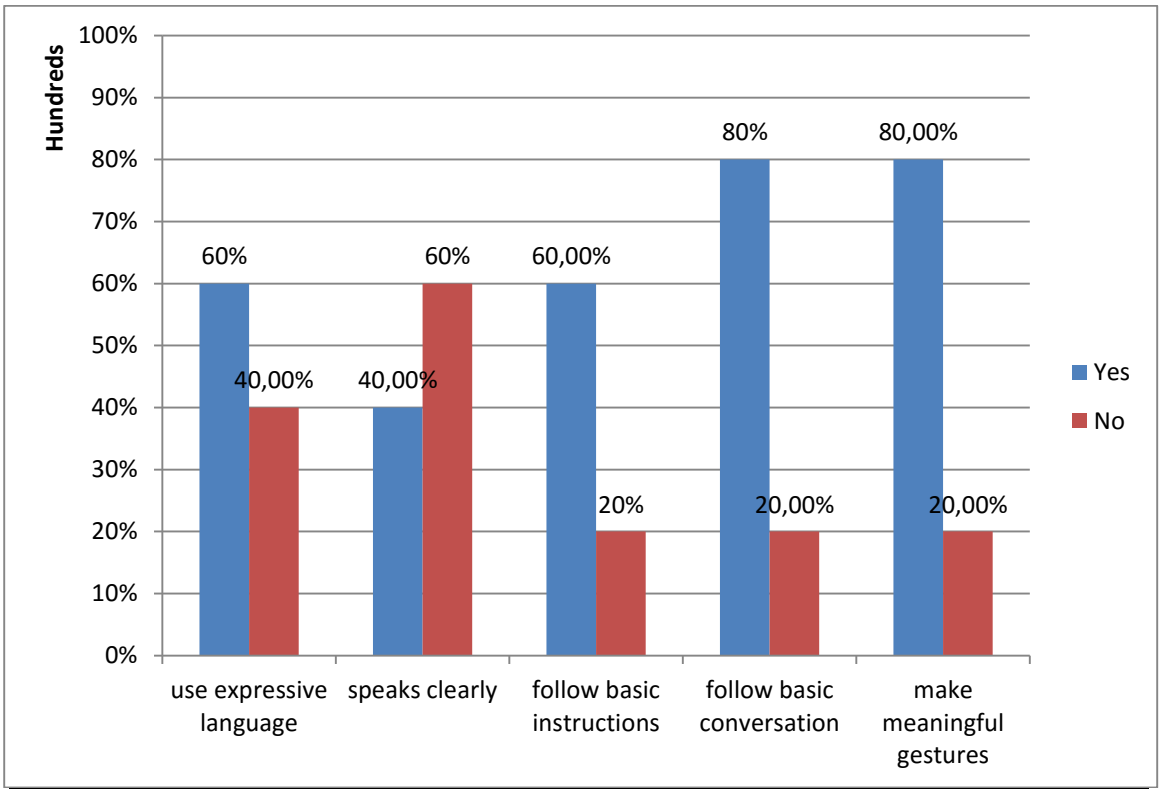

Figure 4.3(a) Communication ability by duration of stay- 4-8 years

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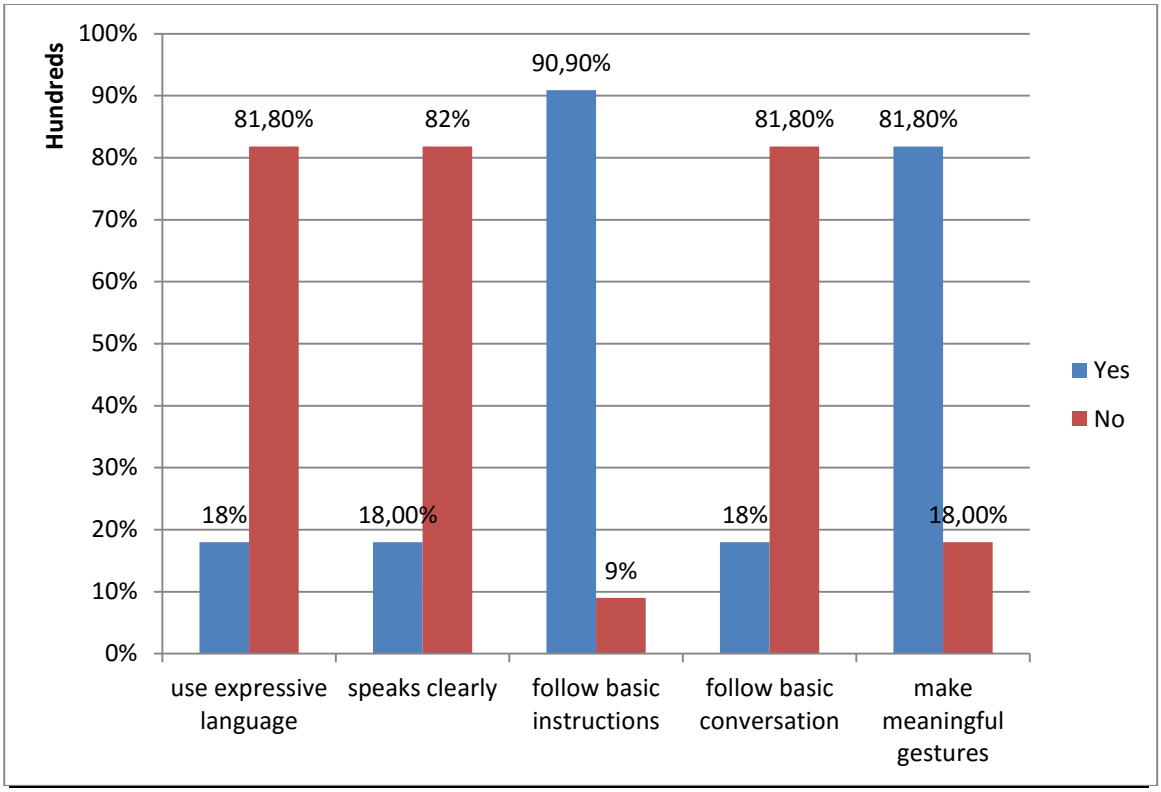

Figure 4.3 (b) Communication ability by duration of stay- 9-14 years

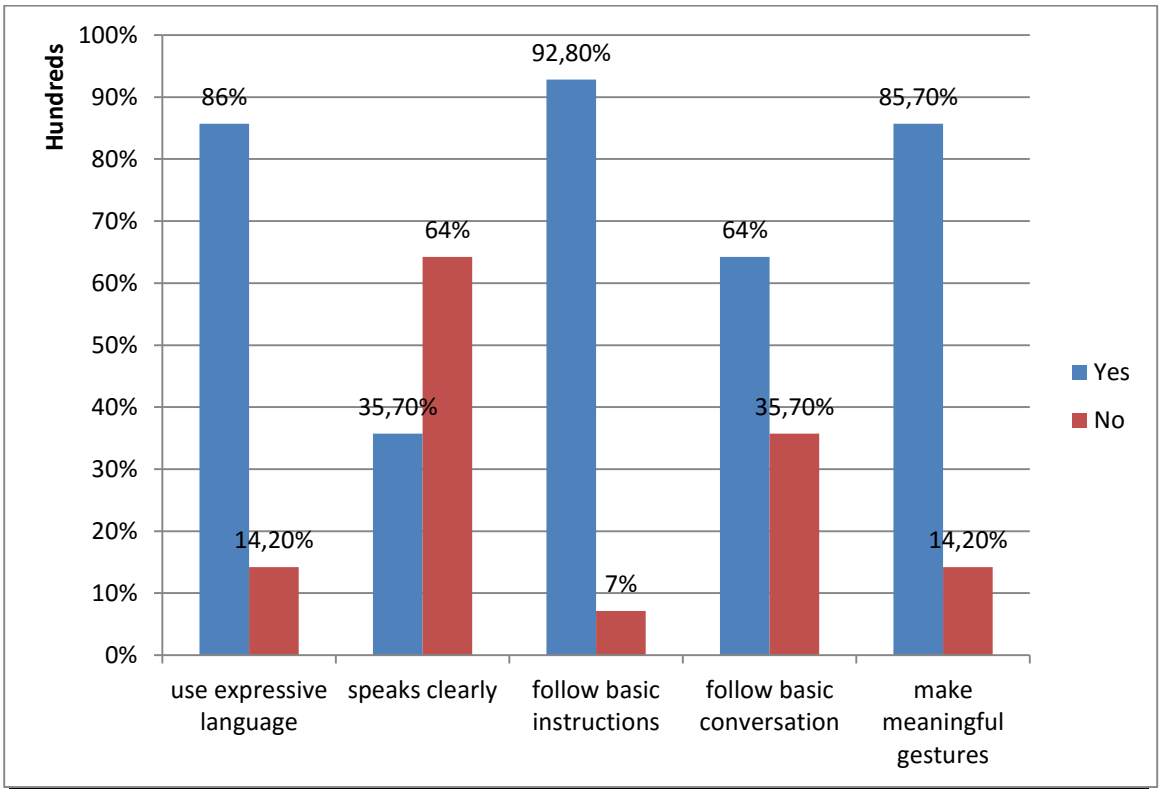

Fig 4.3(c). Communication ability by duration of stay- 15-19 years

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- **Section 4: Ability to acquire simple physical & social skills.**

As shown on Table 4, 5 indicators were used to measure the patients' ability to acquire simple physical & social skills. As at the time of admission, none of the patients displayed good rapport ability and element of being exposed to activities involving peers; only between 1 and 5 displayed acts that were appropriate to their gender and age, engage in adequate recreation and stimulation activities, or interact appropriately with their peers. .However, none of them was reported to be engaging in deviant sexual behaviour. Following rehabilitation, between 66 and 96% could act appropriately to their gender and age level, engage in adequate recreation and stimulation activities, showed good rapport and so on. Three were reported to be engaging in deviant sexual behaviour.

The patients' ability toacquire simple physical & social skills was compared along the continuum of care/rehabilitation by looking at the progress made by them according to the duration of stay in the centre (Fig. 4.4 (a-c). As shown in Fig. (4.4 a), by the time the patients spent 4- 8 years at the center, they were all able to engage in adequate recreation and stimulation activities and benefit from social interaction with peers. Between 60 and 80% were able to display acts that were appropriate for their gender and age, display good rapport, and interact adequately with their peers. Furthermore, none of them was involved in deviant sexual behaviour. Analysis of Fig. 4.4 (b) shows that the patients maintained the progress observed under the 4-8 years duration category, however, it is worthy of note that over 50% of them were able to perform well with regards to the 6 indicators or ability categories (Fig. 4.4 (b). For those who had spent 15-19 years at the centre, a range of 71 % to 92% was observed to have improved in all the ability categories (Fig.4.4(c).

- **Table 4.4: Distribution of the patients according to their abilityto acquire simple physical & social skills: comparison between condition on admission and period following rehabilitation(N=30).**

Indicators	On admission		Following rehabilitation	
	No	Percentage	No	Percentage
Acts appropriate to gender and age.	No :25	83.3%	No :8	26.7%
	Yes :5	16.7%	Yes :22	73.3%
Can engage in adequate recreation and stimulation activities.	No :28	93.3%	No :2	6.6%
	Yes :2	6.7%	Yes :28	93.3%

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Good rapport	No :30	100%	No :6	20%
	Yes: 0	0%	Yes :24	80%
Social group exposure.	No :30	100%	No :1	3.3%
	Yes: 0	0%	Yes :29	96.7%
Engages in sexual deviant behaviour.	No :30	100%	No :27	90%
	Yes: 0	0%	Yes :3	10%
Appropriate interaction with peers.	No :29	96.7%	No :10	33.3%
	Yes :1	3.3%	Yes :20	66.7%

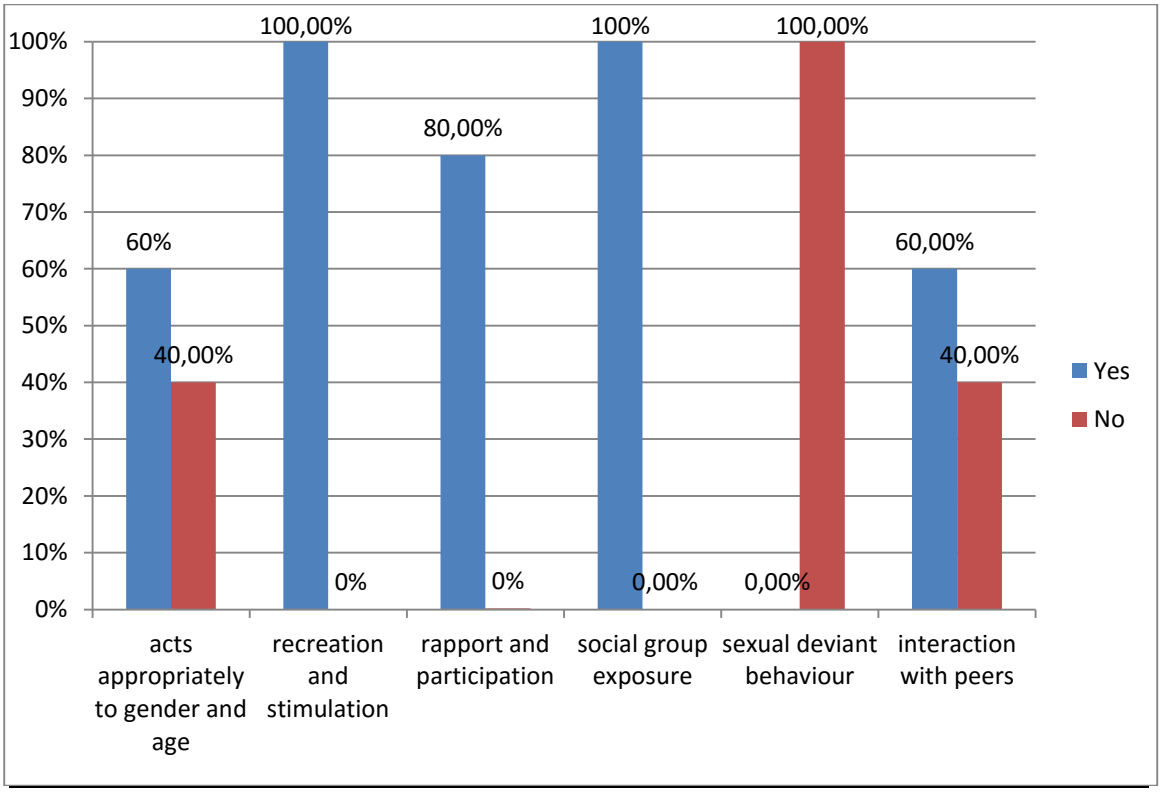

Figure 4.4(a): Ability to acquire simple physical & social skills by duration of stay - 4-8 year.

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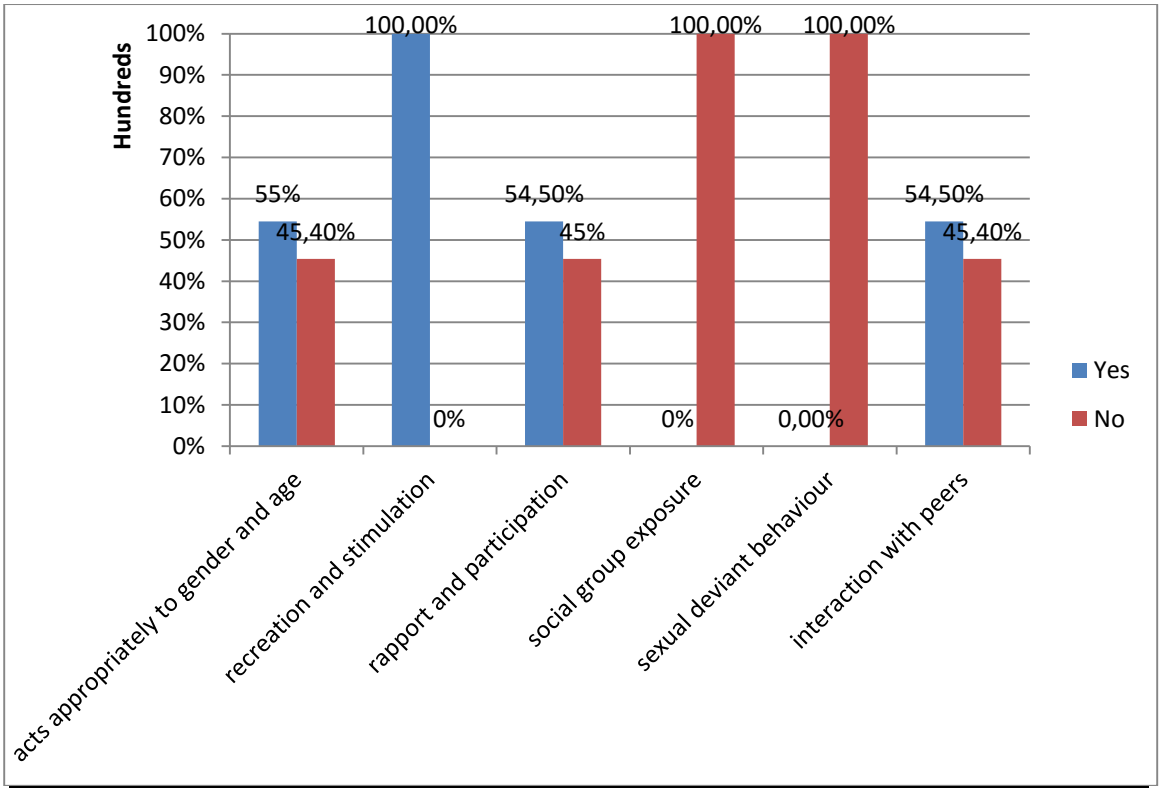

Figure 4.4(b): ability to acquire simple physical & social skills by duration of stay- 9-14 years.

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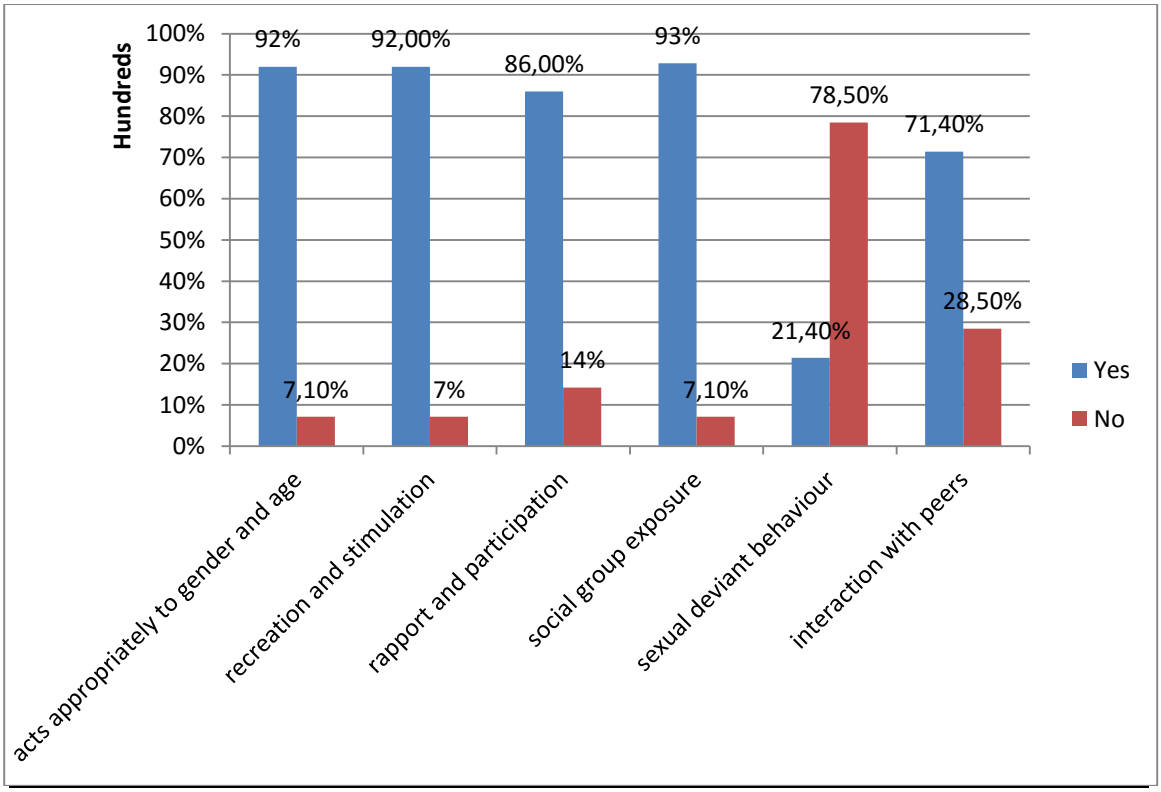

Figure 4.4(c): ability to acquire simple physical & social skills by duration of stay- 15-19 years.

- **Section 5: Health and Quality of life related behaviour/activities**

As shown on Table 5, on admission, of the 30 patients in the center, only between 1 and 6 could either make a report of their illness/discomfort, take own medication, take an initiative on when to take medication, were able to participate meaningfully during leisure activities, exhibited traits of emotional adaptation to the environment or manage personal relationship. None of them had insight into their condition. Following rehabilitation, more than two-third of them showed signs of emotional adaptation and being able to participate meaningfully during leisure activities respectfully. Forty three to fifty percent were able to report self-illness/discomfort, had insight to own condition and can manage personal relationship. It is noteworthy that only about 27 % was able to take own medication while 33% can take initiative on when to take medication.

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- **Table 5:Distribution of the patients according to their behaviour/ activities which were related to their health and Quality of life (N=30).**

Indicators	On admission		Following Rehabilitation	
	No	**Percentage**	**No**	**Percentage**
Can Reports Illness and discomfort	No :24	80%	No :17	56.7%
	Yes :6	20%	Yes :13	43.3%
Can Take Own Medication	No :29	96.7%	No :22	73.3%
	Yes :1	3.3%	Yes :8	26.6%
Can make an Initiative on time for medication	No :27	90%	No :20	66.7%
	Yes :3	10%	Yes :10	33.3%
Have insight into Condition	No :30	100%	No :16	53.3%
	Yes: 0	0%	Yes :14	46.7%
Adequately participate in leisure activities	No :29	96.7%	No :2	6.6%
	Yes :1	3.3%	Yes :28	93.3%
Emotional adaptation to the environment.	No :28	93.3%	No :10	33.3%
	Yes :2	6.6%	Yes :20	66.7%
Can Manage personal Relationship	No :29	96.6%	No : 15	50%
	Yes :1	3.3%	Yes :15	50%

For those who had stayed in the cener for 4 to 8 years, 80% can adequately participate in leisure activities, were well adapted to their environment and can manage personal relationship. Furthermore, 60 % of them can report illness/discomfort, take own medication and take initiative on when to take medication. As shown on Fig. 4.5 (b), after spending between 9 and 14 years in the center, all the patients were able to participate meaningfully during leisure activities while about 55% had adapted well to their environment. Fig. 4.5 (c) shows that for those who have spent over 15 years in the center, 64% to about 93% already have insight to their condition, can report self-illness/discomfort, engage adequately during leisure activities, had adapted to their environment and can manage personal relationship.

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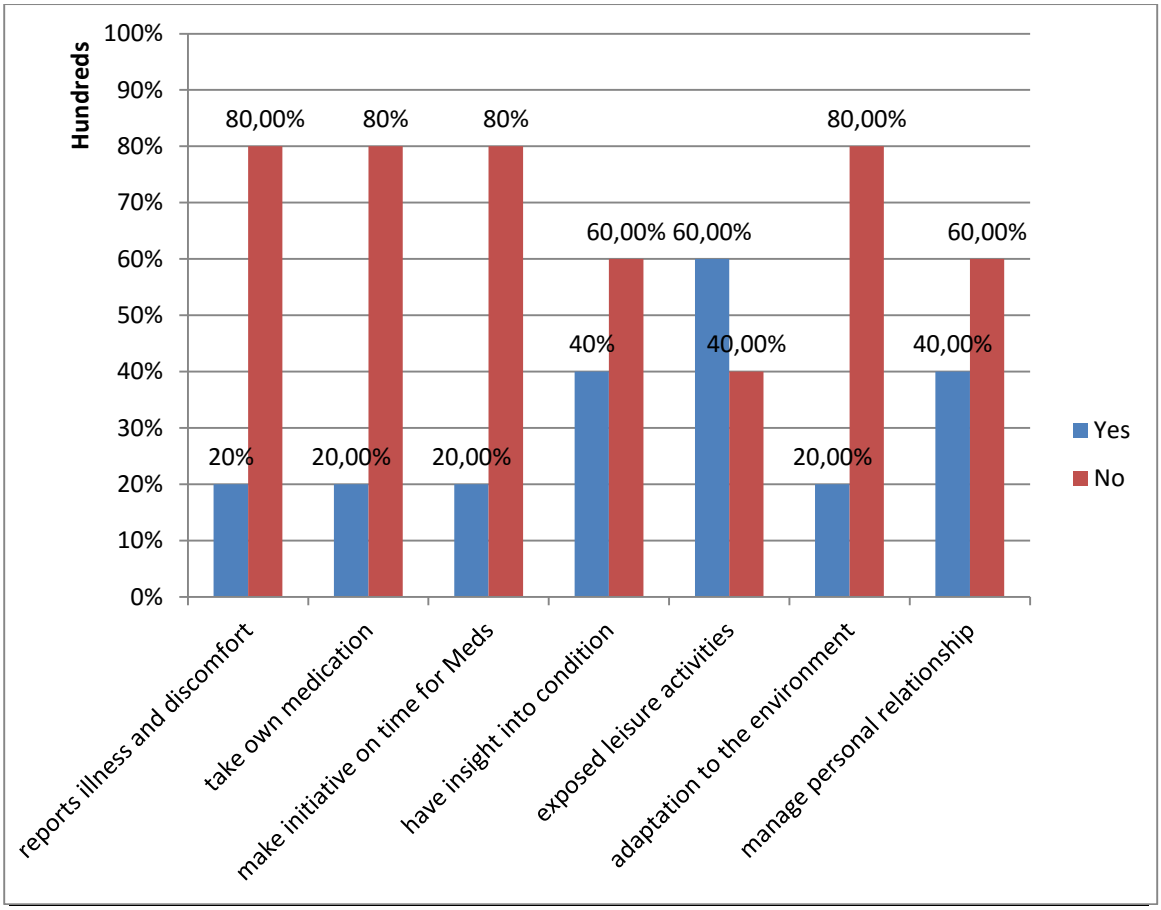

Figure 4.5(a) Distribution according to health/quality of life related behaviour/activities and duration of stay - 4 to 8 years.

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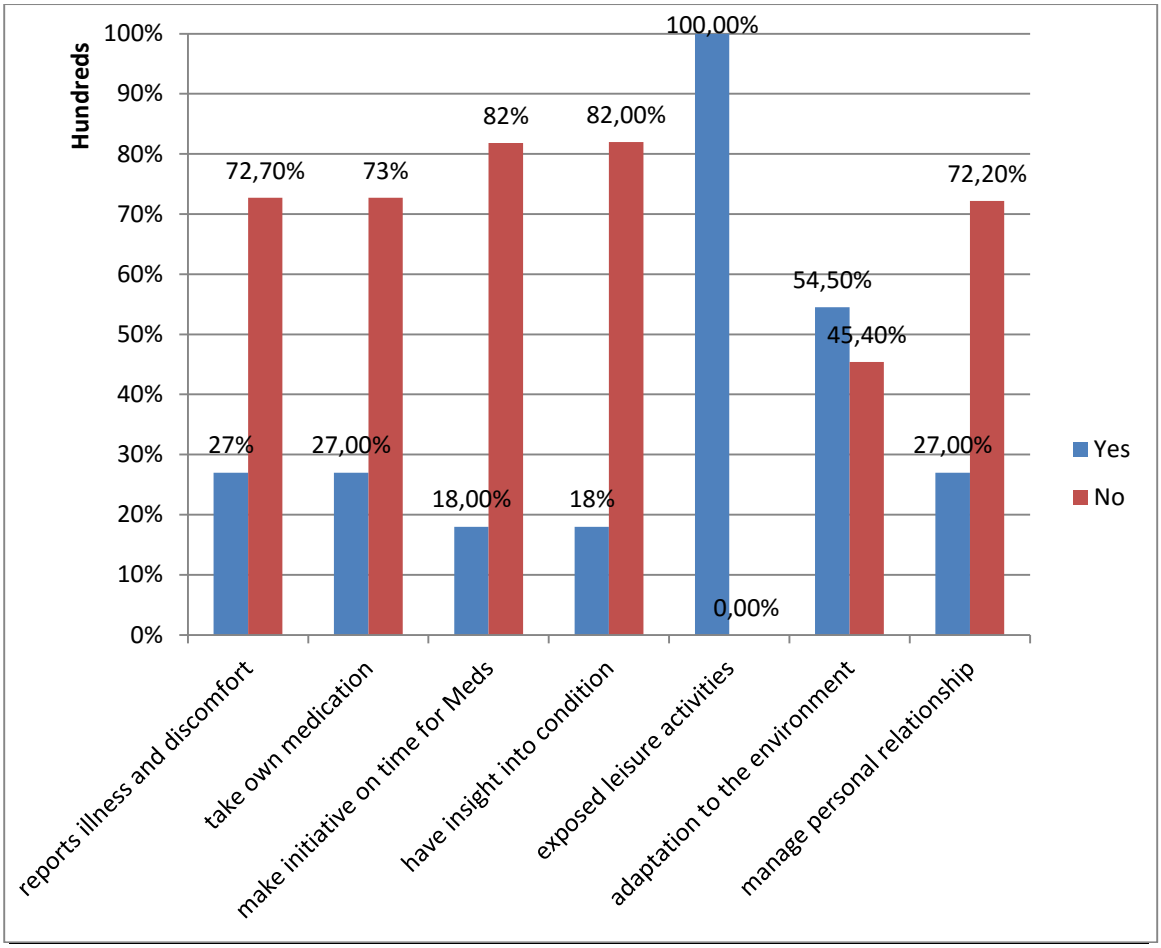

Figure 4.5(b) Distribution according to health/quality of life related behaviour/activities and duration of stay –9 to 14 years

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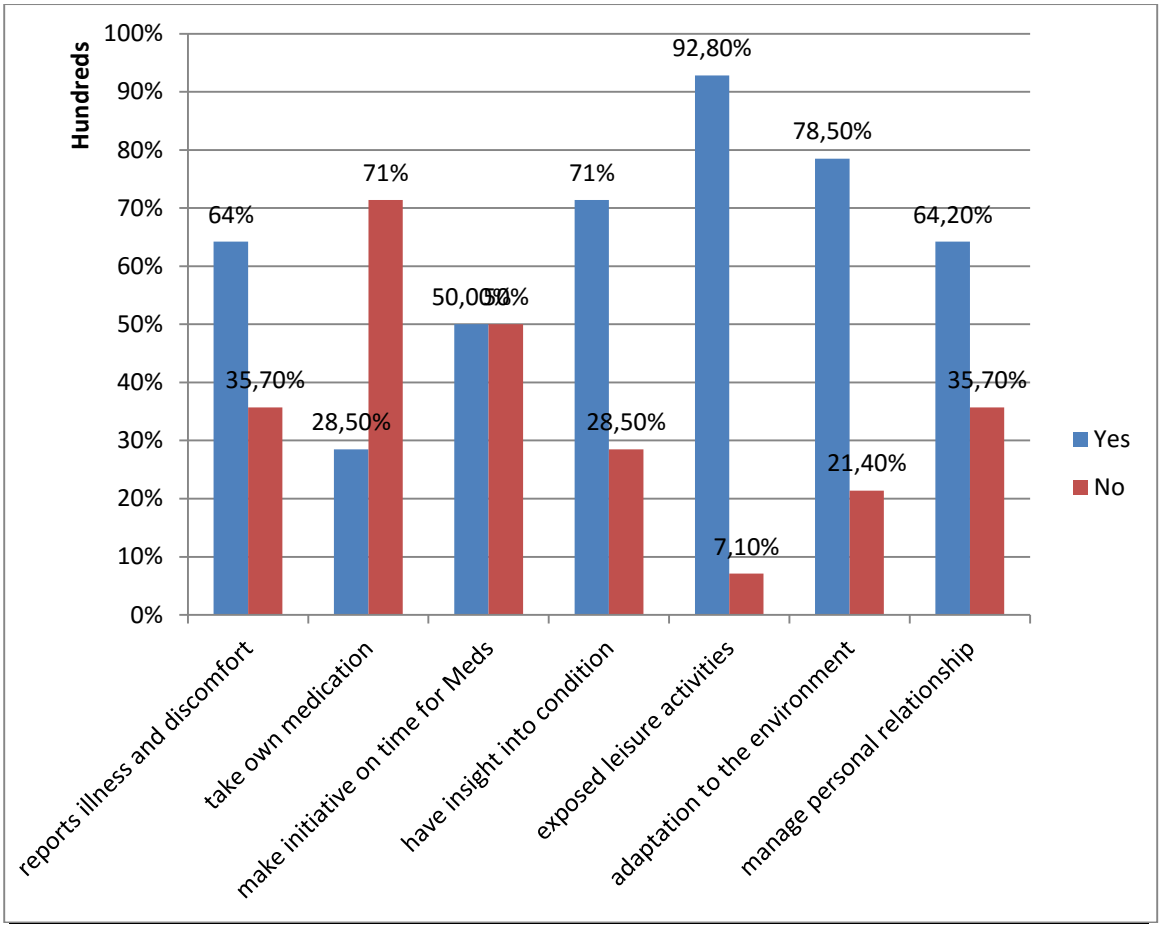

Figure 4.5(c) Distribution according to health/quality of life related behaviour/activities and duration of stay –15 to 19 years.

5.Summary

This chapter presented the study findings on the impact of rehabilitation programme for cerebral palsy patients admitted into a care centre. The findings were presented based on the following six sections namely: social demographic and clinical characteristics, performance of activities of daily living, communication abilities, ability to acquire simple physical and skills as well as health and quality of life related behaviour or activities.

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CHAPTER 5: DISCUSSIONS, CONCLUSIONS AND RECOMMENDATIONS.

5.1: Discussions

The result of this study shows that there were more females than males (ratio 3: 1) and the range of age distribution was 20 to 37 years. In a study in Alabama, USA, there were ten males and sixteen were females, with a mean age of 42.3+11.2 years. However, the finding of this study on age distribution is at variance with a study conducted in Iraq (Al-Azzawi, 2011) which showed that males were more affected than females (ratio 1.4: 1). It is not surprising that the age range in this study is wide. According to Parkes and Hill (2010), cerebral palsy is a disability that affects movement and body position of children, the part of the brain that controls movement is damaged and the damage does not get better. In a study by Ashour and Sewasi (2013), the cerebral palsy condition was accompanied by several complications, including epilepsy, microcephaly, anemia and mental retardation. In this study, the patients also presented with some complications, such as epilepsy, blindness and hydrocephalus

The result of this study shows that although there was progress made by some of the patients following rehabilitation, however, there was no tangible result. For example, after spending an average of 12 years at the center, less than 17% could bath independently, developed good personal hygiene habits or dress self. This is not surprising considering the fact that, according to Parkes and Hill (2010), the damage caused by cerebral palsy does not get better. This implies that rehabilitation can only have minimal effect but it can improve the quality of life of the patients. For example, the result of this study shows that for those who had spent 4 to 8 years in the center, 60% could use toilet appropriately and also identify personal belongings.

In this study, with regards to communication, the outcome of the rehabilitation programme seems to be better in the sense that following rehabilitation, between 57% and 80% could use expressive language, following basic instructions, etc. This finding was confirmed by the

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results of the study that showed that even though there is no clear pattern to show the progress made according to duration of stay at the center, however, there is consistency in the manner of progress made at the different points during their stay there. In a study conducted by Van der Dussen et al (2011) at rehabilitation centre at The Hague the Netherlands among 134 young adult, large percentages of young adults with CP indicated that there is no dependency or difficulty in performing activities such as self-care activities, mobility and communication. According to CP Group (2015), speech therapy is beneficial because a plan of treatment is individualized, allowing a child and therapist to work extensively on very specific issues that, once addressed, can progress quickly. Speech therapy has widespread benefits for cerebral palsy patients. Not only does the process improve communication interactions, but speech therapy can also be used to strengthen and improve facial and oral muscle control (CP Group, 2015).

The result of this study also shows that the rehabilitation programme at the centre where these patients live has had a feasible impact on the patients' ability to acquire simple physical and social skills. The results in Table 4 which shows their situation on admission and following rehabilitation shows that the percentages of those who had made improvements based on all the indicators used was from 66.7% for appropriate interaction with peers to 96% for social group exposure. This appears to be very remarkable considering the level of disability of the patients. Looking at Fig. 3 (a-c), one can also observe that the patients made a steady improvement right through from those who had spent 4 to 8 years to those who had been there for long, 15 years and above. One of the roles played by occupational therapist working with CP patients is to conduct cognitive stimulation. Since cerebral palsy not only affects motor development but also the cognitive and social development, it seems beneficial to focus an intervention program also on the cognitive stimulation of children and young adults with cerebral palsy. Because one of the most important ways through which children learn and explore actively is play, one could gain insight into a child's cognitive development by observing play performance (Messier et al, 2008).

Based on the results on Table 5 and those in Fig. 4 (a-c), it appears that there is a mixture of success and failure in the outcome of the rehabilitation programme on the CP patients in this study. According to Table 5, following rehabilitation, there were levels of improvement ranging from 26.6% to 93%. The picture shown in the charts (Fig. 4 (a-c) also makes one to believe that there is no steady progress made by the patients. For example, judging from Fig. 4 (b), one is inclined to feel that majority of the patients made progress, and so also is

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the picture painted in Fig. 4 (c). However, in Fig. 4 (b), it appears that many of the patients relapsed.

In ability to acquire simple physical and social skills, the results shows that by the time patients spent 4-8 years at the centre they were all engaged in adequate recreation and stimulation activities. This implies that once patients get into the rehabilitation they have equal opportunity to participate in the rehabilitation rather than staying at home.

5.2 Conclusions.

Based on the results of this study, the following conclusions are made:

1. There is a relative difference in the ability of the patients to perform activities of daily living judging from their performance during admission and after exposure to rehabilitation. Furthermore, duration of stay in the center did not greatly influence the outcome of the rehabilitation programme.
2. The rehabilitation programme helped the patients in this study to improve on their communication ability. Secondly, the improvements made by the patients cut across the duration of their stay at the center.
3. There is no even or steady pattern in the progress made by the patients in the area of social interaction based on the rehabilitation programme according to the duration of stay at the center.
4. Overall, the quality of life of the CP patients in this study improved based on the rehabilitation programme being run at the center. However, a lot needs to be done to drastically improve the patients' quality of life.

5.3 Recommendations

Based on the above conclusions, the following recommendations are made;

1. Since this study has find that cerebral palsy patients have several complications such as epilepsy, mental retardation and hydrocephalus which also worsen or relapse their condition. It is therefore recommended that rehabilitation be initiated at an early age so that complications be identified and attended to by multi professional team.
2. Awareness campaign about the impact of rehabilitation services should be conducted so that everyone can be aware.
3. Training of care givers or parents of children with cerebral palsy must continue and monitoring and evaluation must be done at their houses by health care professionals in a regular basis if they don't want to place their child at rehabilitation centre.

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APPENDIXES

Appendix A: Consent letter/ information sheet.

Date: November 2016

Dear participant

Iam a master's student at the University of Venda conducting a study entitled: **The impact of rehabilitation programme for cerebral palsy patients admitted in a care centre, Mopani, South Africa**. I would like you to participate in the study by giving consent for your son or daughter to be observed during his or her stay in the care centre.

The purpose of this study is to assess the impact of rehabilitation programme on the quality of life of young adults living with cerebral palsy admitted into care centre, the study is conducted for educational purposes and also aimed at fulfilling the requirements towards my masters degree in public health.

Should you wish to participate in this study, read the attached consent form (appendix B) and sign if you agree. The information provided by you will be treated in a confidential manner, your participation is voluntarily and you are allowed to withdraw from the study if wishes to do so.

Your co operation is highly appreciated.

Yours truly

JamelaNgoveni

Signature ----------Date----------

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Appendix B: Consent form

Date: February 2017

Participants Family

I_____, hereby consent for my son or daughter to participate in the research study. I understand that participation is voluntary and that he/she is free to withdraw from the study should I wish to do so at any time of the study without any repercussions. The conditions of this study have been fully explained to me and understand the circumstances of my child's participation.

Signature of participant's family:_____

Date _____

Signature of researcher: _____

Date:_____

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Appendix C: Letter of Permission to Provincial Department

P. O. Box 856
Giyani
0826

The Head of Department
Department of Social Development
Private Bag x9302
Polokwane
0700

Dear Sir/ Madam

REQUEST FOR PERMISSION TO CONDUCT A STUDY

I JAMELA NGOVENI , a registered post-graduate student in the Department of Public Health, University of Venda would like to request a permission to undertake a research study titled **"The impact of rehabilitation programme for young adult living with cerebral palsy into Care Centre , Mopani District, South Africa".**

The aim of the study is to describe the impact of rehabilitation programme for young adults with cerebral palsy. The study might help reduce the high rate of abuse for young adult living with disability who lock them in houses.
Participation is voluntarily and anonymity of participants will be maintained.

Yours faithfully

JamelaNgoveni (contact number: 083 7526 350

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APPENDIX D

RESEARCH INSTRUMENT

OBSERVATIONAL CHECKLISTFOR PARTICIPANTS

THE IMPACT OF THE REHABILITATION PROGRAMME FOR CEREBRAL PALSY PATIENTS ADMITTED INTO CARE CENTRE.

SECTION 1:DEMOGRAPHIC OF RESPONDENTS	Age :					
	Date of admission :					
	Diagnosis :					
	Gender :					
Questions /objectives	**During admission** (Indicate Pt. abilities) By choosing scale of 0-1 or 2		**Recently** (Indicate Pt. abilities) By choosing scale of 0-1or 2			**comments**
	Scale no: 0 0r 1	No:2	Scale no: 0 or 1	No: 2		
SECTION 2: PERFORMANCE IN ACTIVITIES OF DAILY LIVING						
2.1.Can patient bath him/herself independently						
2.2. Dressing and undressing the upper half of the body clothing, accessories, including the choice of clothes.						

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2.3.Wakes up independently(Getting in and out of bed						
2.4.Usethe toilet and bathroom appropriately						
2.5.Attends to personal hygiene(washing yourself doing						
2.6.Identifies personal belongings And does own washing.						
SECTION3:COMMUNICATION ABILITIES 3.1.Can the patient use expressive language						
3.2.Speaks clearly to be understood by others						
3.3.Follow basic instructions						
3.4.Follow basic conversation						
3.5 can make meaningful gestures to be understood.						
3.6.Make sounds to make needs known						
SECTION 4: Ability to acquire simple physical and social skills. 4.1. Acts on culture, role, gender and age appropriately.						
4.2. Involved in recreation stimulation.						
4.3.Builds rapport with fellow patients						
4.4. Exposed to social groups and events.						

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4.5. Shows sexual deviant Behaviour.						
4.6. Interact socially appropriately with people within and outside the centre according to age and gender.						
SECTION 5: HEALTH QUALITY OF LIFE 5.1.Reports illness or discomfort						
5.2.Takes own medication						
5.3.Shows initiative on time for meds						
5.4.Has insight into her/his condition						
5.5.Type of leisure activities involved						
5.6. Emotional adaptation, anxiety or stress within the environment.						
5.7. Management of personal relationships.						

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