HOME-BASED CARE AND QUALITY OF LIFE FOR PEOPLE WITH PHYSICAL DISABILITIES IN GREATER JOHANNESBURG

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Declaration

I, Aldrian P. Mungani, declare that this research report is my original work, submitted in partial fulfilment of the requirements for the degree of Master of Public Health, in the field of Social and Behaviour Change Communication, in the University of the Witwatersrand, Johannesburg. I have made no use of sources, materials or assistance other than those which have been openly and fully acknowledged in the text. This report has not been submitted to this or any other university before, for any degree or examination.

Signature:

Date: 11 May 2016

Abstract

Introduction: Persons living with disability are among the most marginalized and vulnerable groups in many communities in South Africa. Having a disability has an impact on how an individual feels about their health status as well as the social and psychological aspects of their lives; referred to as an individual's quality of life. Efforts to improve quality of life for people with disabilities have included provision of home based care services which entail day to day care (medical, psychological and material) that a person receives in his or her own community. The overall objective of this study was to determine the relationship between exposure to Home Based Care services and Quality of Life for people with physical disabilities in greater Johannesburg with a view to offer recommendations that seek to improve the service and ensure improved quality of life for people with disabilities. The quality of life domains examined are physical functional status, emotional well-being, social relationships, social support and ability to practically engage with the environment. In addition, the study also described the type and frequency of home based care services available for people with disabilities.

Materials and methods: This study was a descriptive and analytical cross-sectional study of 96 people with physical disabilities 18 years and older. A questionnaire, adapted from the WHO QOL BREF tool was interviewer-administered among participants drawn from clients of the Association of People with Physical Disabilities (APD). Bivariate and multi variate analysis was conducted to detect associations between the demographic characteristics, HBC characteristics and quality of life (both QOL rating and the different domains of QOL).

Results: The majority of the sample (60%) was female and the mean age was 55 with a standard deviation (SD) of 17.8. Three-quarters of the sample (75%) was over the age of 40; with the mean age for males and females at 48 (SD-15.6) and 59 (SD-17.9) years respectively. More than half of the sample (65%) was exposed to HBC services, primarily provided by APD. The most common HBC components among the clients were basic care (52%) as well as basic body exercises (54%). On self-reported QOL, 44.8% considered their QOL to be good. A quarter (25%) would neither describe it as good or bad, stating that life has good and bad moments. About 26% thought their QOL was very poor, with 11.5% considering it to be very poor. Five dimensions of QOL were examined; physical and functional status; emotional/psychological well-being; social support, social relationships and practical environment; and associations tested for each of these with demographic factors sex, age, marital status, and education. Only marital status was positively associated with emotional well-being (p=0.04) while none of the demographic factors were associated with social relationships and practical environment. Married people and people living with partners tended to report better states of emotional well-being as opposed to those who were single, widowed or divorced. Social support was significantly related to HBC (p=0.01) and HBC was also positively associated with physical and functional status (p=<0.01) with the majority of people receiving HBC being in the low (88.9%) and medium (82.5%) physical functionality categories respectively.

Conclusion: The strongest relationship was between HBC and the social support dimension of QOL. The comparison group were people with physical disabilities who received social work services. HBC was shown to increase social support pointing to the fact that the HBC caregivers are seen as a social support structure in the absence of such or contribute to building stronger social support systems for persons with disabilities and their families, which has a positive influence on their quality of life. Study revealed a strong relationship between physical functional status and HBC for persons with physical disabilities, with clients of low functioning status requiring and needing more services. This reveals the importance of augmenting rehabilitation services through specialised therapy support and increasing capacity of HBC caregivers in providing the requisite support. As a result of limited resources and capacity of the HBC caregivers, the HBC program reviewed offer rudimentary services to some who may require more specialised therapy and psychosocial support service. For people with physical motor disabilities, access to multi-disciplinary services including, but not limited to rehabilitation therapy (physio and occupational therapy), psychosocial support and accessibility/mobility improvement support, as proposed in the CBR guidelines, is crucial to enhancing the quality of their lives.

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Contents

Chapter 1: Introduction, Aims and Objectives; and Literature Review

Chapter 2: Methodology

Chapter 3: Results

Chapter 4: Discussion

Chapter 5. Conclusion and Recommendations

List of Acronyms

AIDS	Acquired Immuno Deficiency Syndrome
APD	Association for the Physically Disabled (Greater Johannesburg)
CBR	Community Based Rehabilitation
DPSA	Disabled People of South Africa
HBC	Home Based Care
HIV	Human Immunodeficiency Virus
HRQOL	Health Related Quality of Life
ICF	International Classification of Functionality
LMIC	Low and Middle Income Countries
MDG	Millennium Development Goals
NPO	Non-Profit Organization
QOL	Quality of Life
SF-36	Medical Outcomes Study 36-Item Short-Form Health Survey
UN	United Nations
WHO	World Health Organization
WHO QOL	World Health Organization Quality of Life tool

List of Tables

Chapter 1: Introduction, Aims and Objectives; and Literature Review

This chapter provides an overview of disability in general and physical disability in particular. Prevalence data is presented from global and local perspectives. Concepts of 'quality of life' and 'home based care' are also discussed and review of literature on these concepts in the context of physical disability. The aims and objectives of this study are provided and the chapter concludes with the statement of the problem and justification for the study.

1.1 Introduction

Disability is defined as when an individual with a health condition experiences difficulty in functioning of the body in one or more domains of life in interaction with various aspects of their context (1). It is an "umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a medical condition) and the individual's contextual factors (environmental and personal factors)"(1). Some refer to disability as the "expression of limitations in individual functioning with a social context that represent a substantial disadvantage to an individual" (2). The United Nations (UN) describes persons with disabilities as those with long-term impairments (physical, mental, intellectual, sensory) which, as they interact with various environmental barriers may inhibit their full participation in community activities (3). Physical disabilities refer to intrinsic biological or acquired conditions causing impairments which result in disability and limited participation in day to day activities(4).

Physical disability is often described in topographical terms referring to the body parts affected commonly used in the definition of cerebral palsy and its manifestations. Below are the major classes of physical disability (5).

- **Monoplegia** means only one lower limb is affected.
- **Diplegia** indicates both lower limbs affected, with upper limbs affected minimally.
- **Hemiplegia** indicates the arm and leg on one side of the body is affected.
- **Paraplegia** means the lower half of the body, including both legs, are affected.
- **Quadriplegia** means that all four limbs are affected.

The construct of disability focuses on a socio-ecological, person-environment fit conception aimed at understanding human functioning and disability in terms of the interactions between personal and environmental characteristics, rather than focusing on the pathological defect of the person (2). The International Classification of Functionality (ICF) recognizes two models of understanding disability; the medical and the social models (6). The medical model views disability as a problem of the individual caused by disease, trauma hence treatment or management of the disability targets the individual and is performed by health professionals. The social model however views disability as a result of social, cultural and environmental barriers that permeate society hence the management of disability requires social action and is a responsibility of society (6). An integration of the two models provides a coherent view of disability as it focuses on the individual with the condition as well as his environment and how to make it better for his/her full participation in society. The biopsychosocial provides an integration of the medical and social models, giving a coherent view of the biological, individual and social perspectives and is the basis upon which the ICF classification is built.

The ICF classification of disability recognizes human functionality at three levels which are at the body/body part; the whole person and the whole person in a social context (7). Disability would therefore involve dysfunction at one or more of the levels. At the body part level, it is the impairment; at the whole person level dysfunction would denote activity limitations and the social context level means the individual has participation restrictions. Disability is described as an interaction between the features of a person (internal) and the features of the context (external) that the person lives in (7).

Global disability prevalence statistics, drawn from country reported prevalence data according to the WHO survey and the Global burden of disease study, indicate that there were around 785 million (15.6%) to 975 million (19.4%) persons 15 years and older living with disability; between 110 million (2.2%) and 190 million (3.8%) of whom experienced significant difficulties in functioning. Including children, over one billion people (about 15% of the world's population, based on 2010 population estimates) were estimated to be living with disability (8). Despite these significant numbers, disability was not explicitly mentioned in the Millennium Development Goals (MDGs), in either the 21 targets, or the 60 indicators for achieving the goals (8).

Persons living with disability are among the most marginalized and vulnerable groups in many communities in South Africa and constitute 7.5 percent (2.9 million) of the population in South Africa, up from two percent in 2001 (9, 10). These statistics may be an under-estimate and the Disabled People of South Africa (DPSA), a non-governmental organization representing the interests of people with disabilities, believes that if the definition of disability was considered in the broader sense, including those who use assistive devices and some who are unable to care for themselves, the number could be as high as 19% of the South African population (11). An analysis of the prevalence of disability by type, from the 2011 census in South Africa, shows that 11% had seeing difficulties, 4,2% had cognitive difficulties (remembering/concentrating), 3,6% had hearing difficulties, and about 2% had communication, self-care and walking difficulties (10). Both the General Household Survey and Census 2011 show the highest prevalence of people with disabilities is in the Northern Cape, Free State and North West and, and the lowest prevalence in Gauteng and the Western Cape (5). Older populations are more likely to have a disability; and Gauteng and Western Cape are generally considered to be relatively youthful, which could account for the differences (9).

Having a disability can affect the quality of a person's life. Quality of life refers to an individual's subjective perception of their health and non-health aspects of their lives (12). It is a multidimensional construct encompassing the physical, mental, social and behavioral components of well-being and function (7). Measurement of quality of life is important as it may identify previously unrecognized issues that could be addressed through appropriate interventions while complementing clinical consultation and allowing health professionals to consider issues beyond the physical well-being of the patient (13). Home-based care may affect the quality of life for people living with a disability.

1.2 Background

Home Based Care (HBC) is defined as the day to day care (medical, psychological and material) that a person receives in his or her own community (14) This includes assistance rendered to clients within their homes as well as assistance to access some service offered within the community. HBC received prominence in the HIV and AIDS discourse in response to the rising economic costs of hospital care and the shortage of beds as well as the recognition of the limited benefits of hospital care for many HIV patients (15). HBC service provision for people with disabilities in the Johannesburg region was started by the Association of the Physically Disabled – Greater Johannesburg (APD) in 1990, but was terminated in 1995 due to financial constraints. Realizing that most people with disabilities, especially adults and the elderly stay alone and do not have families to take care of them, the need for a HBC service was highlighted again and services were resumed in 2004, with support from the Department of Social Development (16).

APD is a non-profit organization (NPO) operating in Johannesburg, running programmes for people with disabilities. It is a registered NPO whose vision is working in partnership with people who have physical disabilities, their families and the community as a whole to promote their integration into society and to enable them to achieve their full potential (17). The organization works with grassroots communities, providing social work services, HBC services for people with physical disabilities as well as awareness to breach the gap between the able-bodied and people with disabilities. Social work services are provided to capacitate people with disabilities with knowledge to access relevant services and skills to resolve their problems and attain their full potential to live as independent lives as is possible (16). Two qualified Social Workers and three Auxiliary Social Workers provide the Social Work services and currently serve a total of 130 direct beneficiaries. The HBC programme provides basic care including bathing, dressing, meal preparation, feeding, treatment and prevention of pressure sores, treatment adherence support and supervision, light house cleaning as well as basic body exercises. Three HBC supervisors and 17 Caregivers provide the HBC services to about 200 clients in the community (16). The caregivers are trained in basic caregiving skills and receive frequent in-house training on various areas of disability management. While there has not been a specific requirement for a caregiving qualification as a condition of hire for caregivers; experience in caregiving is a pre-requisite and APD has an internal programme of training to develop skills of the caregivers.

Services for people with physical disabilities in South Africa in general and Gauteng in particular are organized per type of disability. The APD works primarily with people with motor disabilities, referring to people with motor defects affecting their physical functionality. There are other NGOs that focus on people with mental illnesses, the visually impaired, the hearing impaired, and epilepsy, respectively. Some organizations focus on specific disabling conditions for example Cerebral Palsy Association and the Muscular Dystrophy Center. It is important to note that APD as an association does not focus on sensory disabilities but provides services to people with motor difficulties who, are a subset in the broader category of people with physical disabilities. Since this study accessed participants through APD, it focuses on people living with motor disabilities only.

In addition to social work and HBC services discussed earlier, APD also offers services outlined below:-

a) Recruitment service for people with disabilities – to help people with disabilities access employment and self-advancement opportunities, APD links clients with companies and employers willing to employ people with disabilities as well as offer internships for people with disabilities to undergo training. This service also includes raising awareness at various institutions and business premises to improve attitudes towards people with disabilities as well as on how to create enabling environments for employees with disabilities.
b) Wheelchair hire and distribution – APD promotes mobility for people with disabilities by offering wheelchairs, conducting mobility assessments and assisting clients acquire suitable assistive devices to improve their mobility. For those who can afford, APD offers a wheelchair hire service for people who may require wheelchairs for short periods of time and is considered as an income generating activity for the organization.
c) Accessibility assessments – APD conducts accessibility assessments for business premises, schools and other buildings and offer advice to improve accessibility to buildings for people with varying kinds and levels of disability, for example, constructing wheelchair ramps and evacuation protocols people on wheelchairs can gain access in out of buildings.

1.3. Literature Review

1.3.1. HBC services for people with disabilities

This section reviews and provides the distinction between community based rehabilitation and home based care as models for service provision for people with disabilities.

1.3.1.1. Community Based Rehabilitation

In 1978, the World Health Organization (WHO) launched Community Based Rehabilitation (CBR) in an effort to decrease the burden of disability in low and middle income countries (LMIC). This CBR is an inclusive community development strategy that aims at the equalization of opportunities, rehabilitation, poverty reduction and social inclusion of the population living with a disability (18, 19). It is a multi-disciplinary programme premised on principles of mobilizing local resources, transfer of knowledge about disability aimed at changing attitudes towards people with disabilities, community involvement (where community members are willing and able to mobilize local resources and provide the appropriate services), providing rehabilitation services (physical therapy, occupational therapy, mobility training), providing educational and training opportunities for people with disabilities as well as utilization and strengthening of referral systems (20). The strategy promotes delivering rehabilitation services to people with disabilities within their homes and communities, through visiting them and their families in their homes to provide appropriate information, therapy, training as well as facilitating the rights of people with disabilities (21).

There have been significant variations in implementation across countries. An evaluation of CBR programmes in 15 countries, mainly in Asia and Africa, showed that there are benefits of utilizing primary healthcare worker/ community based rehabilitation workers in provision of services to people with disabilities in the community although it has been difficult to meet all the needs of people with disabilities (20). CBR programmes however have encountered challenges in dealing with the impairment aspects of severe disabilities as most CBR programmes do not have adequately trained personnel to deal with this group of people.

1.3.1.2. Home Based Care

Home based care services (sometimes referred to as home rehabilitation or home care), for people with disabilities refers primarily to services offered to people with disabilities in their own homes to assist restore functionality and to perform activities of daily living. This service is often offered by community based organisations, collectives of people with disabilities or families of people with disabilities and other volunteer groups. The main resource is local people who are willing to invest time in service for people with disabilities. Financial resources and technical expertise including rehabilitation is often outsourced.

The efficacy of home based care; for persons with physical disabilities; has been highlighted in numerous studies. A study conducted in Denmark with stroke patients revealed that home rehabilitation was cost effective as compared to standard care and patients rehabilitated at home experienced both increased quality of life as well as improved and increased functional outcomes (22). Home care has become an alternative to hospitalisation and institutionalisation as it reduces inpatient time and cost of care (23). Another study in India, assessing the effectiveness of home rehabilitation on disability and quality of life had similar findings, concluding that early home rehabilitation leads to better management of disability and increased quality of life (24). Home-care services can sustain QoL for people with disabilities, and was shown to prolong stroke survivors' ability to live independent lives while contributing to a positive sense of identity (25). Home-based healthcare requires stroke-survivors to find new ways to solve their problems within their families and with their social relations and therapists (26).

Notwithstanding the documented benefits of both CBR and HBC, some scholars have questioned the cost effectiveness of community and home based care as compared to institutional care, arguing that the cost of the effort, time and emotional cost to those volunteers or providers of the service may be much higher (27). A study on home based care for people with HIV in services showed that HBC was not a cheap service as it proved that the cost of a single home visit would be equivalent to the cost of several inpatient days in a district hospital (14). In addition the study also concluded that HBC was cost inefficient as a substantial amount of resources did not benefit the patient as it endeavours to support the family to care for the patient (14).

1.3.2. Quality of life (QOL)

There is a lack of a consistent and concise definition of the concept of quality of life. The WHO defines QOL as an “individuals’ perception of their position in life in the context of the culture and the value system in which they live, and in relation to their goals, expectations, standards and concerns” (28). The United Nations define quality of life as a notion of human well-being that is measured by social indicators rather than by quantitative indicators of income and production (29). The University of Toronto refers to quality of life as simply “the degree to which a person enjoys the important possibilities of his/her life” (30). Consistent is the notion that it is a subjective concept where the individual’s perception of him/herself in interaction with various factors in their environment is paramount.

Some models and theories of understanding and applying the quality of life concept have been proposed. The University of Toronto proposed the “Quality of life profile” which focuses on three domains of quality of life: being, belonging and becoming (31). “Being” refers to who one is in terms of the physical, psychological and spiritual components; while “belonging” is the connection with one’s environment, including with family and friends in the home and community environments. “Becoming” focuses on one’s achievement of personal goals, aspirations and hopes and involves one’s ability to engage practically in leisure and personal growth (skills and competencies) activities (31). The model holds that an assessment of quality of life should look at the three domains as each has an influence on the other and collectively determines the quality of life of an individual.

There is a rapid growth in QOL research in the developed world aiming at understanding the experiences of patients, their needs as well as measuring how effective the services and interventions on QOL are. In Africa, however, very little research has covered this area (32).

1.3.3 QOL for people with physical disabilities

Research has been conducted that shows the factors influencing QOL for people with disabilities (19, 32-35). In a study to examine the effect of physical disabilities on QOL in adolescents in Taiwan, the subjective well-being of people with physical disabilities was shown to be higher than their non-disabled peers, although their self-reported QOL was poorer in health and material well-being (33). It also showed that older adolescents had lower QOL scores and female adolescents were affected more (33). However, in another study, severity of the disability and age at onset/diagnosis of disability had no effect on the quality of life or satisfaction with life in general (19). Other studies corroborate these findings (34, 35). Having mentioned that, it is highly unlikely that findings from high income countries would be applicable in the African context, given the poverty and stigma associated with issues like HIV and disability in some African communities (32).

1.3.4 Quality of life domains

1.3.4.1 Physical and functional status

Functional status is defined as everyday behaviours necessary to maintain activities of daily living which encompass areas of physical, cognitive and social functioning (36) which is of key importance to health outcomes of people with disabilities. The physical and functional status is based on the measurement of physical capabilities by observation of the client, thereby providing an objective and quantifiable appraisal of patient's performance status (37). In a study on the QOL of black South Africans with physical disabilities, mainly rheumatoid arthritis (RA) and systemic lupus erythematosus (SLE), the findings suggested that for people with disabilities, physical function and general health related QOL are severely affected, mainly as a function of rate of disease progression (38). Specific tools including the Karnorfsky Performance Scale (KPS) and the Physical Performance Test (PPT) have been developed to assess functional status and used for assessing the elderly and cancer patients (37). Other valid measures of disability include the Barthel index of activities of daily living, which aims to establish extent of independence and the Oswestry disability scale which measure permanent functional disability (39).

1.3.4.2 Emotional and psychological well-being

The concept of emotional and psychological well-being is premised on a subjective analysis of an individual's experiences, both negative and positive; and includes the satisfaction with various life domains like family, health and work as a sub-construct. (40). An understanding of how individuals with disabilities view themselves is important in the determination of their quality of life and has been central to rehabilitation psychology (41). The ability to effectively integrate disability into their self-concept has important implications on overall adaptation to disability and therefore overall well-being and quality of life as high levels of subjective well-being is related to positive affective states and high levels of overall life satisfaction (40, 41).

1.3.4.3 Social relationships and social support

Social support relates to an individual’s level of satisfaction with his/her social relationships and (23) including the nature and extent of connections with social relations that provide one support. Despite the pain and symptoms associated with incurable disease and permanent conditions, being active and physical comfort were considered to be less important to QOL than close relationships, feeling at peace and having a sense of meaning in life, in a study on QOL conducted in South Africa and Uganda(32). Also supporting this notion, a study on the association between social participation domains and QOL in older adults with disabilities in Canada showed the importance of social participation such as interpersonal relationships, social roles and responsibilities were highly associated with QOL compared with ability to perform daily activities (42).

In a study of QOL after stroke, one of the frequent issues raised by stroke patients was the importance of maintaining strong social relationships and scholars maintained that failure to measure social relationships would be missing an important dimension of QOL for patients after stroke (43). Most people with disabilities need to depend on others for support with activities of daily living, and disability puts immense stress on social relations resulting often in breaks with family and other support systems. Maintenance of social relationships is therefore critical and may be the most prominent influence of stroke and other disabling conditions on QOL (43). Social support is particularly crucial for the physical and mental health of persons with disabilities as it contributes to how they deal with social vulnerability, stress and illness (23).

1.3.4. Practical engagement with the environment

The concept of engagement with the environment refers to the extent to which people with physical disabilities are able to interact with their environment, including physically accessing their environment and participating in activities of daily living and participating in community activities of interest. Scholars suggest that participation of people with physical disabilities is influenced by interaction between the individual and multiple factors in the environment (44). Literature shows that improved participation and practical engagement of people with disabilities, is a positive result of the intersection of the environmental factors (45) operating at the individual (immediate built environment at home), community (social networking within the community including access to transport and information) and societal (economic and political influence as well as managing societal attitudes) levels (45, 46). An effort to change the environmental barriers at these levels is crucial to ensuring transformative participation for people with physical disabilities (45).

1.3.5 QOL Measurement tools

The types of measurement used to assess QOL are influenced by theoretical perspectives regarding what constitutes QOL; most available measures use a structured approach, typically including factors such as physical, social and role functioning, emotional and material well-being as well as general health (47). The Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) is the most widely used health related QOL tool (48). It assesses eight health concepts by using multi item sub-scales that measure physical functioning, role limitations caused by health problems and emotional problems, social functioning, emotional well-being, pain and general health perceptions (48). The SF-36 is a short and comprehensive measure of health status, designed to be applicable to a range of social and demographic groups in different settings; its validity and reliability has been confirmed for populations in the developed world and has been used in the developing world as well (47). The SF-36 has increasingly become the generic QOL measure of choice across a variety of conditions (47). The SF-36 was used in a study of QOL among epileptic patients in South Africa and it is widely used and regarded as a valid and reliable tool in the South African context (49).

The EQ5D is a standardized instrument applicable to a variety of health conditions and treatments. It is used as a measure of health outcome and is designed to be completed by the respondents themselves as it is a simple and easy to complete questionnaire, with guidelines for completion given on the questionnaire (50). the tool evaluates health related quality of life in the five dimensions of self-care, mobility, pain, activities of daily living and depression/anxiety, providing an index value that can be used to assess health status (50). multiple country study conducted in South Africa and four European countries (Spain, Sweden, Germany, Italy) proved that the EQ5D is a feasible, reliable and valid measure for HRQOL in children and adolescents (51). It would be less useful though when dealing with people with physical disabilities as it strongly relies on respondents completing the questionnaires unaided.

Some researchers suggest the WHO QOL assessment is the outcome measure to be used in community based rehabilitation programmes for people with physical disabilities (20). This assessment includes 100 items and 24 facets relating to quality of life, which are categorized into four groups or domains of physical, psychological, social relationships and environment; and includes a separate aspect measuring perceptions of quality of life and health in general including one facet examining overall quality of life and general health perceptions (28).

The criticism for the WHO QOL and SF- 36 assessments has been that they fail to consider the individual's perception or satisfaction with their condition in the context of their past experiences and future plans (47). Perceptions of what constitutes a meaningful life (QOL) will invariably differ among individuals and since these assessments employ external, pre-determined value systems; an individual's particular goals and activities may not be included in the assessment (47). These criticisms have led to the development of the Patient-Generated index (PGI), which allows the respondents to nominate the domains to be measured, based on what they consider to be important for their own QOL (52). An assessment of the validity of the PGI showed it to be highly correlated to the SF-36, particularly in the scales measuring pain, social functioning and role limitations attributable to physical problems (52).

1.3.6 Relationship between QOL and HBC

Limited research has looked into the quality of life of people with disabilities receiving HBC in low and middle income countries (LMIC). Some information exists on the QOL of people receiving palliative care, mostly from the developed world. Palliative care refers to individualized healthcare and services to people who have intractable chronic or terminal illnesses in the environment of the person's choice, thus providing the best QOL for the client and family (53). Palliative care can therefore be considered a component of home based care. In a study looking at health-related QOL (HRQOL) of palliative care clients in metropolitan Sydney, Australia, while scores for individual scales of HRQOL were highest for support, psychological well-being and existential well-being, overall HRQOL was rated very poorly (54). Findings from another study in Australia suggested that QOL was substantially higher among people with physical disabilities who received rehabilitation services compared to those who did not receive physical rehabilitation, community based rehabilitation or labour market assistance, with the highest scores being recorded from those who received a combination of the three services (55).

1.4 Statement of the Problem

WHO defines health as a "state of complete physical, mental and social well-being and not merely the absence of disease". This definition means that the measurement of health and health care need not only indicate changes in the frequency and severity of disease but also an estimation of well-being as measured through improvements in the quality of life (28), is important, to attain health as depicted by the WHO definition. A gap exists in information that describes the effectiveness of HBC programmes particularly for people with physical disabilities as these programmes are meant to support beneficiaries and contribute to their attainment of a better life by improving their health.

1.5 Justification

People with physical disability constitute the largest subgroup of people with disability (PWD), but not many studies focusing on PWD have been conducted (56). The HBC programme component for PWD aims to assist the PWD with activities of daily living and it is of critical importance to investigate if there is a correlation with the resultant perceived quality of life for the recipients of the service. A gap exists in research in South Africa, as no study has looked at the association between home-based care service provision and QOL, which forms the purpose of the proposed research. The research will provide relevant insight on the quality of life for people with physical disabilities with a view to establishing if there is an association between participating in a HBC programme and QOL in order to come up with recommendations for effective interventions that will improve QOL for people with disabilities. Findings from this research are expected to inform policy and improvements of interventions targeting people with physical disabilities in communities with a view to contributing towards an improvement in their quality of life.

1.6. Aim and Objectives

1.6.1. Aim

To determine the relationship between exposure to Home Based Care services and Quality of Life for people with physical disabilities in greater Johannesburg in 2014 to 2015.

1.6.2. Specific Objectives

i. To describe the type, extent of physical disability and the functional status of people living with physical disability in the greater Johannesburg.

ii. To describe the HBC services offered to people living with physical disabilities in Johannesburg in 2014/15

iii. To measure and describe the dimensions quality of Life (including emotional well-being, social support, social relationships and practical engagement with the environment) for people with physical disabilities in Johannesburg in 2014/15

iv. To establish the relationship between receiving HBC service and QOL of people with disabilities in Johannesburg 2014/15.

1.7. Hypotheses

1.7.1. Null Hypothesis

There is no relationship between receiving HBC services and quality of life for people with physical disabilities

1.7.2. Alternative Hypothesis

People with physical disabilities who are in receipt of HBC services experience better quality of life than those who do not receive the service

Chapter 2: Methodology

2.1. Study Design

This study used a quantitative descriptive and analytical cross-sectional study design. A survey questionnaire was administered among people with physical disabilities. The overall aim of the study was to determine the relationship between exposure to home based care services and quality of life for people with physical disabilities.

2.2. Study site

The study was conducted in the Greater Johannesburg region which includes Johannesburg and areas of the East and West Rand. It consists of different local government units including Ekhurhuleni, West Rand district municipality and the City of Johannesburg Metropolitan municipality. The APD's HBC programme is offered in the areas of Johannesburg and surrounding areas of Alexandra, Soweto, Tembisa and Zandspruit, which all fall within the Greater Johannesburg Region. These areas constituted the communities from which the respondents were drawn.

2.3. Study Population and sampling

The study population included all adults over 18 years of age with physical disabilities in Greater Johannesburg, South Africa, who are served by APD's Social work and HBC programmes. Adults with a physical disability aged 18 years and above, with no known mental /cognitive disorders and were able to respond to questions were included in the study. Exposure to the programme for more than six months was an inclusion criterion. Because of the inclusion and exclusion criteria for the study, the ideal of having an equal number of participants from the HBC and Social Work programme components respectively was not met as the Social Work programme involved a greater number of children who were excluded in the study. The sample size was calculated using the STATA Sampsi command. A difference of 10% in the proportion of those with high quality of life (45% vs. 35%) was anticipated. The sample size was calculated with power of 80% with an alpha of 0.05. The eligible population after considering the inclusion and exclusion criteria was 198 and the target sample size was 150. However, at the time of the study only 118 clients were available due to seasonal variations, that is, most people travel out of Johannesburg to rural homes and other destinations during public holidays like Christmas. The data collection occurred shortly after the December holiday season when many clients were not in Johannesburg. Of the 118 who were available, 13 refused to participate and nine interviews were not completed as the clients were either too sick to participate fully or had major recall challenges. Responses from 96 clients were included in the analysis.

2.4. Data collection

Data were collected using an interviewer-administered structured questionnaire (Appendix A). The questionnaire, adapted from the WHO QOL BREF tool was structured, making use of close ended questions, allowing respondents to choose most applicable response from set response categories (See adaptations in table 1 below). The questionnaires were translated into the Zulu language, which is widely used in the areas where the study was conducted. Back translation was conducted to ensure the concepts and understanding is common and both the English and Zulu versions were used to allow participants to select. The survey questionnaire was pre-tested among a small group of four participants and refined.

Table 1: Questionnaire adaptations

WHO QOL BREF	Adapted QOL Questionnaire	Reliability co-efficient	Comment
1 question – How often do you have feelings such as blue mood, despair, anxiety, despair	Emotional & Psychological well being 4 Questions on feelings of cheerfulness, active, interesting life, ability to share feelings with family/friends	0.76	High internal consistency
3 Questions on ability to partake in leisure activities, daily activities, and capacity to work	Practical and Environment – 5 additional questions on assessing ability to visit family, and attending family and community gatherings including religious activities	0.71	High internal consistency

As indicated in table above, the adaptations scored very high when tested for internal validity on the parameters stated.

Data for this study were collected by the researcher, assisted by trained research assistants who are competent HBC Supervisors and auxiliary social workers, fluent in local languages and have experience working with people living with physical disabilities. The research assistants were trained on the tool to ensure a common understanding of the purpose of the study as well as the concepts under measurement. None were regular providers of home-based care services and during the consent process participants were assured that a decision not to participate in the study would not influence their service provision in any way.

Respondents were called to secure appointments and interviews were conducted in the homes of the clients, upon securing their informed consent. Data collection was conducted over the period January and February 2015.

2.5. Measurement

The questionnaire comprised 50 close-ended questions designed to gather information on the physical, psychological/emotional, social relationships and environment domains of quality of life. The QOL outcomes of interest for this study were self-reported QOL measured using domain-specific items. Each domain was measured through a number of items which were then summed to reflect domain measure (see table 4).

HBC exposure was measured through collecting information on the frequency and type of HBC service received as well as a description of the source of the HBC services. Different clients received different services depending on their needs at a particular time and a list of services provided by APD was provided, from where clients would indicate which service they had received over the reference period. Frequency was rated for overall HBC services and not per type and was placed into categories of weekly, bi-weekly or monthly.

Functional status was measured by use of the Karnorfsky performance status scale which allows clients to be classified as to their functional impairment where a lower Karnorfsky score reflects the most difficulty in ability to perform basic functions and may be associated with serious illness (57). This scale classifies clients, based on their condition, into categories on a scale from 10 which signifies full functionality with no complaints, for example, a person may have a paralysis but is able to carry on normal activities of daily living, down to 1 which signifies a moribund state, where client has a condition that is rapidly deteriorating and requires urgent hospital attention for example advanced muscular dystrophy. The ten categories are shown in table 2 below:-

Table 2: Karnofsky Performance Scale(58)

Criteria	Category
Normal no complaints; no evidence of disease.	**10**
Able to carry on normal activity; minor signs or symptoms of disease.	**9**
Normal activity with effort; some signs or symptoms of disease.	**8**
Cares for self; unable to carry on normal activity or to do active work.	**7**
Requires occasional assistance, but is able to care for most of his personal needs.	**6**
Requires considerable assistance and frequent medical care.	**5**
Disabled; requires special care and assistance.	**4**
Severely disabled; hospital admission is indicated although death not imminent.	**3**
Very sick; hospital admission necessary; active supportive treatment necessary.	**2**
Moribund; fatal processes progressing rapidly.	**1**

The Karnofsky performance scale is an objective scale that relies on physicians' aggregated clinical judgements to provide a global score of physical functionality. It has been shown to have modest interrater reliability between physicians and other health service providers (58).

Information on age group, presence of other people to support in the household, and type of disability was collected and treated as potential confounders on testing the association between HBC and QOL. Information on socio-demographic characteristics for the study participants was also collected and presented. These are age, sex, race, household income level and marital status.

Table below presents the concepts that are presented in the Quality of Life: A systems model and how information on each of these was measured by the study instrument.

Table 3: Incorporation of concepts of the Quality of life: A systems model; into measuring instrument

Model Concept	**How instrument measures (adapted WHO QOL Bref)**
Culture	Not measured
Demographic characteristics	Collected information on age, sex, marital status
Socio-economic conditions	Main source of household income, highest education level
Exposure to HBC	Type and frequency of HBC services, HBC service providers
Family/Friends	Type of and level of support from spouse, immediate family, extended family and friends
Work	Ability and frequency of engaging in daily work routines
Education	Highest education level
Community/neighbourhood	Type of and level of support from community structures (community leaders, support organizations, health centres)
Health	Physical and functional status Severity of pain and its interference with daily work routines Emotional well-being of respondents
Spiritual	Type of and level of support from spiritual leaders Ability and frequency of participation in religious activities

2.6 Data processing and analysis

The researcher received all completed questionnaires on a weekly basis and captured the data on an Epi Info template. Data entry occurred within a week of receiving completed questionnaires and, after checking the required information and that all sections are duly completed. Data cleaning was conducted through checking original questionnaires and where discrepancies were noted, clarifications were sought from the respondents where possible. The researcher also conducted a 10% random check to ensure quality of data entry.

The Epi Info data was transferred onto STATA 11 which is the statistical programme that was used for data analysis. Bivariate-Chi squared test were used to compare the proportions and determine associations between the outcome and exposure variables. Where cell count data were small, Fisher's exact test was used. Binary logistic regression analysis was conducted to test the hypothesized relationship between HBC and QOL while controlling for possible confounders. Frequencies and proportions were used to describe numbers and percentages of participants who were classified into particular categories and presented in the next chapter in table format for easy reading.

Table 4: Description of variables, transformation and analysis conducted by objective

Objective	Variable	Transformation of variable	Analysis
i. To describe the type, extent of physical disability and the functional status of people living with disability in the greater Johannesburg.	Type of disability Cause of disability Physical and functional status	The 10 classes in the Karnorfsky were further categorised into 3 broad categories.	Frequencies and proportions
ii. To describe the HBC services experienced by people living with physical disabilities in Johannesburg in 2014/15	Exposure to HBC (Categorical) Type Frequency Service provider		Frequencies and proportions
iii. To measure the dimensions of Quality of Life for people with physical disabilities in Johannesburg in 2014/15	**QOL dimensions:** Emotional well-being (Score =continuous) -Social support (Score= continuous) Social relationships (Score =continuous) and practical engagement with the environment(Score =continuous) - Overall QOL	A composite variable on each variable was generated, summing together responses from questions that were used to determine the emotional/ psychological well-being, Social support, social relationships, practical environment The 4 variables were further summed to create a QOL index score which was categorized into final QoL categories of low, medium and high	-Proportions in each category (QOL) were reported. -Tables were used to present the categories
iv. To establish the relationship between receiving	-Outcome variable: Quality of life score(Score - continuous)-	Categorised into low, medium & high	-To present the data, a cross tabulation was done.

HBC service and QOL of people with disabilities in Johannesburg 2014/15.	- Main exposure variable: Exposure to HBC (categorical) -Potential Confounders: Age (continuous) Marital status (categorical) Education status (categorical) Sex (Categorical)	Age groups (age was categorised into age-groups)	- Bivariate-Chi squared and Fisher’s exact tests (when there were a small number of observations) were used to compare the proportions and determine associations between the outcomes (QOL dimensions) and exposure variable (HBC) including socio-demographic characteristics -Multivariate analysis using Binary Logistic regression was done and Odds Ratios observed. Four models were designed, with outcome as each of the QOL dimensions and HBC as the focal independent variable as well as physical status and any of the socio-demographic characteristics that was significant in the bivariate analysis e.g. marital status for the emotional well-being dimension.

2.7. Ethics

Ethical approval for the study (Protocol M140858) was obtained from the University of the Witwatersrand's Human Research Ethics Committee (Appendix D). Permission to access beneficiary registers and clients was obtained from the Association for the Physically Disabled (Appendix E).

Participation in the study was voluntary and written informed consent was obtained from all respondents (see Appendix C). The purpose of study was explained to the respondents, as well as assurance that participation in the study is voluntary, they could withdraw at any time during interview (see Appendix B). It was also important to mention that decision not to participate in study would not affect the service they currently receive from the organization. Confidentiality of information discussed in the interview was assured to all participants and the handling of all information from data collection, recording and analysis was conducted in strict confidence, by the researcher and the research assistants. Clients' identities were protected through the use of codes on the questionnaires and their names were not recorded on the questionnaires. Consent forms were kept separately from the completed questionnaires. Questionnaires were stored in a lockable cabinet at the researcher's office. The data set is stored in the researcher's computer, which is password-protected and only the researcher and supervisor had access to the data.

For management of potential distress among participants arising from the interviews, the data was collected by the researcher who is a qualified, experienced social worker, assisted by competent social auxiliary workers and HBC Supervisors who are trained to identify and deal with issues affecting people with disabilities. Provision was also made for specialized counseling services through the APD established referral system.

Chapter 3: Results

The overall objective of this study was to determine the relationship between exposure to HBC services and QOL for people with physical disabilities in greater Johannesburg in 2014. This chapter will present the socio-demographic and disability characteristics of the study sample. QOL outcomes based on each of the domains of quality of life are also presented including an analysis of how each of the domains interacts with the demographic characteristics of people with physical disabilities.

3.1. Socio-demographic characteristics of people with physical disabilities in the study

Table 5: Socio-Demographic Characteristics of PWD

Characteristics	Frequency (n)	Percentage%
Sex (*n=96)*		
Male	38	39.6
Female	58	60.4
Age (years) *n= 96*		
20-39	24	25.0
40-59	33	34.4
60-79	32	33.3
> 80	7	7.3
Mean (SD)	*54.8 (17.8)*	
Education (*n=96)*		
Primary	23	23.9
Secondary	42	43.8
Tertiary	13	13.5
Vocational	8	8.3
None	10	10.4
Marital Status (*n=96)*		
Married/Staying with partner	15	15.6
Single/Never married	57	59.4
Widowed	17	17.8
Divorced/Separated	7	7.3
Household main livelihood source (*n=96)*		
Employed	4	4.2
Social Grant	82	85.4
Remittances	3	3.1
Petty trade	6	6.3
Self-Employed	1	1.0
Client's main caregiver (*n=96)*		
Spouse	6	6.3
Parent	19	19.8
Brother/sister	12	12.5
Son/daughter	18	18.8

Other relative	7	7.3
Self	34	35.4

The demographic characteristics of the participants in this study are described in Table 5. The majority of the sample (60%) was female and the mean age was (55±17.8). Three-quarters of the sample (75%) was over the age of 40, with the other quarter being between the ages of 20 and 39 years. The mean age for males and females was (48±15.6) and (59±17.9) years, respectively.

Ninety percent of the sample had at least some primary education with 43.8% reaching secondary school. While 10.4% had not received any formal education, 13.5% had gone further to tertiary education and 8.3% had been to some vocational training.

The majority of the participants (59.4%) had never been married. About one in eight 15.6% were either married or cohabiting with a partner while some were widowed (17.8%).

A government social grant constituted the main and in most cases the only source of income for most households in the sample (85.4%). Most received the disability grant and few (6.3%) were involved in some petty trade involving sale of small food items and cigarettes. Only four respondents were formally employed while one person was self-employed.

While a third of the sample cared for themselves (35.4%), some were cared for by a parent (19.8%), a sibling (12.5%) or a child (18.8%).

3.2 Disability characteristics and functional status of people receiving HBC or SW services

Table 6: Disability characteristics

Characteristic	Frequency	Percentage%
Assistance with communication		
No assistance required	67	69.8
Spouse	2	2.1
Parent	6	6.3
Sibling	5	5.2
Child	9	9.4
Other relative	8	7.3
Underlying cause of disability		
Stroke	36	38.0
Violence related injury	18	18.8
Other	17	17.7
Motor vehicle accident	10	10.4
Post-polio paralysis	8	8.3
Cerebral Palsy	4	4.2
Gun related injury	3	3.1
Nature of disability		
Hemiplegia	34	35.4
Other	26	27.1
Paraplegia	25	26.0
Diplegia	6	6.3
Quadriplegia	5	5.2

Nearly 70% of the sample had an ability to verbally communicate clearly while others would receive some assistance from caregivers as indicated in Table 6 above. Strokes were responsible for most of the disabilities in the sample (38.0%; n=36). Motor vehicle accidents (10.4%; n=10) and violence (22.0%) accounted for more than a quarter of the disabilities. A significant number had epilepsy while a few were born with physical deformities, for example club foot, which together constituted the ‘other’ category (17.7%). The disabilities manifested in different forms. Most (35.4%) had hemiplegia (substantial loss of function on one side of the body i.e. arm and leg) and about 26.0% had paraplegia which entails a significant loss of function in the lower part of the body. Only 5.2% presented with quadriplegia, which is a more severe form involving loss of function of all the four limbs and a further 6.3% had paralysis of symmetrical parts of the body (diplegia).

3.2.1 Physical and functional status

Table 7: Physical and functional status

Category	Description	Frequency	Percentage %
A	Able to carry on normal activity and to work; no special care needed.	18	18.8
B	Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed	40	41.7
C	Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.	38	39.5

The assessment revealed that the majority of the respondents were in the lower categories in terms of functional status. Only one in five 18.8% were in category A which signifies full functionality and ability to perform activities for daily living. Forty percent were in the low functionality category and were severely disabled, requiring special care and attention. The middle category (41.7%) comprises those who would require occasional assistance but may also be able to care for some of their own needs.

3.3 Home based care and social work services

Table 7 below describes the HBC services. More than half of the sample (65%) was exposed to HBC services, primarily provided by APD; although some (10.4%) also received some services from other mainly faith based organisations in their communities, in addition to APD HBC services. The other 32% received social work services only and served as the comparison group in terms of analysing the association between HBC and quality of life. Two of the respondents had been in receipt of both HBC and social work services.

Table 8: HBC and SW services

Characteristic	Frequency	Percentage%
Exposure to home based care services		
HBC	63	65.6
Social Work	31	32.3
Both	2	2.1
Respondents received HBC from other organisations besides APD		
Yes	10	10.4
No	86	89.6
HBC service component received		
Basic care		
Yes	49	51.0
No	47	49.0
Exercises (therapy)		
Yes	52	54.2
No	44	45.8
Meal preparation		
Yes	4	4.2
No	92	95.8
Treatment		
Yes	11	11.5
No	85	88.5
Adherence support		
Yes	4	4.2
No	92	95.8
Cleaning		
Yes	12	12.5
No	84	87.5

The data showed that the most common HBC components among the clients were basic care (51%) as well as basic body exercises (54.2%). Basic care includes bathing and dressing whereas basic exercises include some physiotherapy, massage, and help with movement of limbs to facilitate blood circulation within the body. Some (11.5%) required treatment of pressure sores while others received services of cleaning and tidying up their residence (12.5%). Support with treatment adherence and meal preparation were the least popular services as only 4.2% of the sample reported having received or required the services. Most of the services were provided on a once per week basis and some, once every fortnight.

3.4 QOL Self-report assessment

Respondents were requested to rate their own QOL, taking into consideration their own standards, hopes, pleasures and concerns. Their responses are captured in table below:-

Table 9: Self-assessed QOL

Characteristic	n	Percentage%
Very poor	11	11.5
Poor	15	15.6
Neither good nor poor	24	25.0
Good	43	44.8
Very good	3	3.1

A significant proportion of the sample considered their QOL to be good (44.8%), although only three respondents described it as very good. A quarter (25.0%) would neither describe it as good or bad, stating that life has good and bad moments. About 26% thought their QOL was very poor, with 11.5% believing it to be very poor.

3.5 Dimensions of QOL

Table 10: QOL Dimension scores

Dimension	Mean (range)	Standard deviation	Kurtosis
Emotional well-being	10.4 (1 - 20)	5.0	2.20
Social relationships	18.7 (3 - 33)	6.0	2.90
Social support	20.9 (2 - 36)	6.9	2.80
Practical & environment	15.8 (1- 40)	8.5	3.02

Table 10 shows the mean scores, standard deviations and distribution for all four dimensions of QOL. The scores are integrated into the sub-sections below that present the results based on key categories.

Table 11: Dimensions of QOL (categorical)

Dimension	Frequency	Percentage%
Emotional Well-being		
High	47	49.0
Low	49	51.0
Social Relationships		
High	44	48.3
Low	47	51.7
Social Support		
High	49	51.0
Low	47	49.0
Practical engagement with the environment		
High	43	45.3
Low	52	54.7

Emotional and Psychological well being

On a scale of up to 20, the mean score for emotional well-being was 10.4, with a standard deviation of five. The categorical variable is presented in Table 8 which shows that 49.0% had higher emotional well-being while the remainder (51%) scored lower.

Social relationships

Social relationships dimension was measured through a series of questions assessing the relationships between the respondent and their family (immediate and extended) including the larger community. Based on the questions, the clients' social relationships had a maximum possible score of 40, where the mean score was 18.7, with a standard deviation of six as shown in Table 10. 48.3% of the sample reported higher quality relationships

Social support

Similar to social relationships, the social support dimension was assessed through questioning the level of support the respondent received from family and the larger community. The mean score for social support was 20.9, with a standard deviation of 6.9.

Practical engagement with environmental

Practical and environment dimension was measured through assessing how respondents interacted with their immediate environment as well as their ability to engage in daily life activities. Of a possible high score of 40, the mean score was 15.8, with a standard deviation of 8.5. The majority (54.7%) reported lower levels of practical engagement with the environment and taking part in activities pf daily living.

3.6. Relationships between socio-demographic characteristics of PWD and QOL Dimensions

Pearson's Chi-squared or Fisher's exact tests were conducted to detect associations between the characteristics of PWD and dimensions of QOL.

3.6.1. Emotional Well-being

Table 12: Associations between characteristics of PWDs and emotional well-being

Characteristic	**Low** **[1]E. Well-being *n (%)***	**High** **E. Well-being *n (%)***	**P-value**
HBC Exposure			
Yes	36 (55.4)	29 (44.6)	0.55 *
No	3 (41.9)	18 (58.1)	
Sex			
Male	21 (55.3)	17 (44.7)	0.50
Female	28 (48.3)	30 (51.7)	
Age			
20-40	10 (41.7)	14 (58.3)	0.45*
40-60	19 (57.6)	14 (42.4)	
60-80	15 (46.9)	17 (53.1)	
80>	5 (71.4)	2 (28.6)	
Marital status			
Married	5 (33.3)	10 (66.7)	
Single	26 (46.6)	31 (54.4)	0.04*
Widowed	12 (70.6)	5 (29.4)	
Divorced	6 (85.7)	1 (14.3)	
Education			
Primary	12 (52.2)	11 (47.8)	
Secondary	22 (52.4)	20 (47.6)	0.87*
Tertiary	5 (38.5)	8 (61.5)	
Vocational	5 (62.5)	3 (37.5)	
No education	5 (50.0)	5 (50.0)	

** Fisher's Exact Test*

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[1] Emotional Well-being

Table 12 presents the associations between the emotional well-being dimension and other characteristics of the sample (n=96). There was no significant relationship between the key independent variable, exposure to HBC services, and the outcome of interest emotional well-being (p=0.55). There were no statistically significant differences with a range of socio demographic characteristics including sex (p=0.50) and education (p=0.87). However, there was a statistically significant difference with marital status (p=0.04). Married people and people living with partners tended to report better states of emotional well-being as opposed to those who were either widowed or divorced.

3.6.2. Social Relationships

Table 13: Associations between characteristics of PWDs and social relationships

Characteristic	Low Soc Rel[2] *n (%)*	High Soc Rel *n (%)*	P-value
HBC Exposure *(n=91)*			
HBC Client	29 (47.5)	32 (52.5)	0.26
Social Work client	18 (60.0)	12 (40.0)	
Sex *(n=91)*			
Male	19 (54.3)	16 (45.7)	0.69
Female	28 (50.0)	28 (50.0)	
Age *(n=91)*			
20-40	10 (43.5)	13 (56.5)	
41-60	16 (51.6)	15 (48.4)	0.31*
61-80	19 (63.3)	11 (36.7)	
>80	2 (28.6)	5 (71.4)	
Marital status *(n=91)*			
Married	8 (53.3)	7 (46.7)	
Single	29 (53.7)	25 (46.3)	0.81*
Widowed	6 (40.0)	9 (60.0)	
Divorced	4 (51.1)	3 (42.9)	
Education *(n=91)*			
Primary	13 (59.1)	9 (40.9)	
Secondary	21 (52.8)	18 (46.2)	0.59*
Tertiary	4 (30.8)	9 (69.2)	
Vocational	4 (50.0)	4 (50.0)	
No education	5 (55.6)	4 (44.4)	

* *Fisher's exact test*

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[2] Social Relationships

For the social relationships dimension data were available for 91 respondents. As described in Table 13, there was no significant relationship between the key independent variable, exposure to HBC services, and the outcome of interest social relationships. None of the demographic factors including age, sex, marital status and education, had a significant influence on the nature of social relationships between the respondents and their larger community.

3.6.3. Social Support

Table 14: Associations between characteristics of PWDs and social support *(n=91)*

Characteristic	**Low Social support *n (%)***	**High Social support *n (%)***	**P-value**
HBC Exposure			
HBC Client	26 (42.6)	35 (57.4)	0.01
Social Work client	21 (70.0)	9 (30.0)	
Sex			
Male	14 (40.0)	21 (60.0)	0.08
Female	33 (58.9)	23 (41.1)	
Age			
20-40	10 (43.5)	13 (56.5)	
41-60	19 (59.4)	13 (40.6)	0.56*
61-80	16 (53.3)	14 (46.7)	
>80	2 (33.3)	4 (66.7)	
Marital status			
Married	5 (35.7)	9 (64.3)	
Single	30 (55.6)	24 (44.4)	0.57*
Widowed	9 (56.2)	7 (43.8)	
Divorced	3 (42.9)	4 (57.1)	
Education Primary	12 (54.5)	10 (45.5)	
Secondary	21 (53.9)	18 (46.1)	0.90*
Tertiary	5 (38.5)	8 (61.5)	
Vocational	4 (50)	4 (50)	
No education	5 (55.6)	4 (44.4)	

**Fisher's exact test*

Table 14 above describes the associations between characteristics of people with disabilities and social support. Data for social support dimension was available for 91 respondents. Sex, age, marital status and education were not associated with social support. Only exposure to HBC services was significantly associated with social support (p=0.01). Most of the people who received HBC services (57.4%) reported significantly higher levels of social support whereas the majority of the comparison group (70.0%), who received mainly social work services, reported lower levels of social support.

3.6.3.1 Support Types

Table 15: Types of support from each support group

Characteristic		Frequency	Percentage%
Spousal support			
Physical	Yes	11	11.5
Emotional	Yes	13	13.5
Financial	Yes	8	8.3
Informational	Yes	4	4.2
Appraisal	Yes	2	2.1
Immediate family support			
Physical	Yes	46	47.9
Emotional	Yes	59	61.5
Financial	Yes	31	32.3
Informational	Yes	14	14.6
Appraisal	Yes	5	5.2
Extended family support			
Physical	Yes	21	21.9
Emotional	Yes	48	50.0
Financial	Yes	13	13.5
Informational	Yes	23	24.0
Appraisal	Yes	4	4.2
Friends support			
Physical	Yes	16	16.7
Emotional	Yes	43	44.8
Financial	Yes	11	11.5
Informational	Yes	30	31.2
Appraisal	Yes	3	3.1
Neighbours support			
Physical	Yes	23	24.0
Emotional	Yes	40	41.7
Financial	Yes	8	8.4
Informational	Yes	31	32.6
Appraisal	Yes	8	8.4
Church/community support			
Physical	Yes	14	14.6
Emotional	Yes	50	52.1
Financial	Yes	6	6.3

Informational	Yes	21	21.9
Appraisal	Yes	2	2.1

Most of those who had spouses in the sample reported receiving mainly physical (77%) and emotional support (90%), with a few receiving financial support from their spouses. The same trend was noticed on support from immediate family members.

Immediate family provided primarily physical (47.9%) and emotional support (61.5%) and about a third (32.3%) received financial assistance from immediate family members. Emotional support appeared to be the most popular kind of support as significant proportions of the sample reported to be receiving it from friends (44.8%), neighbours (41.7%) and church/community groups (52.1%). While the extended family system, friends, neighbours and church groups met some of the sample's informational needs**,** appraisal as a form of support was the least solicited and supplied by any of the support systems. Appraisal refers to an individual's capability to get advice when going through difficulties (59).

3.6.4. Practical Engagement with the Environment

Table 16: Associations between characteristics of PWDs and practical engagement with environment

Characteristic	**Low Practical/Env *n (%)***	**High Practical/Env *n (%)***	**P-value**
HBC Exposure			
HBC Client	33 (51.6)	31 (48.4)	0.37
Social Work client	19 (61.3)	12 (38.7)	
Sex			
Male	24 (63.2)	14 (36.8)	0.37
Female	28 (49.1)	29 (50.9)	
Age			
20-40	14 (58.3)	10 (41.7)	
41-60	22 (66.7)	11 (33.3)	0.17*
61-80	14 (45.2)	17 (54.8)	
>80	2 (28.6)	5 (71.4)	
Marital status			
Married	9 (64.3)	5 (35.7)	
Single	31 (54.4)	2 (45.6)	0.84*
Widowed	8 (47.1)	9 (52.9)	
Divorced	4 (57.1)	43 (42.9)	
Education			

Characteristic	Low Practical/Env[3] *n (%)*	High Practical/Env *n (%)*	P-value
Primary	10 (45.5)	12 (54.5)	
Secondary	20 (47.6)	22 (52.4)	0.31*
Tertiary	9 (69.2)	4 (30.8)	
Vocational	6 (75.0)	2 (25.0)	
No education	7 (70.0)	3 (30.0)	

** Fisher's exact test*

As shown in Table 16, none of the factors age (p=0.17), sex (p=0.37), marital status (p=0.84), education (p=0.31) and exposure to HBC (p=0.37) was statistically associated with level of practical engagement.

3.7. Relationships between QOL and HBC

Due to some missing data in some of the domains, QOL rating data was available for 88 respondents as shown below:-

Table 17: Categorisation of QOL composite score

Characteristic	Frequency	%
Low	9	10.2
Medium	56	63.7
High	23	26.1

The majority (63.7%) of the sample was in the medium QOL category, with only 10.2% recording low QOL. About 26% were in the high QOL category.

3.7.1. Relationship between HBC and QOL composite

Table 18: Relationship between HBC and QOL composite

Characteristic	Low QOL *n (%)*	Medium QOL *n (%)*	High QOL *n (%)*	P-value
HBC	5 (8.6)	36 (62.1)	17(29.3)	0.55*

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[3] Environment

Social Work	4 (13.3)	20 (66.7)	6 (20.0)	

**Fisher's exact test*

Chi square test on the relationship between QOL composite, as the outcome variable and receipt of HBC service as the main exposure variable was conducted. The findings reveal a very weak relationship (p=0.55) indicating that the recipients of HBC were not significantly different from the comparison group who did not receive HBC in terms of their QOL score.

3.7.2 Relationship between Physical and functional status and QOL variables

Table 19: Relationship between physical and functional status and QOL composite (including other QOL dimensions)

Characteristic Physical status	**Low** ***n (%)***	**Medium** ***n (%)***	**High** ***n (%)***	**P-value**
QOL Composite				
Low	2 (11.8)	8 (47.0)	7 (41.2)	0.89*
Medium	10 (20.8)	10 (41.7)	18 (37.5)	
High	5 (21.7)	8 (34.8)	10 (43.5)	
Emotional well-being				
Low	11 (22.5)	22 (44.9)	16 (32.6)	0.33
High	7 (14.9)	18 (38.3)	22 (46.8)	
Social Support				
Low	10 (21.3)	16 (34.0)	21 (44.7)	0.54*
High	8 (18.2)	20 (45.4)	16 (36.4)	
Social Relationships				
Low	8 (17.0)	20 (42.6)	19 (40.4)	0.92
High	9 (20.5)	18 (40.9)	17 (38.6)	
Practical engagement				
Low	12 (23.1)	23 (44.2)	17 (32.7)	0.32
High	6 (14.0)	17 (39.5)	20 (46.5)	

**Fisher's exact test*

Table 19 shows that none of the dimensions of QOL was significantly associated with physical and functional status of the respondents. Also there was no relationship between physical and functional status and QOL composite (p=0.89).

3.7.3. Relationship between HBC and QOL dimensions

Table 20: Relationship between dimensions of QOL and HBC

Characteristic	HBC *n (%)*	Social Work *n (%)*	P-value
Emotional Well-being			
Low	36 (73.5)	13 (26.5)	0.22
High	29 (61.7)	18 (38.3)	
Social Support			
Low	26 (55.3)	21 (44.7)	0.01
High	35 (79.5)	9 (20.5)	
Social Relationships			
Low	29 (61.7)	18 (38.3)	0.26
High	32 (72.7)	12 (27.3)	
Practical Environment			
Low	33 (63.5)	19 (36.5)	0.37
High	31 (72.1)	12 (27.9)	

As indicated in Table 20, only social support was positively associated with HBC (p=0.01). No significant association was noted with any of the other dimensions of QOL. HBC was however positively associated with physical and functional status (p=<0.01) as can be seen in table 21. The majority of people receiving HBC tended to be in the low (88.9%) and medium (82.5%) physical functionality categories respectively.

3.7.4. Relationship between HBC and Physical and functional status

Table 21: Relationship between HBC and Physical and functional status

Characteristic	Social Work *n (%)*	HBC *n (%)*	P-value
Physical & functional status			
Low	2 (11.1)	16 (88.9)	<0.01*
Medium	7 (17.5)	33 (82.5)	
High	22 (57.9)	16 (42.1)	

3.8. Multivariate Logistic regression models

Table 22: Model 1 - Multivariate logistic regression for Emotional well-being, adjusting for HBC, Physical& functional status and marital status (n=96, p=0.10)

Characteristics	AOR[4]	95% CI[5]	P-value
HBC	0.9	0.30 – 2.55	0.81
Physical & Functional			
Low	*Ref*		
Medium	1.2	0.36 – 3.96	0.78
High	1.8	0.49 – 6.71	0.37
Marital status			
Married	*Ref*		
Single	0.6	0.17 – 2.02	0.40
Widowed	0.2	0.04 – 0.95	0.04
Divorced	0.1	0.01 – 1.04	0.05

Table 22 shows the logistic regression model results testing the relationship between emotional well-being HBC when adjusting for physical & functional status. Only two of the marital status categories were significantly associated with emotional well-being. People who are widowed were 79% less likely to have high emotional well-being (p=0.04) as compared to those who were married. Being divorced also tended to lean towards the same direction although the relationship was not statistically significant as the 95% confidence interval crossed one.

Table 23: Model 2 - Multivariate logistic regression for social support, adjusting for HBC and physical & functional status (n=91, p=0.01)

Characteristics	AOR	95% CI	P-value
HBC	4.5	1.48 – 14.03	0.01
Physical & Functional			
Low	*Ref*		
Medium	1.3	0.40 – 4.59	0.64
High	1.5	0.40 – 5.41	0.56
Sex			
Female	*Ref*		
Male	2.87	1.08 – 7.62	0.02

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[4] Adjusted Odds Ratio

[5] Confidence Interval

The hypothesised relationship between higher social support and HBC was supported. In addition gender was significantly associated with higher social support in the second multivariate logistic regression model (n=91, p=0.01), while adjusting for physical status as shown in Table 23. People receiving HBC were 4.5 times more likely to report high social support compared with people receiving social work services, while controlling for physical and functional status. In addition, males were three times more likely to report higher levels of social support as compared to the female counterparts.

Table 24: Model 3 - Multivariate logistic regression for practical engagement with the environment, and HBC, adjusting for age and Physical& functional status (n=95, p=0.17)

Characteristics	AOR[6]	95% CI[7]	P-value
HBC	1.79	0.55 – 5.88	0.34
Physical & Functional			
Low	*Ref*		
Medium	1.64	0.49 – 5.51	0.42
High	3.57	0.91 – 13.96	0.06
Age			
20-40	*Ref*		
41-60	0.73	0.23 – 2.29	0.56
61-80	1.53	0.45 – 5.21	0.50
>80	3.41	0.47 – 24.74	0.22

None of the categories of physical and functional status were associated with practical engagement with the environment.

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[6] Adjusted Odds Ratio

[7] Confidence Interval

Chapter 4: DISCUSSION

The overall objective of this study was to determine the relationship between exposure to home based are services and quality of Life for people with physical disabilities in greater Johannesburg in 2014. The findings of this study will contribute towards improving programmes targeting people with disabilities. This chapter discusses the findings relating to some demographic characteristics of people with disabilities, home based care services available as well as the relationship between receiving home based care services and QOL for people with disabilities. Limitations of the study are also presented at the conclusion of the chapter.

4.1. Socio-demographics for people with disabilities

The age characteristics of the sample support the finding that disability is positively correlated with age as the proportion of people with disabilities increased with age (10). Three quarters of the sample were over the age of forty while the younger population accounted for only 25%. This is not peculiar to South Africa as prevalence information from other countries also show that older people are disproportionately represented in disability. The World Report on Disability reports (8) that in Sri Lanka, older people (aged 64 years and over) were 6.6% of the general population yet represented 22% of people with disabilities; similar to Australia where older people made up 10.7% of the general population and 35.2% of people with disabilities were older people. Country comparisons by income level revealed that the prevalence of disability in lower income countries among people aged 60 years and above was 43.4%, compared with 29.5% in higher income countries (8).

Although the relationship between age and disability follow a similar pattern to global trends there is a disproportionate proportion of people in the sample who are under the age of 40. Census data for South Africa shows that about 18% of persons living with disability were between the ages of 15-40 years (10); while this study found that a quarter of people living with physical disabilities were under 40.

The majority (59%) of the sample in the current study were single and had never been married. Similar findings were reported in studies in India (46.2%) (60) and Bangladesh (47.5%) (61). In the study, of the 39 respondents between the age of 20 and 40; widely considered the prime marriage period, as much as 33 (85%) were still single. The trend continues in older respondents where the majority are single. The findings suggest that physical disability may affect marriage or the formation of marriage unions. Other studies confirm lower rates of marriage among people with disabilities as compared to their peers without disabilities, adding that there was an even lesser likelihood of marriage for people with profound disabilities (62, 63). Other scholars however critique these studies for being cross-sectional hence, while persons with physical disabilities were less likely to marry, they may have married at a later age or less likely to remain married over their life span (64), a critique which may stand true for the current study.

Fourteen percent of the sample had tertiary education, which is consistent with the profile of people with disabilities in South Africa, noting that only about a fifth of persons with disabilities attended tertiary education adding that persons with severe difficulties had the lowest educational outcomes (5,3% had attained higher education, 23,8% had no formal education and 24,6% had some primary education) (10).

4.2. Type and extent of physical disabilities

The majority of respondents in this study had suffered a stroke and this manifested primarily in hemiplegia, which is paralysis of one side of the body, usually opposite the part of the brain affected by the stroke. In 2013, a study estimated the incidence of strokes in South Africa at 75 000 per year (65). Risk factors for stroke include high blood pressure, high blood glucose, tobacco use and inadequate physical activity among South African population have been well documented (66, 67). Paraplegia was also common and could be associated with motor vehicle and violence related casualties. Country level statistics on the incidence of disability caused by accidents and violence remain unreliable despite widespread occurrence but in 2009, road traffic injuries ranked second to interpersonal violence as a cause of mortality (68). The disability presents disadvantages in terms of mobility, physical independence and social participation, in addition to placing limitations on clients' ability to work and earn an income. As a result the main source of income for all the respondents was the disability grant.

4.2.2. Physical functional status

Thirty-nine percent of the study participants were unable to care for themselves, requiring some care at an institution or a hospital due to severity of their disabilities. This proportion of the people with disabilities in this category is nearly consistent with WHO estimation that about thirty percent of people with disabilities comprise those with severe and multiple disabilities who would require specialist interventions including institutionalisation, services which may not be available in the local community and hence cannot be offered through HBC (20). The other seventy percent could be helped at the community level as their needs may not be too complicated. The majority of the people in the study were in the second and third categories of the Karnorfsky scale reflecting diminished ability to work for self, requiring substantial assistance and up to the point of hospitalisation. According to the ICF classification of human functioning, these would fall into the second category of persons dysfunctional at the levels of the body or body part and the whole body.

4.3. Home based care services experienced by people with disabilities

The majority of the participants in the study (65%) received HBC services and of these, 90% received the service from the Association of Persons with Physical Disabilities. Others providing the service were church based organisations on a need basis and not as part of a systematic programme The services rendered include basic care, body exercises, treatment and adherence support. The services provided are consistent with the description of HBC service provision, in line with supporting clients with activities of daily living, and not adequate for managing chronic physical disability. The service forms only a part of the provisions of the Community Based Rehabilitation (CBR) introduced by the World Health Organisation as a strategy to achieve health for all by 2000 (20). The CBR approach aims at enhancing opportunities for people with disabilities to live as they choose. The services the people with disabilities in this study were receiving are an integral but initial process of restoring functionality but fall short of the comprehensive service package required to ensure the people with disabilities realise their potential and live as they choose.

Non-Governmental Organisations (NGO) have played a key role in the provision of community based disability services (69). The adequacy of services provided by NGOs remains a huge issue. Census data for South Africa in 2011 revealed that there was a total of 485 331 people with disabilities in Gauteng province (10). The APD, for instance provides services to about 300 people with physical disabilities revealing the existing gap in terms of number of people requiring similar support. This is further exacerbated by the funding crisis that has hit the NGO sector in South Africa inhibiting the capacity of NGOs to provide comprehensive services to people with disabilities.

Results of the study support the value of engaging people with disabilities in the design and development of programmes targeting them. Of the service components rendered by APD, only basic care and physical exercises were taken up at by least half of the respondents. The other components, including meal preparation, adherence support and cleaning were taken up by less than 15% of the respondents. This result could be a reflection on the nature of disability and needs of the target group. The majority of the sample have motor disabilities and may not, for example, be suffering from any ailment requiring medication hence the uptake of medication adherence support is rather low.

However, this finding could reflect inadequate levels of consultation with the group of people with disabilities to understand their felt needs and how their needs may be addressed through the programme. This could also reflect the dynamic nature of the needs of people with disabilities where the service components under the programme could have ministered to their needs at some point but may need to be adjusted to accommodate new and changing needs of the target group. Lang maintains that it would be appropriate for CBR (HBC) programmes to adopt and apply a Frierian approach of social transformation, if they aim to empower people with disabilities (69). The Freirian approach says all individuals have an innate ability to transform their social and economic situation but effective transformation will only occur when marginalised groups like disabled people critically analyse their constraints and inform efforts and strategies for alleviation of their problems (69).

4.4. Quality of life for people with physical disabilities per domain measured

Emotional well-being

The results of the study showed that the majority of the sample scored low in psychological/emotional well-being. This finding is supported by evidence that found that scores are lower on the psychological domain of QOL reflecting on negative feelings, poor body image, appearance, spirituality, and self-esteem of people with disabilities (60). The study found no differences related to level of education and participants' emotional well-being but indicated an association between marriage/living with partner and higher levels of emotional well-being. Other studies corroborate the findings, concluding that marriage has psychological benefits and married people tended to have lower risks of depression, are less likely to experience declines in self-rated health and suffer from fewer chronic conditions (70). This is because of the social support married people provide for each other and through their pooled support systems, married people are also able to "curtail the deleterious consequences of senescence" (70). The current study also provides evidence for this. Of the 15 respondents who were married or staying with partners, the majority reported that they received physical and emotional support; while about half reported financial support from their spouses.

There appears to be inadequate psychosocial support for the clients as indicated by the emotional well-being scores and the lack of significant differences between the two groups. HBC workers have limited training in providing psychological support. While the study did not measure specific mental health issues such as: depression, and anxiety, the emotional well-being score is a relevant indicator. Many people who participated in the study became physically disabled after traumatic experiences like violence, accidents and strokes. Provision of psychosocial services including counselling and self-awareness activities is crucial for improving the clients' emotional well-being which contributes towards an improved quality of life.

Social Support

Social support was the only QOL domain that had a relationship with the main exposure variable (exposure to HBC). Exposure to HBC services was significantly related with social support. Most of the people who received HBC services reported significantly higher levels of social support whereas the majority of the comparison group, who received mainly social work services, reported lower levels of social support. People with disabilities require and depend to a large extent on support from their family, friends and other support systems hence tended to use services of HBC caregivers who also encouraged them to utilise support from other systems. These findings support the evidence that social support is crucial for the physical and mental health of persons with disabilities as it contributes to how they deal with social vulnerability, stress and illness (23, 32, 43) thereby increased quality of life.

Social relationships

There was no statistical significance between social relationships and any of the demographic characteristics but social relationships had a significant relationship with QOL (p=0.000). This is consistent with other studies as a study on QOL conducted in South Africa and Uganda concluded that despite the pain and symptoms associated with incurable disease and permanent conditions, physical comfort and being active were judged to be less important to QOL than close relationships, feeling at peace and having a sense of meaning in life (32). The majority of the respondents had caregivers at home, mostly parents, siblings, children or other relatives. The influence of having a caregiver and a strong social support system on the well-being of persons with disabilities is reported in many studies. Social relationships contribute to attributing meaning to life, thereby increasing security for both the client and the caregiver (23).

Practical engagement with environment

At the practical environment level, there was no association to any of the demographic characteristics of age, sex, marital status or educational level. In regression analysis, physical and functional status was significantly associated with practical engagement with the environment, showing that people of high physical functional functionality were 3.5 times likely to report higher levels of practical engagement with the environment. Given mobility difficulties, the perception of QOL for persons with physical disabilities is heavily dependent on their ability to access their environment and to partake in activities that interest them. Other scholars have proposed models that give credence to the findings, maintaining that participation in activities of daily living for people with disabilities is influenced by environmental factors at the individual (micro), community (mesa) and societal (macro) levels (45).

4.5. QOL and physical and functional status

Poorer physical and functional status was found to be positively related with receiving HBC service. Physical and functional status was associated with poorer scores on the QOL life domain of practical engagement with environment. Participants who received HBC tended to have lower functionality indicating a greater need, or perceived need, for support with exercise and basic care. There was however no direct relationship between physical functional status and the other domains of QOL or the composite QOL score. While physical functional status may represent a strong indicator of overall health status and has been shown elsewhere to be a powerful predictor of quality of life (71), it does not, in isolation determine quality of life. In fact, this study found that those with very low functionality had medium and high QOL scores. This could be explained by greater social support among people with limited functionality and the positive relationship between social support and both HBC and QOL (presented earlier).

Some participants with very low functional and physical status based on Karnofsy scale classification may in other settings be placed in institutional care. However, due to the limited resources in the South African setting and the unavailability of such specialised services in local communities HBC is the only option. The higher QOL scores support the WHO notions that community-based rehabilitation and care is preferable to institutionalised care (19).

The study results have implications for the design of HBC programmes especially when taking into consideration the clients' physical functional status and their specific needs. Some people with severe difficulties and limited functionality may require substantial and varied support in line with the CBR guidelines. WHO estimates that 70% of people with disabilities could be helped at the community level but the remainder, consisting of people with severe and multiple disabilities require specialist interventions which are not available at the community level (20). In developed countries the services available to clients in their homes, through the CBR programme are more specialized, including medical care, access to mobility technologies, therapy by trained professionals, including physio and occupational therapy and psychosocial support services (18). On the other hand, the HBC programme reviewed in this study offered rudimentary services to some people who require specialized services. The HBC caregivers are primarily lay people, driven by altruistic passion, with basic training in care giving but are not well equipped to offer medical care, specialized therapy and psychosocial support as may be required by the clients.

4.6 Conceptual framework: Applicability of model to the study

"The Quality of life: A systems model" (Figure 1) was developed by the University of Oklahoma, although limited information about it is available (72). The model is premised on that life has domains (family and friends, neighborhood/community, work, religion, health education), which are influenced by inputs like culture, demographics and socio-economic conditions. An individual's perceptions and opinions of the domains therefore contribute to his/her assessment of their state of being (quality of life) (72). The model illustration below shows the components that relate to contribute to QOL.

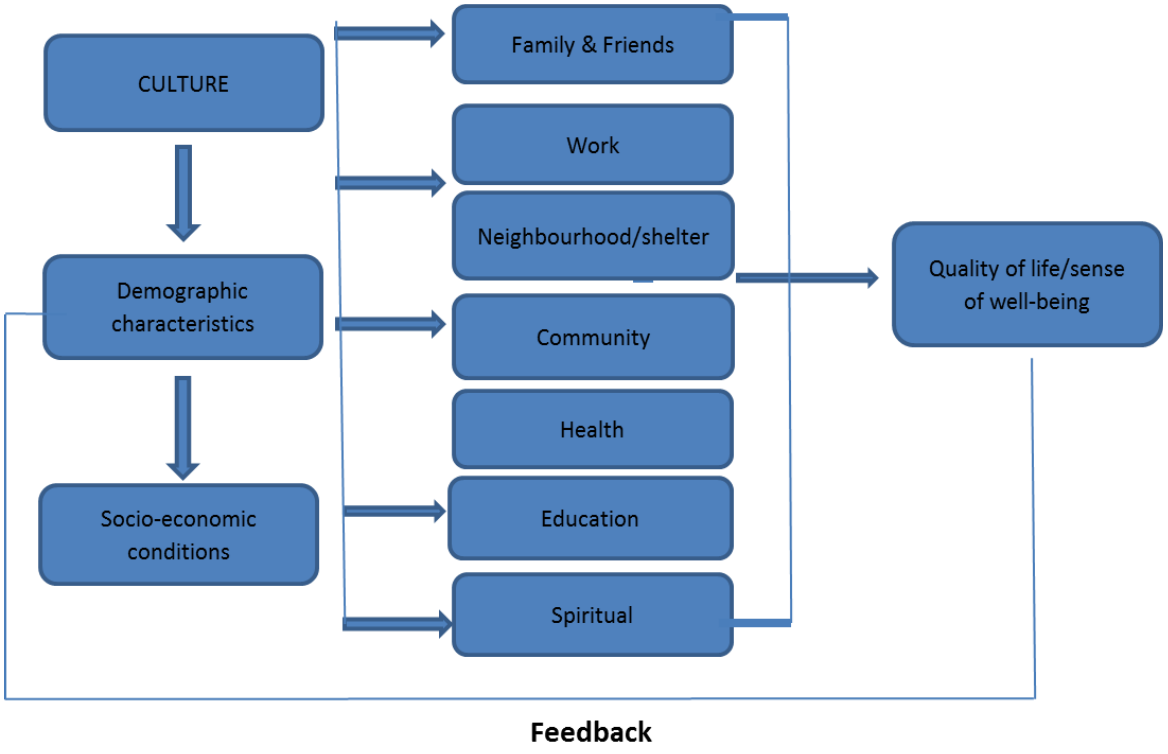

Figure 1: Quality of Life: A Systems Model (30)

The model considers quality of life as measured through particular domains or dimensions which fulfils its assessment. The idea of assessing QOL along multiple dimensions means departing from a simple linear scale with excellent and greatly diminished quality of life on each extreme respectively but focuses on how the dimensions interact with each other to influence the quality of life for an individual (73).

The Quality of Life: A Systems model is useful in understanding the factors that inter-relate to influence QOL. This study examined some socio-demographic factors (age, sex, marital status, education and availability of caregiver) and how they contribute to an individual's perception of their family, work, community, health and spiritual life in relation to their consequent quality of life. The findings revealed that of the socio-demographic factors, marital status was more important in influencing emotional well-being. Married people and people living with partners tended to report better states of emotional well-being as opposed to those who were either widowed or divorced, and as a result would record higher QOL outcomes. Males were three times more likely to report higher levels of social support as compared to the female counterparts. The other socio-demographic factors assessed were less related to the nature of social relationships as well as the support received by people with physical disabilities from family, friends and the community. The study findings therefore support the link between socio-demographic and economic factors and clients' perceptions of support from family and communities which influence their quality of life, as depicted by the Quality of life: A systems model. While the study provided an understanding of main sources of income for households of people with disabilities, the findings present a gap in examining the influence of level of household income on the individual functionality as well as ability to access support from different support structures which is imagined to have a distinct influence on QOL.

Exposure to HBC was added and tested as an additional factor influencing individuals quality of life. From the study, people who received HBC services reported significantly higher levels of social support (from family/friends, community) and experienced better states of general health, supporting the depiction of the systems model.

While the Quality of Life: A systems model offer opportunities to better understand the factors that influence quality of life, its applicability in the current study is limited and the study focused on the effect of receiving a particular package of HBC services on the quality of life for people with physical disabilities. The influence of culture, for instance, is prominent in the model and this was not measured in this study, making it difficult to apply the model full to the study.

4.7. Relationship between exposure to HBC and QOL for people with disabilities

The hypothesis that this study was premised on was that HBC services is positively associated with higher QOL was not fully supported by the findings. Respondents receiving HBC services were no better than those in the comparison group in terms of most QOL outcomes. The exception to this was in the domain of social support. The finding is surprising and inconsistent with other studies of people with disabilities particularly stroke patients which revealed that HBC clients experienced higher quality of life (22, 25). However, research has found that the benefits of HBC reached a plateau after one year (24), and the authors recommended that early home rehabilitation (HBC) was essential. Most of the clients who participated in this study had been disabled for most of their lives which could account for the limited differences in QOL among the two groups. In addition, it should be noted that the comparison group in this case did receive social work services and that the findings may have been different if the comparison groups received no services at all.

The interaction of the different dimensions between the respondents receiving HBC and social work requires more scrutiny. All the respondents were receiving some service from APD, coupled with the occasional overlaps between the programme components, where, for example, HBC clients received social work assistance to acquire wheelchairs, food parcels, or to access social grants, makes it difficult to interpret some of the study findings. The overlaps may account for limited differences between the two groups.

There appears to be inadequate psychosocial support for the clients as indicated by the emotional well-being scores and the lack of significant differences between the two groups. HBC workers have limited training in providing psychological support. While the study did not measure specific mental health issues such as: depression, and anxiety, the emotional well-being score is a relevant indicator. Many people who participated in the study became physically disabled after traumatic experiences like violence, accidents and strokes. Provision of psychosocial services including counselling and self-awareness activities is crucial for improving the clients’ emotional well-being which contributes towards an improved quality of life.

An analysis of the criteria for selection of clients onto the HBC programme revealed that the programme targeted the frailer and mostly bed-ridden clients to assist in recovering some level of functionality. The other people with physical disabilities who are active are then offered relevant social work services including welfare and development services as well as referral to services for people with disabilities.

4.8. Limitations

In considering the findings of this study, it is important to bear in mind its limitations. This study was a cross sectional study, where information on the exposure and outcome variable were collected at the same time and as a result it is impossible to draw causal inferences.

The study participants were people with disabilities who are served/beneficiaries of a particular welfare organisation. Some differences with the general disabled population may exist making it difficult to make the findings generalizable to all people with physical disabilities. In addition, all the respondents in the study were actually recipients of some kind of service, either HBC or social work; which is beneficial to some extent, as opposed to, for instance; some rural clients not receiving any kind of service or support. The groups compared in this study therefore may have been more similar than different, by virtue of being in receipt of services from APD, which offers a limitation in terms of interpretation of the comparative findings, since there were also some overlaps between social work and HBC services received by clients. In addition, despite ensuring that the respondents were not interviewed by staff who offered them direct services, some people may have reported higher QOL since the interviewers worked for the organization that provides services.

Data collection was conducted in January and February 2015 and some of the clients, mainly social work clients who had travelled to their rural homes for the festive holidays, had not yet returned. This affected the ability to reach the target sample.

The small sample size may have resulted in inadequate power to detect differences which present another limitation of the study. Some of the findings were marginal and could show statistical significance with a bigger sample, and it would have been possible to detect the differences.

The study measured emotional well-being as a dimension of QOL but did not measure actual mental health status or the presence of mental illnesses that could have an impact on their QOL. As a result it was not possible to control for mental illness in assessing the relationship between emotional well-being and QOL.

The study utilised only quantitative methods and as a result missed some of the qualitative information about the subjects, in relation to QOL. Discussion on level of satisfaction with the HBC service received and collection of most significant change (MSC) stories covering reference period of receipt of HBC/Social work service could have strengthened the analysis.

While the questionnaire has been validated for study of persons with disabilities in other countries, it has not been validated in South Africa with this group. The instrument has, however, been validated for other groups in South Africa like people living with HIV and AIDS. Compared with other available scales, this appeared to be the best suited for comparing results with other studies, as a standard.

The domain not investigated through this study is culture.

Chapter 5 Conclusion and Recommendations

5.1. Conclusion

Overall findings of this study show a weak association between the HBC and dimensions of QOL of people with disabilities. While this does not suggest that the programme is of no benefit to the recipients, it points out to a need for improvements in the structure and content of the programme if enhanced QOL is the desired goal. The study revealed a strong relationship between physical functional status and HBC for persons with physical disabilities, with clients of low functioning status requiring and needing more service. This reveals the importance of augmenting rehabilitation services through specialized therapy support and increasing capacity of HBC caregivers in providing the requisite support. HBC was shown to increase social support pointing to the fact that the HBC caregivers are seen as a social support structure in the absence of such or contribute to building stronger social support systems for persons with disabilities and their families, which has a positive influence on their quality of life.

The Quality of Life - Systems model was a useful framework in conceptualising the dimensions of QOL and how the HBC programme components supplies inputs into the system. It offered a basis to understand the perceptions of the subjects from the family, social and environmental viewpoints, although not all its dimensions were measured in this study. The model was expanded to include components found significant including physical functional status.

Notwithstanding the limited capabilities of the survey tool to capture some psychiatric and cognitive detail of the respondents for a richer analysis, the adapted WHO QOL Bref tool was a useful tool in understanding the factors at play in influencing QOL and the versatility of its use in an evaluation of a programme intervention was proven.

For people with physical motor disabilities, access to multi-disciplinary services including, but not limited to rehabilitation therapy (physio and occupational therapy), psychosocial support and accessibility/mobility improvement support, as proposed in the CBR guidelines, is crucial to enhancing the quality of their lives. As a result of limited resources and capacity of the HBC caregivers, the HBC programme reviewed offer rudimentary services to some who may require more specialised therapy and psychosocial support service. Limited physical functionality hinders full participation in the community and community-home based care rehabilitation services which are informed by a deeper analysis of the needs of the people within a particular cultural context are an essential aspect of service provision for people with physical disabilities.

5.2. Recommendations

5.2.1. Service Implications

Psychosocial support services for persons with disabilities

The findings showed that the majority of people with disability had low levels of emotional-well-being and considering the positive relationship between emotional well-being and QOL, it is recommended that the HBC programme intervention introduces deliberate efforts to address the emotional well-being of clients. The HBC programme as delivered by APD involves limited interaction of Social Workers with the HBC clients as the HBC caregivers are involved with day to day provision of services. Additional provision of psychosocial support services (PSS) by Social Workers or other trained professionals to promote emotional well-being of the clients is vital and will contribute to an improved quality of life. Given that about a third of the participants in this study had acquired disabilities through traumatic experiences (motor vehicle accidents and violence related injuries), PSS support (which is beyond the capacity of the HBC caregivers in the current programme) is critical to boost their self-esteem and self-worth. There is need for the HBC and Social work components of the programme to be inter-linked in order to offer a holistic package of services to people with physical disabilities with a view to improving their quality of life.

Capacity development for HBC caregivers and social workers

Given the role of the programme staff in supporting the emotional well-being and strengthening the social support structures for persons with physical disabilities, it will be prudent to invest in capacity development, in the form of formal training as well as on-the-job mentorship support, particularly in the aspect of psychosocial support provision, considering its immense contribution to a sense of well-being for the clients. In addition, stronger linkages between the two programme components is advised as it became apparent that all the clients will have varying needs supported by both HBC caregivers and social workers at different times of their lives. It is recommended that HBC caregivers receive mentorship support, including regular refresher training by qualified physiotherapists and occupational therapists to enhance their capacity to provide efficient community based services.

Use of participatory approaches in design of interventions

Organisations providing support to people with disabilities should incorporate Freirian approaches which views the people not as passive recipients of care and support but as active participants whose opinions matter in designing programmes targeting them (69). As discussed earlier, the findings regarding the service type offered and service most taken up reflect a disconnect between the needs of the target group and the services offered, indicating a lack of consultation and involvement in the design of programmes. It is recommended that for APD and other organisations with a similar mandate to conduct needs assessments to inform their programmes as well as conduct regular reflection and review processes with the people with disabilities to ensure their programme are responding to the most felt needs of their target population.

5.2.2. Policy Implications

The majority of the sample depended on the disability grant as a sole source of income for their households. The grant is insufficient to meet the basic needs of the household as well as supply for the care and support needs for a person with a disability, which may include paying for health and other services. The South African social security system provides for a care dependency grant, which is a monthly income support that is given to biological or foster parents and caregivers of children (under 18 years of age) with disabilities who require permanent care and support (REF: SASSA). There is no care dependency for people with disabilities that are over the age of 18 and this has an impact on the type of care they can access. Specialised care comes at a price that most cannot afford, given the meagre disability grant. A policy providing for a properly means tested dependency grant system for adults with disabilities who require care would be recommended. More research around the specific support and care needs of this peculiar group would be required to inform policy design and ensure that they are able to acquire the support they require.

The study underscored the importance of physiotherapy and occupational therapy for people with physical disabilities. Given the inhibitive cost of employing qualified physio and occupational therapists in such community based programmes as well as the low numbers of such skill in the health system, it is recommended that training programmes, similar to that of auxiliary social workers and nurses be considered to train auxiliary physio and occupational therapists to offer services to people within communities. This will make the services accessible to more people with disabilities, improve their physical and functional status and contribute to improved quality of life.

5.3. Further study

An examination of the influence of culture on the quality of life for people with disabilities would be crucial to provide a better understanding of the concept of quality life for people with disabilities. The researcher found limited literature describing the influence of culture on quality of life for people with disabilities. The “Quality of Life: Systems model” identifies culture as one of the inputs of the model. Disability is defined by culture and without an awareness of how disability is perceived in the target culture; a disability programme does not stand much chance of being relevant or sustainable (74). Awareness of cultural issues surrounding disability is a key part of the process of integrating disability into general development activities and would be best suited to inform interventions targeting people with disabilities.

A study comparing quality of life for people with disabilities who are receiving services and support with those that are not receiving any kind of service would offer feasible comparison points and assist in developing programmes and interventions targeting people with disabilities.

A review of CBR programme evaluations revealed the importance of encompassing family members of people with disabilities in QOL measurements given the influence of their QOL on the QOL of persons with disabilities (20). HBC programmes will then focus on indicators that are identified in family QOL measurements as of high importance but low satisfaction (20) in terms of planning for service provision targeting the family as a whole and not only the person with a disability. Studies on family QOL measurements in the South African context would be crucial in understanding patient needs, clarifying the role of families in rehabilitation and integration and cultivating sense of community responsibility for the care and support of persons with disabilities. This would also help in building literature around CBR programmes in South Africa. In an evaluation of CBR programmes in 2007, there was no information on South Africa (20) and the gap still exists.

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APPENDIX A: QUESTIONNAIRE

QUALITY OF LIFE QUESTIONNAIRE

Date of Interview day / month / year

IDENTIFICATION DETAILS

INTERVIEWER'S FULL NAME: ☐

UNIQUE ID NUMBER: ☐

DEMOGRAPHIC INFORMATION

1. **Client's Age (years):** ☐ **2. Sex** *1 = Male 2 = Female*

3. **Marital Status of Client** *(circle appropriate response code)*

1 = Married	*2 = Single*	*3 = Widowed*	*4 = Divorced/ Separated*

4. **Client's Highest Education** *(circle appropriate response code)*

1 = Primary	*2 = Secondary*	*3 = Tertiary*	*4 = Vocational*	*5 = None*

5. **Who is the Client's main caregiver?** *(circle appropriate response code)*

1 = Spouse	*2 = Parent*	*3 = Grandparent*	*4 = Brother/Sister*
5 = Son/Daughter	*6 = Other Relative*	*7 = Other*	*8 = Self*

6. **Client's Household Main Sources of Livelihood** (*Tick and specify all that apply)*

Employed ○	*Social Grant* ○	*Remittances* ○	*Petty Trade - Specify:* ○
Self Employed - Specify: ○	*Other – specify* ○	*Other – specify* ○	

7. **On a Scale of 1 to 5, rate Client's ability to Communicate Verbally** (From **1** = 'Very Poor' to **5** = 'Very Clearly')

Client's ability to communicate verbally	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

8. **If Client was unable to Communicate verbally, indicate who helped interpret**

1 = Spouse	*2 = Parent*	*3 = Grandparent*	*4 = Brother/Sister*
5 = Son/Daughter	*6 = Other Relative*	*7 = Other*	*8 = Self*

9. Type of disability (Request client to indicate disability type if known, from list below. If unknown make own assessment of disability)

Disability: Underlying Condition	Circle
a. Cerebral Palsy (Muscle incoordination due to damaged brain, usually at birth)	1
b. Stroke	2
c. Post-polio Paralysis (weakness in muscles and underdevelopment of some limbs)	3
d. Motor vehicle / motor cycle accident	4
e. Occupational injury	5
f. Gunshot or violence-related injury	6
g. Other (specify)	7
h. Unknown	8
10. Nature of the disability	
a. Quadriplegia (substantial loss of function in all 4 limbs)	1
b. Paraplegia (substantial loss of function in the lower part of the body)	2
c. Hemiplegia (substantial loss of function on one side of the body i.e. arm and leg)	3
d. Diplegia (refers to paralysis affecting symmetrical parts of the body).	4
e. Other (specify)	5

11. Indicate what service client receives from APD

a) HBC Yes=1 No=2	*b) Social Work Yes=1 No=2*

12. Do your receive HBC services from any other organization?

1 = Yes *Specify*	*2 = No*

HBC COMPONENT – skip if participant is not receiving HBC

13. Please indicate which of the services you have received and the frequency *(Circle number for each relevant service and tick to indicate frequency)*

#	Service	Frequency			
		Weekly	Bi-weekly	Monthly	> Month
A	*Basic care including bathing and dressing*				
B	*Meal preparation & feeding*				
3	*Treatment and prevention of pressure sores*				
4	*Treatment adherence support*				
5	*Light house cleaning*				
6	*Basic body exercises*				
7	*Other (Specify)*				
8	*Other (Specify)*				
9	*Other (Specify)*				

Physical and Functional Status

Assessment of the physical functioning and role limitations caused by the disability

14. Assess the Client's Functional Status and classify him/her accordingly using the categories given in the table below; *(circle appropriate code 1 to 10)*

Broader Category	**Select the relevant condition of the client**		
Able to carry on normal activity and to work; no special care needed.	Normal no complaints; no evidence of disease.	**10**	
	Able to carry on normal activity; minor signs or symptoms of disease.	**9**	
	Normal activity with effort; some signs or symptoms of disease.	**8**	
Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed	Cares for self; unable to carry on normal activity or to do active work.	**7**	
	Requires occasional assistance, but is able to care for most of his personal needs.	**6**	
	Requires considerable assistance and frequent medical care.	**5**	
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.	Disabled; requires special care and assistance.	**4**	
	Severely disabled; hospital admission is indicated although death not imminent.	**3**	
	Very sick; hospital admission necessary; active supportive treatment necessary.	**2**	
	Moribund; fatal processes progressing rapidly.	**1**	

15. Please keep in mind your standards, hopes, pleasures and concerns. I ask that you think about your life **in the last four weeks (ONE MONTH).**

How would you rate your quality of life?

Very poor	Poor	Neither poor nor good	Good	Very good
1	2	3	4	5

	Over the last ONE MONTH	Very severe	Severe	Moderate	Mild	Very mild	None
14	How much bodily pain have you had during the past 4 weeks?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
	Over the last ONE MONTH	All the time	Most of the time	More than ½ the time	Less than ½ the time	Some of the time	At no time / Never
15	During the past 4 weeks, how much did pain interfere with your normal work (work outside and/or housework)?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

Emotional and Psychological Well-being

Please indicate for each of these statements below how you have been feeling over the last 3 months. Notice that higher numbers mean better well-being.

	Over the last ONE MONTH	All the time	Most of the time	More than ½ the time	Less than ½ the time	Some of the time	At no time / Never
16	Have you been feeling cheerful, in good spirits, calm and relaxed (not worried)?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
17	Have you been feeling active and vigorous.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
18	Has your daily life been filled with things that interest you?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
19	Have you been able to share how you were feeling with your family & friends?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

Social relationships & Community

Assessment of the client's social relationships, support from family and larger community is important as it has impact on QOL.

Over the last MONTH, how has been your relationship with;		Excellent	V. Good	Good	Fair	Bad	Terrible	N/A
20	Your Spouse?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	
21	Your immediate family?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	
22	Your extended family?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	
23	Your friends?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	
24	Your neighbors / the community?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	
25	Church/religious groups?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	
26	Community Organizations	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	
27	Health Centers	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	
How has been the Support from;		Excellent	V. Good	Good	Fair	Bad	Terrible	N/A
28	Your **Spouse**?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	
29	Your **immediate family**? *Specify:*	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	
30	Your **extended family**? *Specify:*	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	
31	Your **friends**? *Specify:*	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	
32	**Neighbours/the community**? *Specify:*	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	
33	**Community leaders**? *Specify:*	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	
34	**Churches/religious groups**? Specify:	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	
35	**Support organizations.** *Specify:*	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	
36	**Health centres**? *Specify:*	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	

	For each, specify type of support received *(probe each and tick as relevant)*	**Physical**	**Emotional**	**Financial**	**Informational**	**Appraisal (affirmation)**	**No Support**	**N/A**
37	Your Spouse?							
38	Your immediate family?							
39	Your extended family?							
40	Your friends?							
41	Your neighbors / the community?							

42	Church/religious groups?							

Practical and Environment

Clients's interaction with environment and ability to practically engage in life activities has an impact of QOL

	Over the last ONE MONTH	All the time	Most of the time	More than ½the time	Less than ½ the time	Some of the time	At no time/Never	N/A
43	Did you partake in any leisure activities (e.g. listen to the radio or watch television or movies) ?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	
44	Have you done any household domestic chores **Specify**…………………….….	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	
45	Have you done any livelihood activities? **Specify**………………………..	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	
46	Did you attend any family gatherings/meetings? Specify………………………..	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	
47	Did you visit any relative?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	
48	Did you participate in any leisure activities e.g. sports, exercises etc) Specify………..	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	
49	Did you attend any church or religious activities? **Specify**………………………..	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	
50	Did you attend any community meetings? Specify………………………..	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	

COMMENTS

APPENDIX B: INFORMATION SHEET

Information sheet: Quality of Life for persons with disabilities Survey

1. Introduction

Good Day, my name is _____________/ (name of assistant researcher). I am from the University of the Witwatersrand (Wits) in Johannesburg. I would like to invite you to consider volunteering to participate in a study about the quality of life of people living with disability. This study is being done in partial fulfillment of Aldrian Mungani's academic studies at the Wits School of Public Health in Johannesburg.

Before volunteering to participate in this study, it is important that you read and understand the following explanation of the purpose of the study, the study procedures, benefits, risks, and your right to withdraw from the study at any time.

This information leaflet is to help you decide if you would like to volunteer. You should fully understand what is involved before you agree to take part in this study. If you have any questions, do not hesitate to ask me.

If there is anything in the form that you do not understand, please ask me to explain. If you want to take some time to think about or discuss your involvement in this study with your family or friends, you may do so before making your decision.

If you agree to take part in this study, I will ask you to sign a form to show that you want to take part. I will give you a copy of this information about the study to keep.

It is important that you understand the following:

- Taking part in this study is completely voluntary.
- You may refuse to take part in this study or leave it at any time.
- Your decision about this study will not affect your participation in any other research studies, nor will it affect services you receive from the association for the physically disabled (APD).

2. Purpose of the Study

I am inviting you to take part in a research study. The research study is about how you perceive your own quality of life as a person with a disability, in relation to home based care/Social Work services that you receive from APD or another organization.

This study involves participating in an interview, where a researcher will be asking questions and you will be invited to respond. We would like to learn more about the quality of your life based on what you have been able to do or not do. We are interested in this information because we want to learn how best programmes targeting people with disabilities can be framed to ensure an improvement in the quality of life for people with disabilities.

3. Length of the Study and Number of Participants

This study is being conducted in Johannesburg and you are one of 150 people whom we are inviting to participate in the study. All of the people being interviewed have been selected because they have a physical disability and are benefitting from services offered by APD.

The total amount of time required for your participation in this study is no more than 30 minutes. The interview will take place at your home and is a one-time event. No other visits will be required.

4. Study Procedures

If you agree to take part in this study you will be interviewed in English or Zulu by a trained researcher who will ask you a series of questions about the topic already mentioned earlier. There are no right or wrong answers. We are interested in your experience or rating to help us:-.

- Learn what home-based care services are available to you
- Understand how HBC services impact on your quality of life, if at all
- Determine your QOL rating

While I hope that you will feel comfortable enough to answer freely, you may skip any questions you don’t want to answer. You may decide to stop the interview at any time.

5. Will any of these Study Procedures Result in Discomfort of Inconvenience?

The interviewer may ask questions or raise issues that are of a sensitive nature that may make you feel uncomfortable. There are no wrong answers in this type of interview. We are interested in your experiences and thoughts. However, you may skip any questions that you don’t want to answer or discontinue the interview at any point. You may discontinue the interview at any time. Your choice not to participate or to stop the interview will not have any effect of services that you receive. There may be other risks and discomforts that are not known at this time.

6. Benefits

You will not benefit directly from taking part in this study. Information gathered from this study may help us learn more about how programmes targeting people with disabilities can be implemented to ensure maximum benefit on the part of people with disabilities

7. Costs and Reimbursement

There will be neither cost nor reimbursement to you for being part of the study.

8. Rights as a Participant in this Study

Taking part in the study is your choice. If you decide to take part, you can always change your mind. You can stop the interview at any time.

9. Ethical Approval

This study protocol has been submitted to the University of the Witwatersrand, Human Research Ethics Committee (HREC) and written approval has been granted by that committee.

10. Confidentiality

Anything that you share in the interview will be kept confidential in the following ways:

- We will use a code instead of your name on our questionnaires so that your identity is not disclosed
- All information obtained during the course of this study, including personal data and research data will be kept strictly confidential. Data that may be reported in scientific journals will not include any information that identifies you as a participant in this study.
- This information will be reviewed by authorised representatives of the University
- The information might also be inspected by the University of the Witwatersrand, Human Research Ethics Committee (HREC).

11. Sources of Additional Information

If you have any questions about this study, you may contact Aldrian Mungani at the University of the Witwatersrand, School of Public Health (Cell: 0842031115).

If you have any questions about your rights as a participant, you may contact Prof Peter Cleaton-Jones at the University of the Witwatersrand, Human Research Ethics Committee: Secretariat (011 717 1234).

12. Psychosocial support

Psychosocial support is available should you experience any distress as a result of participating in this survey. Please do not hesitate to call the Association for the Physically Disabled at 011 646 8331.

APPENDIX C: Consent Form

Quality of Life for persons with disabilities Survey: INFORMED CONSENT:

I _______________________ have read the information sheet (or had it read to me), I fully understand what is involved in this study.

I hereby confirm that I have been informed by the researcher (Aldrian Mungani) about the nature, conduct, benefits and risks of the QOL research study.

I have also received, read and understood the above written information (Participant Information Leaflet and Informed Consent) regarding the study. I am aware that the results of the study, including any personal details will be anonymously processed into a study report.

In view of the requirements of research, I agree that the data collected during this study can be processed in a computerised system by the researcher.

I may, at any stage, without prejudice, withdraw my consent and participation in the study.

I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.

PARTICIPANT:

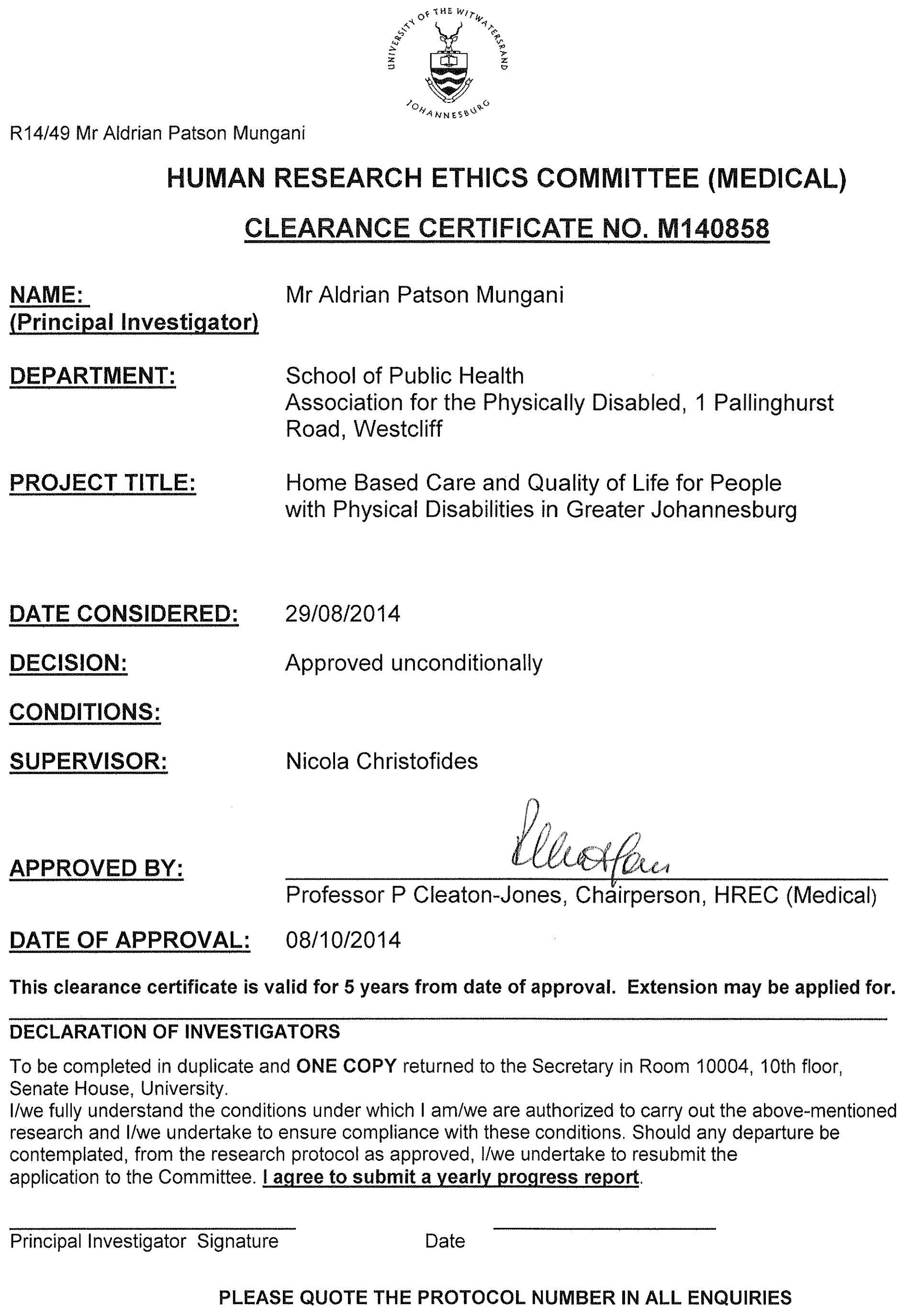
Printed Name Signature Date and Time

I, ______________________ herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

INTERVIEWER*:*

Printed Name Signature Date and Time

APPENDIX D: ETHICS APPROVAL



UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

R14/49 Mr Aldrian Patson Mungani

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M140858

NAME: **(Principal Investigator)**	Mr Aldrian Patson Mungani
DEPARTMENT:	School of Public Health Association for the Physically Disabled, 1 Pallinghurst Road, Westcliff
PROJECT TITLE:	Home Based Care and Quality of Life for People with Physical Disabilities in Greater Johannesburg
DATE CONSIDERED:	29/08/2014
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Nicola Christofides
APPROVED BY:	Professor P Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	08/10/2014

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**.

Principal Investigator Signature   Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX E: AGENCY CONSENT LETTER

THERE IS LIFE AFTER DISABILITY

THE ASSOCIATION FOR THE PHYSICALLY DISABLED

Greater Johannesburg
NPO 000-865 PBO 930006515

Tel: (011) 646 8331
Fax: (011) 646 5248
E-mail: info@apdjhb.co.za
Website: www.apd.org.za

Pallinghurst Road Westcliff,
Johannesburg,
Private Bag X1
Parkview 2122

19 June 2014

Dear Aldrian Mungani

RE: CONSENT FOR RESEARCH STUDY ON CLIENTS OF THE ASSOCIATION FOR THE PHYSICALLY DISABLED (APD).

This letter serves to confirm that the Association for the Physically Disabled – Greater Johannesburg is aware of and in support of the research you wish to conduct on Quality of life for persons with physical disabilities in Johannesburg.

I confirm that you have been granted access to APD client registers (Social Work and HBC case registers) and to interview clients for the purposes of gathering information for the study, on condition that you secure clients' individual consent before each interview. APD staff (HBC Supervisors and Auxiliary Social Workers) will assist in data collection and APD will cover the cost of their time and transport.

Should you require further clarity on the contents of this letter please contact the undersigned.

Sincerely

Miemie Retsuri
Assistant Director: Community Services

We provide the following Community Services at grassroots level:

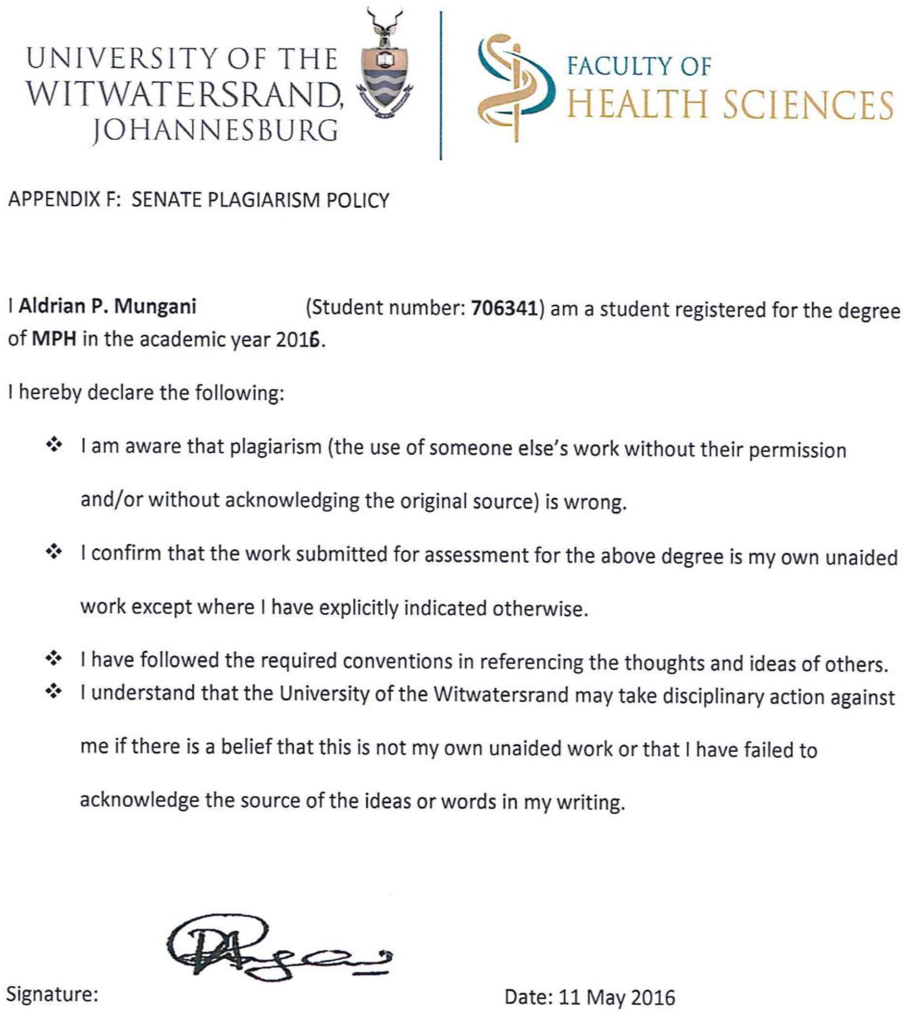
SOCIAL WORK SERVICES
HOME-BASED CARE / ATTENDANT CARE SERVICES

APD
Association for the Physically Disabled

We provide the following Commercial Services to raise funds for the Community Services:

BARRIER BREAKERS (BB) Public Awareness Campaigns & Environmental Assessments.
BARRIER BREAKERS RECRUITMENT SERVICES
BARRIER BREAKERS WHEELCHAIR RENTAL SERVICES
LEAN ON US HOME AGENCY

APPENDIX F: PLAGIARISM DECLARATION



UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

FACULTY OF
HEALTH SCIENCES

APPENDIX F: SENATE PLAGIARISM POLICY

I **Aldrian P. Mungani** (Student number: **706341**) am a student registered for the degree of **MPH** in the academic year 201**6**.

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.

Signature: Date: 11 May 2016