University of Pretoria
Faculty of Health Sciences
School of Health Systems & Public Health

Identifying contributing factors for poor adherence to rehabilitative services in patients with neurological conditions

Author: Hazel Mapipa
Student number: 29271356
Qualification: MPH

Contact details:
Address: Faculty of Health Sciences
School of Health Systems and Public Health
5th Floor, HW Snyman Building North
31 Bophelo Road
Gezina
0031
Cell: 072 982 1397
E-mail: hazzymapipa@gmail.com

Supervisors: Mrs L. Wolvaardt and Dr F. Senkubunge
Date: August 2014
DECLARATION

I, Hazel Mapipa declare that this research report is my own work. It is being submitted in partial fulfillment of the requirements for the Degree of Master of Public Health at the University of Pretoria, Johannesburg. It has not been submitted before, for degree or examination at this or any other University.

Signature:

Date:

At:
Contents

Declaration
Abstract
Introduction
Methods
Results
Discussion
Recommendations
References
Annexures
  - Tables and figures
  - Instruction to authors
  - CEO letter
  - Assessment tool
  - Protocol
Adherence to rehabilitative services of patients living with neurological conditions: a South African context

Hazel Mapipa¹, JE Wolvaardt¹, F Senkubuge¹

¹ School of Health Systems and Public Health University of Pretoria.

Abstract

Introduction

Good adherence to rehabilitative services is critical for optimal health. Practitioners assume that if the patients fail to show up for their appointments they have lost interest. This study sought to establish the reasons for the poor adherence of patients with different forms of neurological disorders at the rehabilitative services of the outpatients department of Tambo Memorial Hospital (TMH).

Methods

This study used a mixed methods study design. One-on-one interviews with patients booked to receive therapy at TNM and who failed to attend therapy were done (n=12). For triangulation purposes interviews were conducted with the patients who have never missed sessions (n=5).

Results

A total of eight of the participants from both groups said that they had not accepted their condition. The participants gave very positive feedback on the rehabilitative services received at the hospital, but said circumstances beyond their control had caused them to miss a session. The need to earn income among those working in the informal sector was a negative influence on adherence.

Conclusion

The reasons for adherence or lack of it are not easily established. Contributing factors however were noted in this study. These include participants not being able to go to their therapy sessions due to a fear of...
losing their jobs, unavailability of a mode of transport, poor services at primary health care clinics when down referred.

Information obtained from the study will assist health professionals at TMH to provide services that are more tailored to the patients and improve adherence.

**Keywords**

Adherence, rehabilitation, stroke, physiotherapy, quality of health care
Introduction

Adherence encompasses numerous health-related behaviors that extend beyond taking prescribed pharmaceuticals (WHO 2009). Stroke is a major source of mortality and morbidity in the world (Edward et al 2013), and its effects require good adherence to outpatient physiotherapy sessions to ensure optimal rehabilitation. Despite rehabilitation, 40% of stroke patients are left with moderate functional impairments and 15% to 30% with severe disability (American Heart Association 2004). The number of people with disabilities is increasing due to chronic diseases, war, HIV/AIDS, malnutrition, accidents and substance abuse (WHO 2005). Population growth and medical advances that preserve and prolong life contribute to this increase in disabilities (WHO 2005), with a resultant increased pressure on the health system.

South Africans aged five years and older were classified as disabled in 2011 and 2012 and women (5,4%) were more likely to be disabled than men (4,8%) (CENSUS 2011). The growing prevalence of people with disabilities places rehabilitation services under pressure and emphasizes the need for adherence to post-acute rehabilitation guidelines as this is associated with improved patient outcomes (Duncan et al 2002). While health systems have a responsibility towards those with disabilities, disabled people should make use of the resources at their disposal. But the availability of resources such as rehabilitation services is not the only factor that affects adherence.

According to the WHO (2003), adherence is a multidimensional phenomenon determined by the interplay of five sets of factors (Figure 1).

Osamor and Owumi (2011) noted that socio-economic status was not found to be an independent predictor of adherence to treatment. It is feasible that in developing countries, low socio-economic status might put patients in the position of having to choose between competing priorities. Some socio-economic factors reported to have a significant effect on adherence are: illiteracy, low levels of education, unemployment, lack of effective social support networks, unstable living conditions, long distances from treatment centers, high cost of transport, high cost of
medication, culture, lay beliefs about illness and treatment, and family dysfunction (Osamor and Owumi 2011).

The effect of the health care system-related factors on adherence is inconclusive. Some system-related factors that have a negative effect on adherence to rehabilitative services include poorly developed health services, lack of knowledge and training for health care providers, overworked health care providers, lack of incentives and feedback on performance, short consultations, weak capacity of the system to educate patients and provide follow-up, inability to establish community support and self-management capacity, lack of knowledge on adherence and of effective interventions for improving it (Jack et al 2010). A growing body of evidence indicates that patients do better within a well-organized, multidisciplinary approach (Stroke Unit Trialists Collaboration 2002), and Albaz (1997) concluded that organizational variables such as: time spent with the health practitioner, continuity of care, communication and interpersonal style of the practitioner are far more important than socio-demographic variables like gender, marital status, age, educational m0level and health status in affecting patients’ adherence. Despite this evidence, there is a tendency to focus on patient-related factors as the cause of adherence problems (WHO 2003).

Condition-related factors represent particular illness-related demands faced by the patient. These influences on adherence may be related to severity of symptoms, level of disability (physical, psychological, social, and vocational), and the rate of progression. Lifestyle factors such as alcohol and drug abuse together with comorbidities such as depression are important modifiers of adherence. Gonzales et al (2007) suggest that even low levels of depressive symptomatology are associated with nonadherence.

Factors such as the duration of treatment are described as therapy-related factors (WHO 2003). Most notable are those related to the immediacy of beneficial effects, side effects, and the availability of medical support to deal with them. Some of these factors challenge earlier findings (Ottenbacher and Jannell 1993) who suggested that the improvement in performance is related to early initiation of treatment rather than the duration. The studies by Verheyden (2008) and Mandip et al (2012)
emphasized a different time factor. They found a strong correlation between neurological conditions and time – recovery is seen within six months after incidence, and very little thereafter.

Adherence is also influenced by patient-related factors such as personal resources, knowledge, attitudes, beliefs, perceptions and expectations. Furthermore patients' knowledge and beliefs about their condition, motivation to manage their condition, confidence in their ability to engage in illness-management behavior, expectations regarding the outcome of treatment, and the consequences of poor adherence interact in ways not yet fully understood to influence adherence behavior (WHO 2003). A patient's motivation to adhere to prescribed treatment is influenced by the value that is placed on following the regime (Casula et al 2012). Patients remain the most important part of the multidisciplinary team and the literature on patient satisfaction generally confirms that utilization of healthcare services and satisfaction are positively related (Keith 1998).

Within the complex interplay of the five interrelated dimensions that affect adherence, only some are modifiable from a service provision perspective. This paper describes the contributing factors of poor adherence to rehabilitative services at a district hospital with the primary aim of informing the rehabilitation services.

**Methods**

The study setting was the physiotherapy outpatient department of the Tambo Memorial Hospital (TMH) in the Ekurhuleni Metropolitan District.

A mixed methods study design was used. The target population was adult patients (eighteen years and older) who had neurological conditions that required physiotherapy rehabilitation and who had missed at least one session. The exclusion criteria included all in-patients receiving rehabilitative treatment and all patients with severe speech and/or communication difficulties. A purposive sampling method was applied and patients who met the inclusion criteria were identified from the out-patients appointment book.

The study sample consisted of 17 adult patients with various forms of neurological
conditions; twelve of whom had been referred for physiotherapy services and failed to attend at least one session on an out-patient basis, and five neurological patients who had not interrupted their treatment were interviewed for triangulation purposes.

The interview guide consisted of questions adapted from the Standardized Stroke Performance Measurement Implementation Guide (2008) and contained 10 open-ended questions and 21 close-ended questions. A pilot study was conducted in the same study population in order to test and refine the interview guide. Each potential research participant was given an informed consent form that outlined the purpose of the study, the length of the interview, risks involved with participation, anonymity, and benefits. Those who agreed to participate signed the consent form after explanation.

Semi-structured in-depth interviews were conducted with all the participants and audio taped for transcription. Once the saturation of data was reached (no new information was forthcoming regarding the variables of interest) the collection of data ended after 12 interviews. On completion of the interviews, the audiotapes were professionally transcribed and checked by the researcher for consistency. The code L was used to represent the less adherent group, and the code A was used for the adherent group.

The qualitative data was coded using the factors described by the WHO adherence model. Ethical approval was obtained from the Ethics Committee at the University of Pretoria (S148/2012) and permission was obtained from the Chief Executive Officer of TMH.

Findings

The demographic profile of the respondents is reported, followed by a description of the factors that affect the respondents’ adherence to rehabilitative treatment. The WHO adherence model is used to structure the findings and quotes are used to illustrate the experience of the participants.
Demographic profile of respondents

The demographic data of both the adherent (A) and less adherent (L) groups is depicted in Table 1. More (n=8; 66%) of the L participants were males compared to only one (20%) in the A group. Group L had a large majority (n=9; 75%) of their patients from the age group 30 to 39 years old, and participants were found in the age group 40-49 years.

Social and Economic factors

Only one (20%) of the participants in group A was employed at the time of the interview, and five (42%) in group L (Figure 2). The largest proportion among the unemployed participants from both groups (35%; n=6) had been employed in the informal sector prior to becoming ill: “Since I got sick, I was unable to work, and my madam hired another lady to clean her house and now my children are hungry” (A3). Those who still have their jobs expressed the difficulty in fulfilling work duties: “The grip on my left hand is still not strong enough, and I tire very easily” (L7), and taking time to attend the rehabilitation classes is a battle: “I couldn’t come because my boss refused to give me authority to come, what can I do, my children need to eat” (L2).

The highest level of education was similar between the two groups with seven (58%) reaching the level of high school and five (42%) never making it beyond primary school in group L. Three (60%) of the participants in group A received government grants compared to seven (58%) in group L (Figure 3), but these were not always the disability grant: “The child support grant for my two children is the only way we are putting food on the table. I am still waiting for the social worker response for my disability grant. We have filled up all the papers. I don’t know how long we can wait. Life is very difficult right now.” (L4). Four (80%) of the adherent participants had between one and five dependents in one family, compared to nine (75%) of the less adherent participants having between one and five participants in one family. The need to generate additional income and their ability to support their families was a concern: “I can’t even wipe my own bum right now so mixing cement is an impossible task” (A1). Feelings of being abandoned were evident: “Our system is very corrupt. I have spent my whole life working, and now that I am sick the system doesn’t care to my needs” (L4).
Health care system related factors

The participants in both groups expressed conflicting views about rehabilitative equipment used at the TMH: “This place has everything from training bicycles, weights for the arms, those walking bars we use to support us when we are walking” (A3). But the availability of the equipment did not necessarily imply that the equipment was functional: “The things here sometimes don’t work. Like the other day we had to use my sock to tie my foot to the footrest of the bicycle. It was really uncomfortable but the therapist tried her best. She is great. (Smiling)”(L6). All of the participants from both groups were NOT satisfied with the current frequency of a fortnightly session. Two (16%) participants from the less adherent group were referred to Reiger Park clinic, a primary health care clinic used for down referral purposes, and neither were happy: “I decided that going there [new site] would be a waste of my time. First you wait for a long time, and then when you finally go through, they just put you on a machine, few minutes, they say goodbye see you next time. Oh no!” (L11).

Condition-related factors

All twelve (100%) of the participants from the group L were all diagnosed with a stroke in the past six months, compared to two (40%) in group A. None of the participants (both groups) reported being aware of any side effects due to the medication received, and none (both groups) reported any drug and alcohol abuse. Furthermore, none of the participants from both groups were aware of being on any prescribed anti-depressants. “The doctor prescribed a lot of pills for me, so if I am getting those anti what what, then I wouldn’t even know” (L5). Participants required an explanation on what anti-depressants are before answering. Once explained, nine (75%) of the group L, thought that they would benefit from anti-depressants compared to only one person in group A: “So you say these pills will help improve my mood? So can I ask just ask the doctor to give them to me at the clinic?” (L7).

Therapy-related

When participants were asked about their views on the rehabilitation received, and the impact rehabilitation has had on their condition, all the participants from both groups (n=17) gave overwhelmingly positive feedback. All the participants had noted great improvements in their mobility and ability to perform general daily activities
since commencement of their rehabilitation journey. Four (80%) of the participants in group A had expressed their desire to have longer sessions but no-one in group L had a similar wish. Group A participants reported that the therapists checked with them for suitable dates and times for future bookings and always tried to synchronize their sessions with that of any other hospital appointments (n=4; 80%) compared to group L (n=5; 42%).

Explanation about their condition was viewed as poor in both groups (40% for group A and 50% for group L). Little effort was made to ensure that any explanations were understood: “The doctor used very big words to explain I think. I didn’t understand a word obviously (laughing), so I later asked the nurse on duty for an explanation. She just said “there has been bleeding in your brain, and the doctor is not sure what caused it” (L11). Only one (20%) of the group A participants was diagnosed more than 6 months ago compared to nine (75%) in group L.

**Patient-related factors**

Every single participant showed a sense of optimism about their prospective levels of functionality: “*When I walk again I will appreciate all the small things that I used to take for granted*” (A4). When the patients were asked whether they had accepted their condition, four (80%) of group A participants said they have not accepted their condition compared to four (33%) in the group L. Eight (66%) of the group L participants believed that their sickness was due to witchcraft compared to two (40%) of group A: “*Once the bad spirits have been cleared from my house, things will improve for me, but I need money to slaughter a cow and I need to make at least three buckets of African beer*” (L11). “*Lots of bad things have been happening in my neighbourhood, so many witches walk amongst us everyday. I never thought they would get me but they did*” (L2). Four of the participants (33%) in the less adherent group reported consuming alcohol compared to none in the adherent group. None of the participants in the study reported the use of any illegal drugs.

**Reasons for missing a session/s**

The participants in group L had several reasons for missing a session/s: five (42%) said they forgot about their appointment; three (25%) said they had to work; and four (33%) said they were not feeling well on the day: “*I really don’t know what happened.*
I guess I just forgot about my appointment. There is always a lot on my mind” (L5). Changing circumstances were another influence: “A lot has changed at home. My wife had to work on that day. She is the one that makes it possible for me to come here every time” (L10).

Discussion
According to the WHO (2003) adherence is a multidimensional phenomenon determined by the interplay of five factors. Socio-economic factors such as employment status seemingly affect the participants’ ability to attend the sessions because the employers and colleagues complain when they take time off to attend rehabilitation services. The majority of the participants were/are employed in the informal sector and has no sick leave benefits, so absence from work results in a loss of income. In this study socio-economic factors did not seem to be the most important factor in adherence. This observation is supported by Osamor and Owumis (2011) who reported that socio-economic factors were not a predictor of adherence to treatment. Rather it is likely that time spent with the health practitioner, continuity of care, communication and interpersonal style of the practitioner is more important as indicated by Albaz (1997).

The health care system is a very broad entity and in the study issues of broken equipment used for exercise purposes were raised as a concern by a few participants, whilst some were satisfied, therefore making it difficult to nominate the state of the physiotherapy equipment as a contributor to lack of adherence. Down referral to the primary health care clinic (Reiger Park clinic) is a possible barrier to adherence with both the less adherent participants referred complaining of the services. An interruption in the continuity of care and perceived inadequate service contributes towards lack of adherence (Albaz 1997). The schedule for each of the participants was one physiotherapy session a fortnight which is inadequate to achieve the general goals of rehabilitation. The adherent group seemed aware of the benefit of having more sessions, but due to the uncompromising patient to therapist ratio, a more regular schedule is unlikely.

In this study, few condition-related differences emerged. All the participants in the adherent group were stroke patients which presented with serious physical
impairments, and subsequently increased their dependency on others. Depression cannot be ruled out in all the patients regardless of them not receiving anti-depressants. The interest in the benefits of anti-depressants among the less adherent participants suggests that depression is overlooked by medical personnel or is merely not a concern. Gonzales et al (2007) found that even low levels of depressive symptomatology are associated with nonadherence.

The therapy-related factors were similar in both groups, and none of the participants could fault the therapy they received. All the participants (both groups) wanted to increase the frequency of their sessions. However only the adherent participants expressed a desire to have longer sessions, possibly because the adherent participants placed more value on physiotherapy. This finding is similar to that of Albaz (1997) who reported that time spent with the health practitioner influences adherence. The majority of the less adherent participants reported that their sessions were not booked to synchronize with that of the other health services in the hospital – a possible contributor to poor adherence as patients do better within a well-organized, multidisciplinary approach to rehabilitation (Stroke Unit Trialists Collaboration 2002). In the South African context, patient to therapist ratios are high making rehabilitation a challenge but good patient-provider relationship assists to improve adherence (Jack et al 2010). The less adherent group participants had been diagnosed more than six months ago and further improvements in their physical abilities are unlikely (Verheyden 2008 and Mandip et al 2012). It is possible that the decline or halt in their rate of improvement since the start of rehabilitation was a contributing factor to poor adherence.

Patient-related factors which include the participants personal resources, knowledge, attitudes, beliefs, perceptions and expectations about their condition and treatment were found similar in both groups. Differences however were noted in the acceptance of their condition and diagnosis. Many in the less adherent group had not accepted their condition, and patients' knowledge and beliefs about their condition affect their motivation to manage their conditions (WHO 2003). A possible explanation for non-acceptance of their condition among the less adherent participants might be due to the lack of a simple and understandable explanation by a healthcare professional. The less adherent participants' belief in witchcraft is
suggestive of yielding control to outside forces resulting in a feeling of helplessness. Until the “powers” are removed little value is placed on the regime and motivation to adhere to prescribed treatment will be poor (Casula et al 2012).

The reasons for missing sessions given by the less adherent group in this study namely, working, forgetfulness, and not feeling well gained more meaning through probing. The little inconsistencies that were found between the adherent and less adherent groups regarding the condition-related and patient-related factors suggest that all the participants had similar challenges but some were more able to overcome these challenges.

**Conclusion**

Adherence is a very simple idea. A patient can adhere, not adhere, or adhere somewhat to a prescribed rehabilitation programme. The reasons for this adherence or lack of it are not easily established. Contributing factors however were noted in this study. These include participants not being able to go to their therapy sessions due to a fear of losing their jobs, unavailability of a mode of transport, poor services at primary health care clinics when down referred, inadequate therapy sessions (one session in a two week period), untreated cases of depression, lack of good understandable education about their condition and treatment.

**Recommendations**

- Screening for depression needs to be a priority for the attending doctor, and once signs are noted by the therapist, a referral needs to be done to the doctor.
- The physiotherapists need to on their first session with the patients, educate using simple terms about their condition, the effects and the importance of adherence within the critical first six months.
- Physiotherapy sessions should be increased to at least two sessions a week for the first six months of rehabilitation and dropped to once a month for those above the six month mark post incident .This approach will utilize the same therapy staff without increasing the load.
REFERENCES


Casula M, Tragni E, Catapano AL 2012 Adherence to lipid-lowering treatment: The patient perspective 6:805–814

Census 2011 Statistical release P0301.4 Statistics South Africa


Edward C, Jeffrey L, Harold P 2013 Guidelines for the early management of patients with acute ischemic stroke: A guideline for healthcare professionals 44:870-872

Gonzalez JS, Safren SA, Cagliero E, Wexler JD, Delahanty L, Wittenberg E, Blais MA, Meigs JB, Grant RW 2007 Depression, self-care, and medication adherence in type 2 diabetes: Relationships across the full range of symptom severity 30:2222-2227


WHO Library Catalogue American Heart Association 2004 Heart and Stroke Statistical Update in Dallas, Texas: American Heart Association
Section 2

Protocol

Information leaflet, informed consent and interview guide

Letter of consent from hospital

Letter of consent from ethics committee
Identifying the reasons for poor adherence to rehabilitative services in patients with neurological conditions at a district hospital

Master of Public Health

Author: Hazel Mapipa

Student number: 29271356

Contact details:
Address: Faculty of Health Sciences
School of Health Systems and Public Health
5th Floor, HW Snyman Building North
31 Bophelo Road
Gezina
0031
Cell: 072 982 1397
E-mail: hazzymapipa@gmail.com

Supervisors: Mrs L. Wolvaardt and Dr F. Senkubunge

Date: July 2012
Identifying the reasons for poor adherence to rehabilitative services in patients with neurological conditions at a district hospital

Executive summary

This research seeks to establish reasons for the poor adherence of patients with different forms of neurological disorders particularly those that are receiving rehabilitative services at the outpatients department of Tambo Memorial Hospital (TMH). TMH functions primarily as a rehabilitation community health centre (CHC) in this regard. Currently it is assumed that if the patients fail to show up for their appointments they have lost interest. The study will allow researchers the opportunity to establish the actual reasons for poor adherence to rehabilitative services especially the physiotherapy services. One-on-one interviews with patients booked to receive therapy and who failed to show up will be done. The valuable information obtained from the patients shall subsequently be utilized by the TMH and other institutions who similarly face issues of adherence.
TABLE OF CONTENTS

1. Background .............................................................................................................................................. 4

2. Aims and objectives

   2.1.1 Research question .................................................................................................................. 14

   2.1.2 Research sub-question .......................................................................................................... 14

   2.2 Aim .................................................................................................................................................. 14

   2.3 Objectives ...................................................................................................................................... 14

3. Methods

   3.1 Study design .................................................................................................................................... 14

   3.2 Study setting .................................................................................................................................... 14

   3.3 Study population and sampling .................................................................................................... 15

   3.3.1 Target population ..................................................................................................................... 15

   3.3.2 Study population ....................................................................................................................... 15

   3.3.2.1 Inclusion criteria .................................................................................................................... 15

   3.3.2.2 Exclusion criteria ................................................................................................................... 15

   3.3.3 Selection Method ..................................................................................................................... 15

   3.3.4 Selection Size ........................................................................................................................... 15

   3.4 Measurement .................................................................................................................................... 16

   3.5 Pilot study ......................................................................................................................................... 16

4. Data management and analysis

   4.1 Data management .......................................................................................................................... 16

   4.2 Data analysis ...................................................................................................................................... 17

   4.3 Data storage ..................................................................................................................................... 17

5. Ethical and legal considerations ................................................................................................................. 17

6. Logistics and time management ................................................................................................................... 19

7. Budget/Resources

   7.1 Available resources ....................................................................................................................... 20

   7.2 Budget and budget motivation ...................................................................................................... 20

8. Reporting of results .................................................................................................................................... 21
SHSPH Research Protocol

9. References .................................................................22
BACKGROUND

Neurologic diseases are disorders of the brain, spinal cord and nerves throughout the body. Together they control all the workings of the body. When something goes wrong with a part of the nervous system, one can have trouble moving, speaking, swallowing, breathing or learning. Some people have problems with their memory, senses or mood.

The way disability is defined and understood has changed in the last decade. Disability was once assumed as a way to characterize a particular set of largely stable limitations. Now the World Health Organization (WHO) has moved toward a new International Classification of Function (ICF) system. The system emphasizes functional status over diagnosis. The new system is not just about people with traditionally acknowledged disabilities diagnostically categorized but about all people. For the first time, the ICF also calls for the elimination of distinctions between health conditions that are 'mental' or 'physical'.

The new ICF focuses on analyzing the relationship between capacity and performance. If capacity is greater than performance then that gap should be addressed through removing barriers. The WHO defines disability as a contextual variable, dynamic over time and in relation to circumstances. One is more or less disabled based on the interaction between the person and the individual, institutional and social environments. The ICF also acknowledges that the prevalence of disability corresponds to social and economic status.

The Fifty- Eight World Health Assembly reported that about six hundred million people live with disabilities of various types. Of this total, 80% live in low-income countries, most of them are poor and do not have access to basic services, including rehabilitation facilities. Their primary struggle is to survive and meet basic needs such as food and shelter, particularly when they are severely or multiply disabled.
The number of people with disabilities is increasing. War injuries, landmines, HIV/AIDS, malnutrition, chronic diseases, substance abuse, accidents and environmental damage, population growth, medical advances that preserve and prolong life, all contribute to this increase. These trends are creating an overwhelming demand for health and rehabilitation services. The WHO aims to ensure equal opportunities and promotion of human rights for people with disabilities, especially those who are poor.

The WHO believes the health care system of a country must be responsive to the needs of its clientele and the system must be applied equitably to all clients in an accessible manner\(^6\).

Rehabilitation services are an integral part of the services provided at the primary level. The rehabilitation service paradigm constitutes a reorientation of rehabilitation from mainly institution-based services to community-oriented and community-based services. The clinic is the first point where people with disabilities, their family members or caregivers meet health staff. Clinics need to become creative in their approach to the problems experienced by these patients. The purpose of rehabilitation at the clinic level is to provide a service to prevent disabling conditions; to detect disabilities early to prevent complications and the worsening of the effects of a disability on a person’s functional ability; to treat disabling and potentially disabling conditions; and to provide access to rehabilitative services for people with disabilities, and to do this by making services appropriate and acceptable\(^7\).

Now with the above responsibilities highlighted, it makes one wonder where the patient’s responsibility lies. It is assumed that when facilities have been built, then patients are expected to use them. Adherence has proven to be an important factor in the outcome of patients. Examples include failure to adhere to a medication regime, exercise regime etc.

The facility that will provide the setting for the study is Tambo Memorial Hospital (TMH). TMH is one of the 38 hospitals in the Gauteng Province, South Africa’s most densely populated province.
TMH is situated in the Ekurhuleni Metropolitan District. The hospital functions both as a regional and a district hospital. The hospital has 540 functional beds and a staff establishment of 1308. Tambo Memorial Hospital is one of the oldest hospitals in Gauteng. It began as a joint venture between the state and the East Rand Property Mines on August 1905. The state assumed full control over the hospital in 1948 and named it the Boksburg-Benoni Hospital. The hospital’s name then changed to Tambo Memorial Hospital on April 1997. TMH has a service package appropriate for a Regional Hospital. These include amongst others Internal Medicine, Surgery, Obstetrics and Gynaecology, Paediatrics, Orthopaedics, Accident and Emergency and Anaesthetics. These clinical services are supported by Allied Medical services.

Ekurhuleni has a total surface area of ±2 000km² that accommodates a population of ±2.8 million. This constitutes ±5.6% of the national population and makes up 28% of the Gauteng population. The population density is approximately 1 425 people per km², making Ekurhuleni one of the most densely populated areas in the country and province. By comparison, population density in Gauteng is 605 people per km² and 40 people per km² in the country.

Migration into the area is a key challenge. This is visible in the number of informal settlements and informal trading activity. The Household Satisfaction Survey 2010 records 896 117 households – a number likely to increase when taking migration into account. The average annual population growth rate within the metropolitan area was 1.8% over the period 2001 to 2009. This exceeds both the national and Gauteng growth figures for this period. Ekurhuleni has a resident population of approximately 2.8 million people, of which 48.4% is economically active. With ±27% of the local population living in poverty and the current unemployment rate at ± 27%, the levels of poverty and unemployment in Ekurhuleni are unacceptably high. The majority of people living below the poverty line live on the urban periphery, far away from job opportunities and social amenities.
Five interacting dimensions affecting adherence

According to the WHO, adherence is a multidimensional phenomenon determined by the interplay of five sets of factors of which patient-related factors are just one determinant (Figure 1). The common belief that patients are solely responsible for taking their treatment is misleading and most often reflects a misunderstanding of how other factors affect people's behaviour and capacity to adhere to their treatment.

Socioeconomic status has not consistently been found to be an independent predictor of adherence. In developing countries low socioeconomic status may put patients in the position of having to choose between competing priorities. Some factors reported to have a significant effect on adherence are: poor socioeconomic status, poverty, illiteracy, low level of education, unemployment, lack of effective social support networks, unstable living conditions, long distance from treatment centre, high cost of transport, high cost of medication, changing environmental situations, culture and lay beliefs about illness and treatment, and family dysfunction.

An interesting study by Albaz in Saudi Arabia concluded that organizational variables e.g. time spent with the health practitioner, continuity of care, communication and interpersonal style of the practitioner are far more important than socio-demographic

---

Figure 1 The five dimensions of adherence (WHO)
variables such as gender, marital status, age, educational level and health status in affecting patients' adherence.

Race has frequently been informally reported to be a predictor of adherence, but no research supports this hypothesis. Often, cultural beliefs are the reason behind these racial differences, but no less often social inequalities confound these findings. For example, in the United Kingdom, HIV-positive black Africans have been found to have a different experience of treatment because of their fear of being experimented on, distrust of the medical profession and fears of discrimination.

Age is a factor reported as affecting adherence, but inconsistently. Race should be evaluated separately for each condition, and, if possible, by the characteristics of the patient and by developmental age group i.e. children dependent on parent, adolescents, adults and elderly patients.

Adherence to treatment by children and adolescents ranges from 43% to 100%, with an average of 58% in developed countries. Several studies have suggested that adolescents are less adherent than younger children. The adherence of infants and toddlers to recommended treatment regimens is largely determined by the ability of the parent or guardian to understand and follow through with the recommended management. As age increases, children have the cognitive ability to carry out treatment tasks, but continue to need parental supervision. School-aged children engage in the developmental task of industry, learning to regulate their own behaviour and control the world around them. As children enter school, they spend less time at home with their parents and are increasingly influenced by their peers and the social environment.

At the same time, increasing numbers of single and working parents have shifted more of the responsibility for disease management to the child. Assigning too much responsibility to a child for management of his or her treatment can lead to poor adherence. A few studies indicate that, like adults, children exaggerate their adherence behaviours in their self-reports to their guardians. Parents need to understand that inaccurate diary reporting may hinder appropriate disease management by clinicians. These findings underscore the value of parental
supervision and guidance of children in their health behaviours. Shared family responsibility for treatment tasks and continuous reinforcement appear to be important factors in the enhancement of adherence to prescribed treatment for the paediatric population. In addition to parental supervision, behavioural techniques designed to help children, such as goal-setting, cueing, and rewards or tokens, have been found to improve adherence in the school-aged population.\textsuperscript{12}

Adolescents are capable of greater autonomy in following treatment recommendations. Adolescents struggle with self-esteem, body image, social role definition and peer-related issues. Poor adherence in adolescents may reflect rebellion against the regimen's control over their lives. Most studies indicate that children and adolescents who assume early sole responsibility for their treatment regimen are less adherent and in poorer control of their disease management. Both sustaining parental involvement and minimizing conflict between adolescents and their parents are valuable in encouraging adherence to treatment regimens.\textsuperscript{14} Providing families with information on forming a partnership between the parent(s) and the adolescent is of considerable importance in promoting adherence to treatment for this age group. Education focusing on adolescents’ attitudes towards their disease and its management should be done extensively, and may be beneficial.

Elderly people represent 6.4 % of the world's population and their numbers are increasing by 800 000 every month.\textsuperscript{16} They have become the fastest-growing segment of the population in many developing countries.\textsuperscript{15} Many elderly patients present with multiple chronic diseases, which require complex long-term treatment to prevent frailty and disability. Adherence to treatments is essential to the well-being of elderly patients, and is thus a critically important component of care. In the elderly, failure to adhere to medical recommendations and treatment has been found to increase the likelihood of therapeutic failure and to be responsible for unnecessary complications, leading to increased spending on health care, as well as to disability and early death.\textsuperscript{16}

Very little research has been conducted on the effects of the health care team and system-related factors on adherence, whereas a good patient-provider relationship may improve adherence. However there are many factors that have a negative effect
on adherence to rehabilitative services. These include, poorly developed health services with inadequate or non-existent reimbursement by health insurance plans, poor medication distribution systems, lack of knowledge and training for health care providers on managing chronic diseases, overworked health care providers, lack of incentives and feedback on performance, short consultations, weak capacity of the system to educate patients and provide follow-up, inability to establish community support and self-management capacity, lack of knowledge on adherence and of effective interventions for improving it\textsuperscript{13}.

Condition-related factors represent particular illness-related demands faced by the patient. Some strong determinants of adherence are those related to the severity of symptoms, level of disability (physical, psychological, social and vocational), rate of progression and severity of the disease, and the availability of effective treatments. Their impact depends on how they influence patients' risk perception, the importance of following treatment, and the priority placed on adherence. Co-morbidities, such as depression, drug and alcohol abuse, are important modifiers of adherence behaviour\textsuperscript{13}.

There are many therapy-related factors that affect adherence. Most notable are those related to the complexity of the medical regimen, duration of treatment, previous treatment failures, frequent changes in treatment, the immediacy of beneficial effects, side-effects, and the availability of medical support to deal with them. Unique characteristics of diseases and/or therapies do not outweigh the common factors affecting adherence, but rather modify their influence. Adherence interventions should be tailored to the needs of the patient in order to achieve maximum impact.

Patient-related factors might be resources, knowledge, attitudes, beliefs, perceptions and expectations of the patient. Patients' knowledge and beliefs about their illness, motivation to manage it, confidence in their ability to engage in illness-management behaviour, and expectations regarding the outcome of treatment and the consequences of poor adherence, interact in ways not yet fully understood to influence adherence behaviour.
Some of the patient-related factors reported to affect adherence are: forgetfulness; psychosocial stress; anxieties about possible adverse effects; low motivation; inadequate knowledge and skill in managing the disease symptoms and treatment; lack of self-perceived need for treatment; lack of perceived effect of treatment; negative beliefs regarding the efficacy of the treatment; misunderstanding and non-acceptance of the disease; disbelief in the diagnosis; lack of perception of the health risk related to the disease; misunderstanding of treatment instructions; lack of acceptance of monitoring; low treatment expectations; low attendance at follow-up, or at counselling, motivational, behavioural, or psychotherapy classes; hopelessness and negative feelings; frustration with health care providers; fear of dependence; anxiety over the complexity of the drug regimen, and feeling stigmatized by the disease.

A patient's motivation to adhere to prescribed treatment is influenced by the value that he or she places on following the regimen (cost-benefit ratio) and the degree of confidence in being able to follow it. Building on a patient's intrinsic motivation by increasing the perceived importance of adherence, and strengthening confidence by building self-management skills, are behavioural treatment targets that must be addressed concurrently with the other factors in order to improve adherence.

Establishing the epidemiology of disability in South Africa is a difficult task because baseline data on disability prevalence is not readily available. Prevalence studies on disability in South Africa have used different definitions of disability which makes comparison of disability rates problematic.

Most of the prevalence studies on overall disability in South Africa have used a two-stage methodology for self-reported disability and confirmed medically diagnosed impairment. The disability survey by the Department of Health (DoH) was a one-stage study for self-reported disability. The major disadvantage of results obtained from self-reported disability is that, they need to be carefully interpreted. For example, reported motor disability may only be an indication of a subjective manifestation of difficulty with body functions.

Crude prevalence rates for disability are given where age/sex-specific adjusted rates are not available. The non-availability of adjusted rates makes the comparison of
prevalence rates in different areas or from different studies difficult. This is further compounded by the variation in the prevalence of different disabilities according to age and sex. The national disability study gave an overall crude prevalence rate of 2.0% for reported movement disability, 1.7% for reported moving around disability and 1.8% for reported activities of daily living disability\textsuperscript{22}.

Therapy services offered to patients at TMH aim to optimise the level of independence of each of the patients scheduled to receive rehabilitative services, and failure to adhere to the full rehabilitation programme makes attaining the goal very difficult.

Despite the clear benefits of adherence to the full rehabilitation programme, adherence remains poor amongst patients with neurological conditions at TMH. The long-term effects of this poor adherence on both the physical functioning of the patient and the cost to the health system are amongst the main motivating reasons for trying to discover the exact reasons for the poor adherence.

AIMS AND OBJECTIVES

2.1.1 RESEARCH QUESTION
What are the reasons for poor adherence of patients with neurological conditions to rehabilitative treatment offered at a district hospital?

2.1.2 RESEARCH SUB-QUESTION
What do neurological patients who do attend the rehabilitation services consider enabling factors to ensure adherence to rehabilitative physiotherapy treatment?

2.2 AIM

To determine the reasons for poor adherence of patients with neurological conditions to rehabilitative treatment at the Tambo Memorial hospital.
2.3 OBJECTIVES

- To explore the reasons for poor adherence to rehabilitative treatment.
- To develop recommendations of possible interventions to curb the given reasons for poor adherence.

3. METHODS

3.1 STUDY DESIGN

A qualitative study design with a component of quantitative study design will be employed for the purpose of the study. In-depth face-to-face semi-structured interviews will be conducted. An interview guide (Appendix A) with both open and close ended questions will be used. Each questionnaire will be anonymous and individually coded.

3.2 STUDY SETTING

Tambo Memorial Hospital Outpatient Physiotherapy Department, Boksburg, South Africa.

3.3 STUDY POPULATION AND SAMPLING

3.3.1 Target population

Adult patients (with ages eighteen and upwards) with different forms of neurological conditions and referred by the physician or the specialist to receive physiotherapy services on an out-patient basis at the TMH.

3.3.2 Study population

Adult patients from the target population who have either discontinued rehabilitation (defined as missing at least one session with a physiotherapist) or who have never started the planned rehabilitation sessions. For triangulation purposes, patients who have been attending the rehabilitation sessions as prescribed will be interviewed as well to determine what the enabling factors that promote attendance are.
3.3.2.1 Inclusion criteria
The study will include:
- All adult patients with neurological conditions scheduled to receive physiotherapy services at Tambo Memorial Hospital on an out-patient basis regardless of sex, or race.
- All patients who meet the criteria of the study population.

3.3.2.2 Exclusion criteria
- All patients receiving rehabilitative treatment as in-patients at the time of the study.
- All patients with severe speech and/or communication difficulties.

3.3.3 Selection Method
A purposive selection method will be used as only those who meet the inclusion criteria of the target population will be sampled. All those who meet the criteria will form part of the study.

Selection frame
The appointment book used by the physiotherapists responsible for treating patients in the outpatient department will be used to acquire the details of the patients who have defaulted by missing at least one appointment with a physiotherapist or who have never attended the planned physiotherapy sessions, and those who attended all the physiotherapy sessions as prescribed.

Selection size
This is a qualitative study with a smaller quantitative component as the study seeks to explore the reasons of non-adherence of treatment in this hard-to-reach population. Patients who meet the inclusion criteria will be included in the sample and interviewed. Once saturation of data has been reached (no new information is forthcoming) the collection of data will end. Until saturation of data is reached, the researcher will continue to interview patients. The minimum amount of interviews to be done is ten.
3.4 MEASUREMENT

A semi-structured in-depth interview will be conducted in the patient’s home (for those who have discontinued attendance) and audio taped for transcription. Similarly semi-structured in-depth interviews will be conducted with those patients who are attending rehabilitation services. These interviews will be done in a separate private room at the outpatient department and will also be audio taped for transcription. Part of the interview schedule includes a researcher-constructed questionnaire as a data capturing tool as there are no suitable standardised questionnaires available. The questionnaire consists of both open and closed-ended questions using Likert type questions. To ensure that the questions on the questionnaire are well understood by the participants, the interviews will be conducted by the researcher in English, Afrikaans, and Zulu. Translation of the questionnaires will be done by the researcher and will be translated back into English by other translators to ensure that the original meaning has been preserved. In those patients with poor literacy levels, or severe disability, people caring for the patients e.g. the spouse or carer will be invited to participate in the interview.

3.5 PILOT STUDY

A pilot study will be conducted in the same study population in order to test the data capturing tool and prepare for subsequent changes. Two Interview guides for each of the languages to be used in the study namely, Afrikaans, English, and Zulu will be included in the pilot study. An interview will be done with each participant in order to obtain their thoughts about the interview guide. Areas of interest will include the clarity and length of the questionnaire as well as the skill of the interviewer.

4. DATA MANAGEMENT AND ANALYSIS

4.1 Data Management

After completion of the interview the audiotape will be professionally transcribed and checked by the researcher. A copy of the audiotape and the transcription will be kept in a password-protected folder on the researcher’s computer.
4.3 Data analysis

The quantitative data will be analysed using STATA version 11.0. The open-ended questions will be coded using an inductive method to create meaning of the text. On completion of the data coding, categories will be formed and subsequently themes will be constructed and linked to the study question to bring meaning to the findings.

4.4 Data storage

All the data obtained during the course of the study such as completed questionnaires, signed informed consent forms, demographic and contact information of the participants, interview guides, and electronic files will be stored safely by the researcher where only the researcher and relevant persons can access the information. The hard drive used for backup to keep the records as well as the completed questionnaires will be kept in a lockable cupboard at the researcher’s home. The documents that will be collected during the sessions will be kept with the researcher at all times. All these safety measures will apply throughout the duration of the study, and at the event of the completion of the study, the supervisor at the School of Health Systems and Public Health will store the data for 15 years to comply with the rules of the University of Pretoria.

5. ETHICAL AND LEGAL CONSIDERATIONS

The researcher will obtain permission from the CEO of Tambo Memorial Hospital. Each potential research participant will be given an informed consent form before the study is conducted and each section of the form will be explained thoroughly. The consent form states the purpose of the study, the length of the questionnaire, risks involved with participation, issues of anonymity, benefits, as well as a declaration that they are voluntarily participating in the study. The participant’s signature is required as indication of acceptance of the conditions stated above. The consent forms will be stored at The School of Health Systems and Public Health in accordance with University of Pretoria rules.

The participants will not be given any financial or other rewards and will not be coerced into participation in any way. For the purpose of absolute anonymity, coding of the questionnaires will be done without the participants name and surname.
SHSPH Research Protocol

included. All the information obtained will solely be used for the purposes of the study and will be kept securely in a password-protected computer. When the research is complete, the researcher will write an article as part of her Master of Public Health mini-dissertation. The participants will be allowed access to the final research publications.
### 6. LOGISTICS AND TIME SCHEDULE

<table>
<thead>
<tr>
<th>ACTION</th>
<th>PROPOSED DATE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complete research proposal</td>
<td>03/07/2012</td>
</tr>
<tr>
<td>Hospital CEO approval</td>
<td>10/07/2012</td>
</tr>
<tr>
<td>Submit to Ethics</td>
<td>30/07/2012</td>
</tr>
<tr>
<td>Research approval</td>
<td>15/08/2012</td>
</tr>
<tr>
<td>Data collection</td>
<td>20/08/2012</td>
</tr>
<tr>
<td>Data management</td>
<td>02/09/2012</td>
</tr>
<tr>
<td>Complete first draft of write up</td>
<td>15/09/2012</td>
</tr>
<tr>
<td>Approval for Masters Research Project</td>
<td>03/10/2012</td>
</tr>
</tbody>
</table>
7. BUDGET/ RESOURCES

7.1 AVAILABLE RESOURCES

The researcher will use their own transport and the travel costs will be covered with a personal budget. The printing of all the questionnaires, audio taping material, as well as other costs involved before completion of the study will be covered by the researcher.

7.2 BUDGET AND BUDGET MOTIVATION

The researcher will cover the cost of the entire project.

Table 1: Proposed Budget

<table>
<thead>
<tr>
<th>RESEARCH EXPENSES</th>
<th>Units</th>
<th>Rate (Rands)</th>
<th>Pages</th>
<th>TOTAL (Rands)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Photocopying and Printing</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Research protocol</td>
<td>8</td>
<td>0.50</td>
<td>25</td>
<td>R96.00</td>
</tr>
<tr>
<td>Research Report</td>
<td>1</td>
<td>0.50</td>
<td>85</td>
<td>R42.50</td>
</tr>
<tr>
<td>Binding</td>
<td>1</td>
<td>50.00</td>
<td>N/A</td>
<td>R50.00</td>
</tr>
<tr>
<td>Data collection tool</td>
<td>30</td>
<td>0.50</td>
<td>2</td>
<td>R30.00</td>
</tr>
<tr>
<td>Professional transcription</td>
<td>1</td>
<td>3,000.00</td>
<td>1</td>
<td>3,000.00</td>
</tr>
<tr>
<td>Transcription</td>
<td>10</td>
<td>200</td>
<td>N/A</td>
<td>2000</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td></td>
<td></td>
<td></td>
<td>R5 218.50</td>
</tr>
</tbody>
</table>
8. REPORTING OF RESULTS

The final results will be communicated through the appropriate forums as advised by my supervisors. Presentation and summarized document of the research findings might be done as a feedback for the rehabilitative staff at Tambo Memorial Hospital, as well as for students and staff at the School of Health Systems and Public Health. A journal article will be submitted to a subsidized peer-reviewed journal. The final mini-dissertation that will include the journal article will form part of the submitted paper for completion of the Master of Public Health.
REFERENCES

16. Ciecharowski PS, Katon WJ, Russo JE. Depression and Diabetes; Impact of depressive symptoms on adherence, function, and costs. Archives of Internal Medical. 27. pg. 3228-3285.
ASSESSMENT TOOL
Dear Participant

1. INTRODUCTION

I invite you to participate in a research study. This information leaflet will help you to decide if you want to participate. Before you agree to take part, you should fully understand what is involved. If you have any questions that this leaflet does not fully explain, please do not hesitate to ask the interviewer Hazel Mapipa.

2. THE NATURE AND PURPOSE OF THIS STUDY

The aim of this study is to explore the reasons why patients miss rehabilitation sessions offered at Tambo Memorial Hospital. You as a patient are a very important source of information.

3. EXPLANATION OF PROCEDURES

This study involves a brief interview. I will ask you some questions about the reasons for not coming to the hospital for your rehabilitation session and your input about the services provided.

4. RISK AND DISCOMFORT INVOLVED

There are no risks involved with participating in the study. Some of the questions I will ask might make you feel uncomfortable but you need not answer them if you do not want to. The interview will take +/- 40 minutes of your time.

5. POSSIBLE BENEFITS OF THIS STUDY

Although you will not benefit directly from the study, the results of the study will be forwarded to the relevant department in the hospital to help improve their services.
6. WHAT ARE YOUR RIGHTS AS A PARTICIPANT?

Your participation in this study is entirely voluntary. You can refuse to participate or stop at any time during the interview without giving reason. Your withdrawal will not affect you or your treatment in any way.

7. HAS THE STUDY RECEIVED ETHICAL APPROVAL?

This study has received written approval from the Research Ethics Committee of the Faculty of Health Sciences at the University of Pretoria and Tambo Memorial Hospital. Copies of each of the approval letters are available if you wish to have one.

8. INFORMATION AND CONTACT PERSON

The contact person for the study is Hazel Mapipa. If you have any questions about the study please contact her on 0729821397 or via email on hazzymapipa@gmail.com

9. COMPENSATION

Your participation is voluntary. No compensation will be given for your participation.

10. CONFIDENTIALITY

All information that you give will be kept strictly confidential. Once we have analysed the information no one will be able to identify you. Research reports and articles in scientific journals will not include any information that may identify you.

CONSENT TO PARTICIPATE IN THIS STUDY

I confirm that the person asking my consent to take part in this study has told me about nature, process, risks, discomforts, and benefits of the study. I have also received, read, and understood the above written information (Information Leaflet and Informed Consent) regarding the study. I am aware that the results of the study, including personal details, will be anonymously processed into research reports. I am participating willingly. I have had time to ask questions and have no objection to participate in the study. I understand that there is no penalty should I wish to discontinue with the study and my withdrawal will not affect any treatment in any way.

I have received a signed copy of this consent agreement.

Participant’s name............................................................(Please print)
Participant’s signature........................................Date..................
Interviewer name...............................................................(Please print)
Interview signature..............................................Date..................
Witness’s name..........................................................(Please print)
VERBAL INFORMED CONSENT

I, the undersigned, have read and fully explained the participant information leaflet, which explains the nature, process, risks, discomforts, and benefits of the study to the participant whom I have asked to participate in the study.

The participant indicates that s/he understands that the results of the study, including personal details regarding the interview will be anonymously processed into a research report. The participant indicates the s/he has had time to ask questions and has no objection to participate in the interview. S/he understands that there is no penalty should s/he wish to discontinue with the study and his/her withdrawal will not affect any treatment in any way. I hereby certify that the client has agreed to participate in this study.

Participant’s name: .............................................................. (Please print)
Interviewer: .................................................................. (Please print)
Signature: .............................................................. Date: ..................
Witness’s name: .............................................................. (Please print)
Signature: .............................................................. Date: ..................

I herewith give consent that the interview may be audiotaped. I understand that the recoding will only be used for this study. Once the study has been concluded the audio material will be archived with the other data collected for this study according to the regulations of the University of Pretoria. Should the researcher wish to use any audio material for any other purpose, additional written permission will be sought.

Participant's name: .............................................................. (Please print)
Participant's signature: .................................................. Date: ..................

Person seeking consent: .Ms Hazel Mapipa
Signature: .............................................................. Date: ..................

Supervisor’s Name: Mrs L. Wolvaardt and Dr F. Senkubuge
Supervisor’s signature: .................................................. Date: 

Interview guide

1. Name:  
2. Sex:  
3. Religion:  
4. Diagnosis:  
5. Age:  
6. Marital Status:  
7. Date of Incidence:  

SOCIAL AND ECONOMIC FACTORS
8. Are you currently employed?  
   YES:  
   NO:  
9. Are you receiving any form of income or grant?  
   YES:  
   NO:  
10. How many dependents do you currently have?  
    NONE:  
    1-5:  
    more than 5:  
11. What is your highest level of education?  
    PRIMARY:  
    HIGH SCHOOL:  
    TERTIARY:  

PATIENT-RELATED FACTORS
12. Did a health professional explain your condition to you?  
    YES:  
    NO:  
13. If so did you understand the explanation?  
    YES:  
    NO:  
14. Would you say that you have accepted your condition?  
    YES:  
    NO:  

THERAPY-RELATED FACTORS
15. Do the therapists check with you the most suitable days and times for the appointments?  
    YES:  
    NO:  
    Non-applicable:  
16. If yes, please state the reason/s why.  
   ............................................................................................................................  
   ............................................................................................................................  
   ............................................................................................................................  

CONDITION-RELATED FACTORS
17. Are you happy with the amount of time spent per session?  
    YES:  
    NO:  
    SOMETIME:  
18. If not happy, why not?  
   ............................................................................................................................  
   ............................................................................................................................  


20. Are you currently on any medication that tries to help improve your mood (Anti-depressants)?

YES: NO:

21. Do you take any alcohol or illegal drugs?

YES: NO: SOMETIMES:

22. If yes, how often do you consume the alcohol or illegal drug?

23. Since diagnosis, do you take alcohol or any illegal drug more than you did before?

YES: NO: SOMETIMES:

24. If yes, please explain why.

25. Do you experience any side-effects from the treatment of your condition?

YES: NO: SOMETIMES:

26. If yes, please tell me more:

Question 27 is only for those who HAVE missed at least 1 physiotherapy session

27. Thank you for spending some of your time to answer my questions. I notice that you have missed some rehabilitation sessions (or have not yet come for rehabilitation). Could you perhaps tell me why? [PROBE]

Question 28 is only for those who have NOT missed any physiotherapy sessions

28. Thank you for spending some of your time to answer my questions. I notice that you always attend your rehabilitation sessions. Could you perhaps tell me what makes it possible for you to attend? [PROBE]
29. Please share with us your thoughts about the rehabilitative services offered at Tambo Memorial Hospital? [PROBE for professionalism, equipment, waiting times, general experience etc]
...................................................................................................................................................................................
...................................................................................................................................................................................
...................................................................................................................................................................................

30. Is there anyone at home that helps you with your exercises? [PROBE]
...................................................................................................................................................................................
...................................................................................................................................................................................

Thank you for sharing this with me.
Do you have any questions you would like to ask?
Permission letter

Hullo Hazel. I am pleased to inform you that the CEO has agreed to allow you to do your research at the hospital. For any assistance contact the Chief physiotherapists, Millie.

Thank you
Johanna Storm (Secretary to CEO)
**Faculty of Health Sciences Research Ethics Committee**

**13/09/2012**

<table>
<thead>
<tr>
<th>Number</th>
<th>S148/2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title</td>
<td>Identifying the reasons for poor adherence to rehabilitative services in patients with neurological conditions at a district hospital</td>
</tr>
<tr>
<td>Investigator</td>
<td>H Mapipa, School of Health Systems and Public Health, University of Pretoria (SUPERVISORS: J Wolfaardt / Dr F Senilibuge)</td>
</tr>
<tr>
<td>Sponsor</td>
<td>None</td>
</tr>
<tr>
<td>Study Degree</td>
<td>MPH</td>
</tr>
</tbody>
</table>

*This Student Protocol was reviewed by the Faculty of Health Sciences, Student Research Ethics Committee, University of Pretoria on 13/09/2012 and found to be acceptable. The approval is valid for a period of 3 years.*

<table>
<thead>
<tr>
<th>Name</th>
<th>Qualification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prof M J Bester</td>
<td>BSc (Chemistry and Biochemistry); BSc (Hons)(Biochemistry); MSc (Biochemistry); PhD (Medical Biochemistry)</td>
</tr>
<tr>
<td>Prof R Deport</td>
<td>(female) BA et Scien, B Curationis (Hons) (Intensive care Nursing), M Sc (Physiology), PhD (Medicine), M Ed</td>
</tr>
<tr>
<td>Dr NK Likibi</td>
<td>Computer Assisted Education</td>
</tr>
<tr>
<td>Dr MP Mathebula</td>
<td>MBChB (Natal); FCS(SA)</td>
</tr>
<tr>
<td>Prof A Nienaber</td>
<td>MBChB(Natal); FCS(SA)</td>
</tr>
<tr>
<td>Mrs M C Nizeku</td>
<td>MBChB(Natal); FCS(SA)</td>
</tr>
<tr>
<td>Snr Sr J Phatolli</td>
<td>BSc (Natal); FCS(SA)</td>
</tr>
<tr>
<td>Dr R Reynolds</td>
<td>MBChB(Natal); FCS(SA)</td>
</tr>
<tr>
<td>Dr T Rossouw</td>
<td>MBChB(Natal); FCS(SA)</td>
</tr>
<tr>
<td>Prof W C van Staden</td>
<td>MBChB(Natal); FCS(SA)</td>
</tr>
<tr>
<td>Prof A Kypkey</td>
<td>MBChB(Natal); FCS(SA)</td>
</tr>
<tr>
<td>Prof T J P Swart</td>
<td>MBChB(Natal); FCS(SA)</td>
</tr>
</tbody>
</table>

Student Ethics Committee

<table>
<thead>
<tr>
<th>Name</th>
<th>Qualification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prof R S K Apatu</td>
<td>MBChB (Lugon, UG); PhD (Cantab); PGDip International Research Ethics (UCT)</td>
</tr>
<tr>
<td>Mrs N Briers</td>
<td>BSc (Stell); BSc Hons (Pretoria); MSc (Pretoria); DHETP (Pretoria)</td>
</tr>
<tr>
<td>Prof M M Eilers</td>
<td>BSc (Agric) Microbiology (Pret); BSc (Agric) Hon Microbiology (Pret); MSc (Agric) Microbiology (Pret); PhD Microbiology (Pret); Post Doctoral Fellow (Pret)</td>
</tr>
<tr>
<td>Dr R Leech</td>
<td>B.Aet et Scien; BA Cur; BA (Hons); M (ECE); PhD Nursing Science</td>
</tr>
<tr>
<td>Mr S B Masambuka</td>
<td>BA (Communication Science) UNISA; Certificate in Health Research Ethics Course (B compliant cc)</td>
</tr>
<tr>
<td>Dr S A S Olorunju</td>
<td>BSc (Hons). Stats (Ahmadu Bello University –Nigeria); MSc (Applied Statistics (UKC United Kingdom); PhD (Ahmadu Bello University – Nigeria)</td>
</tr>
<tr>
<td>Dr L Schoeman</td>
<td>CHAIRPERSON: (female) BPharm (Lugon, UG); BPharm (North West); BAHons (Psychology)(Pretoria); PhD (KwaZulu-Natal); International Diploma in Research Ethics (UCT)</td>
</tr>
<tr>
<td>Dr R Sommers</td>
<td>Vice-Chair (Female) MBChB; M.Med (Int); MPharmMed.</td>
</tr>
<tr>
<td>Prof L Sykes</td>
<td>BSc, BDS, MDent (Pros)</td>
</tr>
</tbody>
</table>

**DR L SCHOEMAN; BPharm, BA Hons (Psy), PhD;**

**Dip. International Research Ethics**

**CHAIRPERSON of the Faculty of Health Sciences**

**Student Research Ethics Committee, University of Pretoria**

© University of Pretoria
Annexure for the paper entitled:

Adherence to rehabilitative services of patients living with neurological conditions: A South African context

Figure 1: The five dimensions of adherence (WHO 2006)

Table 1: Demographic profile of the study participants

Figure 2: Employment status of the participants

Figure 3: Grant status
Figure 1: The five dimensions of adherence (WHO 2006)

Table 1: Demographic profile of the study participants

<table>
<thead>
<tr>
<th>Variables</th>
<th>Categories</th>
<th>Number of participants (n)</th>
<th>Percentage (%)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>L</td>
<td>A</td>
<td>L</td>
</tr>
<tr>
<td>Age</td>
<td>20-29</td>
<td>2</td>
<td>3</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>30-39</td>
<td>9</td>
<td>2</td>
<td>75</td>
</tr>
<tr>
<td></td>
<td>40-49</td>
<td>0</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>50+</td>
<td>1</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>Gender</td>
<td>Male</td>
<td>8</td>
<td>1</td>
<td>66</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>4</td>
<td>4</td>
<td>33</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>CVA/Stroke</td>
<td>6</td>
<td>5</td>
<td>50</td>
</tr>
<tr>
<td></td>
<td>Spinal injuries</td>
<td>2</td>
<td>0</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>Cerebral Palsy</td>
<td>1</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>TB spine</td>
<td>3</td>
<td>0</td>
<td>25</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>12</strong></td>
<td><strong>5</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Figure 2: Employment status of the participants

Figure 3: Grant status
Guidelines for Authors (South African Journal of Physiotherapy)

Contributions to the South African Journal of Physiotherapy are invited on any topic related to physiotherapy or rehabilitation. All articles that are submitted to the journal for publication must be accompanied by two questions with the correct answers.

Types of Manuscripts
1. Research
2. Case report
3. Clinical report
4. Technical report
5. Literature review
6. Short Report

All manuscripts should be accompanied by a reference list.

Legal Considerations
Contributions will be considered for publication in the South African Journal of Physiotherapy on condition that;
• they have not been published previously.
• they have not been submitted for publication elsewhere.
• the Publications Division of the SASP reserves the copyright of all material published.

Acceptance of manuscripts
All manuscripts will be reviewed by two appointed referees.

Preparation and Presentation of Manuscripts

Articles
1. Articles should be restricted to between 2 000 and 2 500 words.
2. Three copies submitted should be typewritten with double spacing and wide margins.
3. A title page should be supplied as a separate sheet and include the name(s), qualifications and affiliation(s) of the author(s), together with addresses and
telephone numbers (at home and at work).

4. Each article must be accompanied by an abstract of not more than 200 words. This should be on a separate sheet and should be intelligible without reference to the main text. Up to five key words should be included.

5. All abbreviations should be spelt out when first used.

6. The metric system is to be used throughout.

7. Headings must be presented in upper and lower case. Avoid using capitals only.

8. Authors must provide contact details; telephone numbers and email as well as postal address and institutional affiliation (hospital, University).

**Letters to the editor**

- if a letter is intended for the correspondence column it should be marked "for publication".
- it should be no longer than 400 words.

**References**

The accuracy and the completeness of references are of the utmost importance, and a maximum of 15 references per paper is required.

1. References in the Text of the Article

When referring to more than one paper, place the names of the principal authors in alphabetical order, eg Armstrong (1990), Jones (1988) and Smith and Jones (1990) refer to similar findings. When there are two authors of a paper, mention both, eg Smith and Jones (1990), but when there are three or more, mention only the principal author and follow with et al, eg Thomas et al (1980).

- Smith and Jones (1990) refer to similar findings.

If quoting directly from another author, place the words in inverted commas and include the page number on which the quotation appears. For example: The clinical significance of increased tension or interruption of free movement in neural tissues is well recognized...” (Yaxley and Jull 1990, p.143) (Reference: Allison G (editor) 1997 Australian Journal of Physiotherapy Guidelines for Authors. In: Scientific Writers’ Handbook. Australian Journal of Physiotherapy (publisher): 117)

2. Reference list

This should appear at the end of the paper in alphabetical order. The author’s name should be followed by the initials (unpunctuated) and separated from the next author by a comma. The names of all the authors should be cited and et al should not be
used in the reference list. Next should follow the date of publication and then the
details of the publication.
a) Journal articles. Having stated the authors and the year of publication, the title of
the article should be given in full. There should be a full stop after the title. This
should be followed by the full title of the journal (abbreviations should not be used),
then the volume number (not the part number) followed by a colon and then the first
and last pages of the publication. The required format is illustrated in the following
example: Erickson M, Upshur C 1989 Caretaking burden and social support:
Comparison of mothers of infants with and without disabilities. American Journal of
Mental Retardation 94:250-258
b) Books. The format as illustrated in the example should be followed. (Note the use
of punctuation and capital letters1).
F.A. Davis Company, Philadelphia
2) Shephard KF 1993 Questionnaire design and use. In: Bork CE (ed) Research in
Physical Therapy, ppl76-204. J.B. Lippincott Company, Philadelphia Illustrations
• Tables and figures should be kept to a minimum and be on separate sheets.
• Each table should be numbered and have a clear title. Tables should not repeat
material stated in the text. All tables and figures must be referenced in the text in
sequential order.
• Don’t send photographs as an integral part of a Word document. Send them
separately as a Jpeg file.
• All illustrations should be clearly marked on the reverse side with arabic numerals,
author’s name and article, and an indication of the top side.
• All legends must be typed on a separate sheet.
• If a figure has been published before, the author must submit written permission
from the copyright holder to reproduce the material.
**Manuscript submission**
• A covering letter, which must include the signature of each co-author, should
accompany each manuscript.
• Permission to reprint figures, extracts or abstracts from other
publications should be included with the manuscript on submission.