COMMUNITY PARTICIPATION FOR PEOPLE LIVING WITH SPINAL CORD INJURY IN THE TSHWANE METROPOLITAN AREA

A thesis submitted to the physiotherapy department at the University of Pretoria in partial fulfilment of the requirements for the degree PhD Physiotherapy

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DEDICATION

This thesis is dedicated to my late farther, Mr Matthews Mabudushane Moswane, who always encouraged his children to work hard and reach for the stars.

'Thanks dad, for all your support and encouragement
– I so wish you were here to see this in person.
You are and will always be PAPA NUMBER ONE!'

DECLARATION

I declare that "An *Assessment Of Factors Influencing Community Participation For People Living With Spinal Cord Injury In The Tshwane Metropolitan Area"* is my own work, and that it has not been submitted for any degree or examination in any other university. All the sources I have used or quoted have been indicated and acknowledged by means of complete references.

DJ Mothabeng
Signature …….. November 2010

Dr. CA Eksteen
Witness…….

STUDY PUBLICATIONS

The following publications emanated in preparation for and during the course of the study:

Published:

Mothabeng DJ, Malinga CP, Van der Merwe CB, Qhomane PT, Motjotji SN (2007): The views of patients with Spinal cord injuries on their rehabilitation experience. *South African Journal of Physiotherapy 63 (3): 22 – 25*

Mothabeng DJ (2007): A perspective on Disability and Rehabilitation. *South African Journal of Physiotherapy 63 (1): 32 – 34*

Submitted for publication:

Mothabeng DJ Factors influencing the participation of people living with Spinal cord injuries in physical activity. *Submitted to: South African Journal of Physiotherapy*

Mothabeng DJ, Measurement in Rehabilitation – a perspective. *Submitted to: Journal of Community and Health Sciences*

Mothabeng DJ, Eksteen CE and Westaway M. Psychometric validation of the Return to Normal Living Index as a measure of participation for people living with spinal cord injury in South Africa. *Submitted to the Journal of Physiotherapy Science.*

Mothabeng DJ, Eksteen CE and Westaway M. Socio-demographic correlates of community participation in people living with spinal cord injury in South Africa. *Submitted to the Disability and Society Journal*

Abstract

Background and Purpose:

People living with SCI (PLWSCI) have to cope with various challenges when they return home after institutionalized rehabilitation, especially with integrating back into and participating in their communities. To date no study has been conducted in South Africa to empirically measure community integration or to evaluate factors affecting the community integration of PLWSCI. The purpose of the study was to investigate factors influencing the community participation of PLWSCI after rehabilitation.

Methodology:

A cross-sectional, analytical research design employing both qualitative and quantitative approaches was used.

Data collection

Phase one: Participants were identified from the databases of two rehabilitation centers, and the snow balling technique. Data were collected by implementing: the socio-demographic and injury profile (SDIP), the Return to Normal Living Index (RNLI), the Spinal Cord Injury Measure – version II (SCIM II) and the Craig Hospital Inventory of Environmental Factors – short form (CHIEF-SF).

Phase two: In-depth face to face interviews were conducted with a purposely selected sample group from participants of phase one of the study to determine how participants perceive their community participation.

Data Analysis:

Phase one: Data were analyzed using version 17 of the Statistical Package for the Social Sciences (SPSS 17). Descriptive statistics, T- tests, Pearson product-moment correlation coefficients and one way analysis of variance (ANOVA), with Bonferroni adjustments for multiple comparisons, was done to examine demographic characteristics and participants' community participation.

Data from Phase 2 was subjected to data-reducing procedures using qualitative techniques.

Results – Phase One

One hundred and sixty PLWSCI (134 males and 26 females) from the Tshwane metropolitan area participated in this phase of the study. The participants were predominantly young, male, unemployed and single and their major cause of SCI was road traffic accidents, which accounted for 71% of the injuries.

The participants' satisfaction with their community participation was generally low, only 20% expressed satisfaction with their community participation. Satisfaction with community participation was significantly associated with the participants' race, level of education, employment, educational qualifications, years of living with SCI, level of SCI, health complications, perceived health status, functional ability and perceived environmental factors such as physical (structural and geographic) barriers and lack of transport.

Results – Phase 2

Fifteen PLWSCI participated in interviews. Two themes influencing participation were identified from the interview transcripts: Personal factors (coping skills, rehabilitation experience, future aspirations, personal needs, psycho-emotional issues and meaningful use of time) and Environmental factors (attitudes of others, social support and accessibility issues).

Conclusion

The results of the two phases revealed that community participation of PLWSCI was mainly related to three major categories of factors: personal factors, disability-related factors and environmental factors. Satisfaction with community participation was greater in participants who had been living with SCI for longer periods, had more years of basic education, were not black Africans, lived in

suburbs, and were employed. A positive outlook on life and engagement in creative activities during free time enhanced community participation.

Disability-related factors included level of SCI, functional ability and perceived general health influenced satisfaction with community participation.

Community participation was greater in participants who experienced fewer environmental barriers. “Attitudes of members of society”, “accessibility of the environment” and “social support” influenced the participants’ satisfaction with community participation.

A framework for facilitating community participation of PLWSCI was developed. Strategies to be implemented by various multi-sectoral stakeholders to enhance community participation are proposed.

Keywords: spinal cord injury, community participation, environmental factors, personal factors, socio-demographic factors

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Firstly, I would like to thank my Lord and saviour Jesus Christ, for being with me throughout my challenging years of study. Without Him I can do nothing. This thesis is testimony that nothing is impossible with God. To Him is the glory!

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May the Almighty God *who is able to do exceedingly abundantly above all that you can think or imagine* (Ephesians 3:20) bless you all.

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PREFACE TO THE THESIS

The preface to this thesis is an anecdotal case study based on a true story. The name and other identifying features of the individual have been changed to protect the individual, in keeping with ethical principles. This preface is intended to highlight the plight of people living with disabilities, specifically those living with spinal cord injuries, thus illuminating the rationale behind this study.

Melita is a 34 – year old single mother who used to live in a two – roomed rented shack in Mamelodi, a predominantly black township n the North-Eastern part of the Tshwane metropolitan area. She has two daughters aged eight and 12 years respectively, living with her mother in a semi-rural village 100km north of Tshwane. She was involved in a car accident a year ago, when the overloaded taxi she had boarded to work overturned and she sustained injuries to her cervical spine resulting in complete C6 Quadriplegia. Prior to her accident, she was a casual labourer, working as a domestic worker in the suburbs near her township twice a week, on Tuesday and Thursdays. The rest of the week she sold vegetables in the street of her township as a means of income generation. These two 'jobs' sustained her family for three years prior to her injury.

After the accident, Melita was admitted to a local hospital where her injuries were stabilized. Two weeks later she was referred to a spinal unit where she underwent rehabilitation. She was fully rehabilitated and after six months in the rehabilitation unit, she discharged home in a wheelchair. She did not qualify for compensation through the Road Accident Fund because the taxi she was injured in was involved in a 'single-vehicle' accident.

Because she was not working for two months, she could not afford to pay the rent for her shack anymore and had to go and live with her children and her mother in the village. She has applied for a disability grant, and is waiting for the outcome – she can barely make ends meet. The question is: (1) was her family and the community at large ready to receive and live with her in her condition and (2) was she physically, mentally and otherwise prepared to face life out in the community? Was the community Prepared in terms of accessibility to accommodate PLWSCI such as Melita?

Melita's wish was 'to work for my children and educate them so they can have a better future'. But what kind of work can an unskilled and uneducated tetraplegic woman expect to find in the rural village? In the deep rural villages, people with severe disabilities are looked down upon as they are seen as a curse. Her aging mother could not look after her, so Melita spent most of the time in bed in her mother's house. Melita was kept indoors while her little girls were fortunately being looked after by relatives. Within two months after going to the village, Melita was re-admitted to hospital with severe pressure ulcers and major depression. She did not make it…… how many others out there are like her?

Melita's story is but one of many, with different causes and trajectories. The psychosocial consequences of a serious disability like SCI which include losing employment are too enormous. Even if Melita had lived long enough to receive the disability grant of R1050 per month, how far would it have stretched to sustain her? One wonders who is failing who in these cases. Are the health professionals not adequately equipping

PLWSC for life outside the hospital during rehabilitation, or are the social circumstances just impossible to survive with a serious SCI?

Melita's life story also poses a number of questions for rehabilitation policy and practice. Was her fate dictated by society's non-preparedness to receive her? Was she adequately prepared for life in the community? If she was completely rehabilitated, why did she not cope with participating in normal life roles in the community? This thesis takes us through a journey that attempts to unravel these questions systematically in an attempt to provide solutions for similar and other situations.

In this study, the community participation of PLWSCI after rehabilitation is investigated. It is hoped that this study will provide an understanding of the community participation challenges experienced by people living with spinal cord injury. It also envisaged that the study will highlight the resources and services needed to improve community participation for these people with specific reference to barriers and facilitators. The information gained from this study is anticipated to facilitate the planning, implementation and evaluation of programs to guide rehabilitation professionals, planners and policymakers in addressing the issues raised by the study.