HOME-BASED REHABILITATION FOR PEOPLE LIVING WITH HIV IN A RESOURCE-POOR SETTING IN KWAZULU-NATAL, SOUTH AFRICA

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Care for us and accept us - we are all human beings. We are normal. We have hands. We have feet. We can walk, we can talk, we have needs just like everyone else - don't be afraid of us - we are all the same!

Nkosi Johnson (1989-2001) at the 13th International AIDS Conference, July, 2000
Durban, South Africa

SUPERVISORS' PERMISSION TO SUBMIT FOR EXAMINATION

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Thesis Title

Home-based rehabilitation for people living with HIV in a resource-poor setting in KwaZulu-Natal, South Africa

As the above candidate's supervisor, I AGREE to the submission of this thesis in the form of integrative material for examination.

The chapters are written as a set of discrete research publications, with an overall introduction and final summary.

This is to certify that the contents of this thesis are the original research work of Saul Cobbing

Supervisors

Professor Jill Hanass-Hancock ____________________________ Date: ___________________

Professor Hellen Myezwa ________________________________ Date: ___________________

Dr Sonill Maharaj ____ Date: ____________________

DECLARATION

I, **SAUL COBBING,** Student number **211558534,** declare that,

(i) The research reported in this thesis, except where otherwise indicated is my **original research**.

(ii) This thesis has not been submitted for any degree or examination at any other university.

(iii) This thesis does not contain other persons' data, pictures, graphs or other information, unless specifically acknowledged as being sourced from other persons.

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a) Their words have been re-written but the general information attributed to them has been referenced; and

b) Where their exact words have been used, their writing has been placed inside quotation marks, and referenced.

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DEDICATION

This PhD thesis is dedicated to the approximately 25.7 million people living with HIV in Africa. Despite the many advances made in science and healthcare that have potentially added many years to your life, I know that you face numerous challenges in achieving the quality of life and access to equitable care that is your basic human right.

I hope that the work described in this thesis contributes, in some small way, to helping ensure that all people living with HIV are able to access rehabilitation services that enable them to realise their full physical, emotional and cognitive potential.

ACKNOWLEDGEMENTS

You can stand out in the crowd only because you have many carrying you on their shoulders.

Desmond Mpilo Tutu

My family

First and foremost, I am immensely grateful to my wife, Mandy, and my two children – Daniel, who has just turned six and Lola, who is three years old. Mandy has been my greatest supporter and sounding board since I first met her 20 years ago. Despite facing challenges with her own work and studies, she has continued to encourage me and show understanding throughout this process. Daniel and Lola have never known their father *not* to be studying a postgraduate degree, so I look forward to giving you my full attention when this process is complete. Your love inspires me to continue the work that I have started in this thesis, to help ensure that those less fortunate can have a chance at reaching the level of happiness that you three give me.

To my parents, Jeff and Mary-Louise, I am eternally grateful that you gifted me with a thirst for reading and a desire for social justice. To my brother, Jude, and my sister-in-law Cleo, the fact that you have recently finished your own doctoral studies has further inspired me and allowed me to share some of the challenges specific to this task. To my other brother Ben, thank you for the G.I.S. expertise you contributed to drawing up maps for this study and thanks to you, Kate and the kids for sharing your home with us. To my in-laws, Rod and Roseann, thank you for your continued support and love you show to me, Mandy and the children.

My supervisors

I have heard horror stories of PhD students falling out with their supervisors who refuse to respond to their queries and only add stress to an already stressful situation. I have had the complete opposite experience with my supervisors. To Jill and Hellen, you have been absolutely key to me getting this far. Your patience in answering all my queries and your diligence in adding such value to my work has made me a better researcher and scientist. You are an inspiration to me and a number of other academics in our field. I hope that you will continue to mentor me and that I can match your dedication in ensuring that our work is translated into policies and practices that make a very real difference to the lives of people living with HIV. Thank you too to Dr Sonill Maharaj for filling the role as my departmental supervisor.

My colleagues

Verusia Chetty, Stacy Lawler and Ntsikelelo Pefile, you have become like family to me over the past six years – you are amazing friends, brilliant teachers and the laughs you have given me have kept me going. To Levin, Rogier, Siyabonga, Tanuja, Nonnie, Preshani, Predeshni and Thaya - I appreciate your support too. Thanks also to colleagues outside the physiotherapy department: to Vishnu, Thuli, Sahil, Val, Pam and Phindi in the School Office, to Pragashnie Govender, Mershen Pillay, Moses Chimbari, and to the late Professor Ratie Mpofu, who helped me start this journey.

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This study would not have been possible without the dedication and skill of the community care workers who assisted me with the testing and implementation of the study intervention: they are Fiseni Biyase, Zama Duma, Purity Khwela, Nombuso Mhlongo, Nonhlanhla Mlambo, Ntombfuthi Mtshali,Zanele Mtshali, Petronella Nkujana, and Sindisiwe Shozi. I hope that the future translation of this research will ensure that you are adequately rewarded for the amazing work that you do. It is people like you who are absolutely key to ensuring that we successfully manage the huge burden of disease in our poorest communities. Thank you also to Mfana Ngcobo for his transcription of interview data and to Deepak Singh for his statistical input.

Research participants

Thank you to the wonderful men and women who participated in this study, particularly those who welcomed us so graciously into their homes, despite often feeling sick, weak or hungry. I sincerely hope that my work ensures that you get the health services you deserve.

Funders

The work conducted in this PhD, as well as the communication of these findings, would not have been possible without funding secured from the National Research Foundation (via the Thuthuka grant) and the support of the South African Medical Research Council, who selected me as a beneficiary of the National Health Scholars Programme, an initiative that aims to fund the education and training of 1000 health sciences PhDs in South Africa over a ten year period. This initiative is generously funded by the Public Health Enhancement Fund, a ground-breaking collaboration between the public and private health sector in South Africa, focused on supporting post-graduate students pursuing health related studies and building additional capacity in the management of tuberculosis and HIV.

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ABSTRACT

This PhD thesis centres on a home-based rehabilitation intervention (HBR) for people living with HIV (PLHIV) in a resource-poor setting in KwaZulu-Natal, South Africa. South Africa has the highest number of people infected with HIV worldwide, with 6.4 million PLHIV out of an estimated global total of 36.7 million. Antiretroviral therapy (ART) has ensured that PLHIV are living longer lives. However, there is a wide range of evidence that shows that PLHIV are prone to a broad range of physical and cognitive disabilities. It is crucial that PLHIV are able to attain a good health-related quality of life and optimal functioning, to support the success of the wide roll out of ART in countries like South Africa. Rehabilitation and exercise have been shown to improve the quality of life and function of PLHIV but there are numerous barriers facing patients who need to access rehabilitation. This PhD study aimed to determine the effect of an alternative approach of service delivery, namely a disability-inclusive HBR intervention, on PLHIVs' perceived disability, quality of life, functional mobility and functional capacity. The study was situated in a resource-poor, semi-rural community in KwaZulu-Natal, the province with the highest HIV prevalence in South Africa. The design of the study intervention was informed by the synthesis of the evidence from a scoping review on HBR interventions for PLHIV, which revealed a paucity of evidence, and the practical experience of the lead author as a rehabilitation practitioner working with PLHIV. Embedded in a wider investigation related to an alternative model of care, this novel intervention, undertaken through a randomised control trial methodology, found that HBR is a safe strategy for treating the functional limitations experienced by PLHIV and may further improve their quality of life. While participants in the intervention group showed greater improvements across all outcome measures, between-group differences were non-significant. The community healthcare workers, who were trained via a task shifting approach to implement this HBR programme, reported feeling empowered by the knowledge and skills they attained through this study and gave valuable advice for improving future interventions. A synthesis of the overall PhD study results demonstrated that this intervention satisfied a number of the fundamental principles of a model of care for the rehabilitation of PLHIV, developed in the same study location. By building on the successes of this PhD study and addressing the limitations of its design and process, researchers can design and implement new rehabilitation interventions that involve multidisciplinary collaboration and the screening and treatment of people with a wide range of chronic conditions. This research should be combined with advocacy efforts to ensure that theoretical findings are translated into policies and practices that benefit all PLHIV, particularly those in resource-poor communities.

LIST OF ABBREVIATIONS

6MWT	Six minute walk test
AIDS	Acquired immune deficiency syndrome
AJAR	African Journal of AIDS Research
ART	Antiretroviral therapy
CBR	Community-based rehabilitation
CCW	Community care worker
CRF	Community rehabilitation facilitator
DOH	(South African) Department of Health
DHET	Department of Higher Education and Training
HAART	Highly active antiretroviral therapy
HBR	Home-based rehabilitation
HCW	Healthcare worker
HICs	High income countries
HIV	Human immunodeficiency virus
ICF	International Classification of Functioning, Disability and Health
ILO	International Labour Organisation
ISI	Institute for Scientific Information
ITT	Intention-to-treat
JANAC	Journal of the Association of Nurses in AIDS Care
KZN	KwaZulu-Natal
LMICs	Low and middle-income countries
MDT	Multidisciplinary team
NGO	Non-governmental organisation
OI	Opportunistic infection
PLHIV	People living with HIV
QoL	Quality of life
RCT	Randomised controlled trial
RMI	Rivermead Mobility Index
UNAIDS	Joint United Nations Programme on HIV/AIDS
UTT	Universal testing and treatment
UKZN	University of KwaZulu-Natal
UNESCO	United Nations Educational, Scientific and Cultural Organization
WHO	World Health Organisation
WHODAS 2.0	World Health Organisation Disability Assessment Schedule
WHOQOL-HIV BREF	World Health Organisation Quality of Life tool (short version)

OPERATIONAL DEFINITIONS

Advocacy can be defined as the public support for or recommendation of a particular cause or policy (Oxford English Dictionary, 2016). Advocacy for improved treatment options for PLHIV by patients' rights groups, healthcare professionals, researchers and NGOs has been crucial to advances in the options of care for PLHIV since the first recorded clinical observation of HIV/AIDS in the United States of America in 1981. In South Africa, collaborative advocacy efforts were central to a turn-around in the policies of the country's Department of Health, ensuring that PLHIV in South Africa gained access to free ART in 2004.

Chronic disease can be defined as a disease "that has a prolonged temporal course, that does not resolve spontaneously, and for which a complete cure is rarely achieved". A chronic disease has further been defined as one lasting three months or more (Remington, Brownson, Wegner, & Davies, 2010). In the early years of HIV treatment, HIV/AIDS was viewed as a terminal disease with little chance of infected individuals achieving a full life span. In the era of widespread access to cheap or free ART, HIV is now commonly classified as a chronic disease.

Community-based rehabilitation (CBR) is defined by the International Labour Organisation (ILO), the United Nations Educational, Scientific and Cultural Organization (UNESCO) and the World Health Organisation (WHO) as "a strategy within general community development for the rehabilitation, poverty reduction, equalization of opportunities and social inclusion of all people with disabilities" The implementation of CBR programmes should be achieved "through the combined efforts of people with disabilities themselves, their families, organizations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services" (World Health Organisation, 2010).

Disability is understood by the International Classification of Functioning, Disability and Health (ICF) framework as an "umbrella term for impairments, activity limitations or participation restrictions", which result from the interaction between the person with a health condition and environmental factors (e.g. the physical environment, attitudes), and personal factors (e.g. age or gender) (World Health Organization, 2001). The Convention on the Rights of Persons with Disabilities (United Nations, 2007), states that disability is an evolving concept and "results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others" . The interrelationship between HIV and disability has been proven, with people living with disability more likely to be infected with HIV and PLHIV more likely to develop physical and cognitive disabilities (Jill Hanass-Hancock & Casale, 2014).

Home-based rehabilitation (HBR) can be defined as a set of activities that prevent or treat an individual's impairments, activity limitations and participation restrictions in or near to their own home. HBR is just one aspect of the broader CBR umbrella and falls under the health component of the WHO's CBR Matrix (World Health Organisation, 2010)

Human rights are internationally agreed standards which apply to all human beings, in which everybody is entitled to basic rights such as food, health and security, regardless of their race, age, gender, religion or other status. These rights are affirmed in the Universal Declaration of Human Rights (United Nations, 1948), adopted by all Member States of the United Nations, as well as in other international human rights treaties which focus on particular groups and categories of populations, such as persons with disabilities. The Constitution of South Africa (Republic of South Africa, 1996), promulgated in 1996, strongly affirms the right of all citizens to enjoy the rights, privileges and benefits of citizenship.

Quality of life is understood to be subjective and multi-faceted, reflecting the full spectrum of an individual's life, including physical well-being, functional ability, emotional well-being and social well-being. In attempting to fully understand the impact of a chosen intervention or treatment on PLHIV's impairment, activities and participation, it is advisable to investigate the effect on their quality of life, in addition to more traditional clinical tests (Cella, 1994).

A **randomised controlled trial** is a study in which people are allocated at random to receive one of several clinical interventions, one of which is the standard of comparison or control (Creswell, 2013).

Task shifting is defined by the WHO as the "rational redistribution of tasks among health workforce teams. Specific tasks are moved, where appropriate, from highly qualified health workers to health workers with shorter training and fewer qualifications in order to make more efficient use of the available human resources for health" (World Health Organisation, 2007).

LIST OF FIGURES AND TABLES

Figures

Tables

RESEARCH OUTPUTS

A. Peer-reviewed publication list

Preliminary publications (added as Appendices 16 and 17)

[1] Cobbing S, Chetty V, Hanass-Hancock J, Jelsma J, Myezwa H, Nixon S (2013). Position Paper: The essential role of physiotherapists providing rehabilitation to people living with HIV in South Africa. *South African Journal of Physiotherapy*. 69 (1): 22-25.

[2] Cobbing S, Hanass-Hancock J, Deane M (2014). Physiotherapy rehabilitation in the context of HIV and disability in KwaZulu-Natal, South Africa. *Disability and Rehabilitation. 36*(20): 1687-1694.

Publications emanating from PhD findings (attached in full in Chapters 2-6)

[1] Cobbing S, Hanass-Hancock J, Myezwa H (2016). Home-based rehabilitation interventions for adults living with HIV: a scoping review. *African Journal of AIDS Research.* 15(1): 77–88.

[2] Cobbing S, Hanass-Hancock J, Myezwa H (2015). A home-based rehabilitation intervention for people living with HIV and disability in a resource-poor community, KwaZulu-Natal: study protocol for a randomised controlled trial. *Trials*. 16:491.

[3] Cobbing, S, Hanass-Hancock J, Myezwa H (2017). A home-based rehabilitation intervention for adults living with HIV: A randomized controlled trial. *Journal of the Association of Nurses in AIDS Care*. 28(1): 105-117.

[4] Cobbing, S, Chetty V, Hanass-Hancock J, Myezwa H (2017). "Knowing I can be helpful makes me feel good inside, it makes me feel essential": community healthcare workers' experiences of conducting a home-based rehabilitation intervention for people living with HIV in KwaZulu-Natal, South Africa. *AIDS Care.* 2017 (on-line):1-5.

[5] Cobbing, S, Hanass-Hancock J, Myezwa H (2017). Assessing home-based rehabilitation within the development of an integrated model of care for people living with HIV in a resource-poor community. *African Journal of Primary Health Care & Family Medicine.* Manuscript submitted for publication (under review).

B. Conferences where aspects of this PhD were presented

International Conferences

Poster Presentation: Cobbing S, Hanass-Hancock J and Deane M. Physiotherapy Rehabilitation in the context of HIV and Disability in KwaZulu-Natal, South Africa. 11th International AIDS Impact Conference, Barcelona, Spain: 29 September – 2 October, 2013.

Poster Presentation: Cobbing S, Hanass-Hancock J and Chetty, V. Designing a home-based rehabilitation programme for people living with HIV and disability in KwaZulu-Natal, South Africa. 20h International AIDS Conference, Melbourne, Australia: 20-25 July, 2014.

Poster Presentation: Cobbing S, Hanass-Hancock J and Myezwa, H. The design and implementation of a home based rehabilitation programme for people living with HIV and disability in KwaZulu-Natal, South Africa. 12th International AIDS Impact Conference – Amsterdam, Netherlands: 28-31 July, 2015.

Poster Presentation: Cobbing S, Hanass-Hancock J and Myezwa, H. A home based rehabilitation programme for people living with HIV and disability in KwaZulu-Natal, South Africa. 21st International AIDS Conference, Durban, South Africa: 11-22 July, 2016.

National Conferences

Poster Presentation: Cobbing S, Hanass-Hancock J and Myezwa, H. A home-based rehabilitation intervention for people living with HIV and disability in a resource-poor community, KwaZulu-Natal: Study Protocol. 7th SA AIDS Conference 2015 – Durban, South Africa: 9-12 June, 2015.

Oral Presentation: Cobbing S, Hanass-Hancock J and Myezwa, H. The design and implementation of a home-based rehabilitation programme for people living with HIV and disability in KwaZulu-Natal, South Africa: Mad dogs and mountains. Rural Health Conference – Dullstroom, South Africa: 23-26 September 2015.

Oral Presentation: Cobbing S. Home-based rehabilitation for people living with HIV and disability in KwaZulu-Natal, South Africa. South African Medical Research Council Research 9th Annual Early Career Scientist Convention – Cape Town, South Africa: 19-20 October, 2015.

CHAPTER 1: INTRODUCTION

HIV is a virus. Stigma isn't. One has a cure already.

Anonymous

1.1. Overview of thesis

This manuscript has been prepared in accordance with the University of KwaZulu-Natal's College of Health Science's current guidelines for presentation of PhD theses by research (see Appendix 1). The chosen method of presenting this work is via the "thesis by publication" option, which is encouraged by the College of Health Sciences. The guidelines state that this option allows for the fact that "the thesis may comprise of at least three published papers or in press in accredited journals; such papers must have the student as the prime author". In addition to an introductory chapter and a concluding synthesis chapter, this thesis presents five original papers, three of which have been published in peer-reviewed journals, one which has been accepted for publication, with the final paper presented in the form of a manuscript that has been submitted for publication. The candidate is the lead author of all five papers. Each paper builds on the work presented in the previous article and as a coherent collective, they address the overall aim and objectives of this research. This thesis is arranged in seven distinct chapters, described in brief below:

Chapter 1: This introductory chapter presents a brief summary of the published literature which provided the motivation for this research. This is necessarily brief due to the extensive review of literature presented in Chapter 2. It further outlines the study aim and objectives, summarises the overall study methodology and introduces a conceptual framework through which to better understand the close inter-relationship between HIV and disability.

Chapter 2: This chapter is presented in the form of a published study, which employed a scoping review methodology to summarise and assess the available evidence on home-based rehabilitation interventions for adults living with HIV.

> Cobbing S, Hanass-Hancock J, Myezwa H (2016). Home-based rehabilitation interventions for adults living with HIV: a scoping review. *African Journal of AIDS Research.* 15(1): 77–88.

Chapter 3: This chapter is presented in the form of a published study, outlining the methodology for the primary intervention of this PhD research.

Cobbing S, Hanass-Hancock J, Myezwa H (2015). A home-based rehabilitation intervention for people living with HIV and disability in a resource-poor community, KwaZulu-Natal: study protocol for a randomised controlled trial. *Trials*. 16:491.

Chapter 4: This chapter is presented in the form of a published study, outlining the results of the novel randomised controlled trial employed in this PhD research.

Cobbing, S, Hanass-Hancock J, Myezwa H (2017). A home-based rehabilitation intervention for adults living with HIV: A randomized controlled trial. *Journal of the Association of Nurses in AIDS Care*. 28(1): 105-117.

Chapter 5: This chapter is presented in the form of a published study, describing the research assistants' experiences of delivering a home-based rehabilitation intervention for adults living with HIV.

Cobbing, S, Chetty V, Hanass-Hancock J, Myezwa H (2017). "Knowing I can be helpful makes me feel good inside, it makes me feel essential": community healthcare workers' experiences of conducting a home-based rehabilitation intervention for people living with HIV in KwaZulu-Natal, South Africa. *AIDS Care.* 2017 (on-line):1-5.

Chapter 6: This chapter is presented in the form of a manuscript, submitted for publication, which assesses the findings of this PhD work in relation to a model of care for the rehabilitation of PLHIV, developed in the same study community. It further urges readers to employ the findings from related research and practice to better advocate for PLHIV and disability.

Cobbing, S, Hanass-Hancock J, Myezwa H (2017). Assessing home-based rehabilitation within the development of an integrated model of care for people living with HIV in a resource-poor community. *African Journal of Primary Health Care & Family Medicine.* Manuscript submitted for publication (under review).

Chapter 7: This concluding chapter presents a general synthesis of the ideas and results incorporated within this thesis. It considers specific limitations of the research and offers recommendations for future practice and research.

1.2. Background and context of the study

Of the 36.7 million people living with HIV (PLHIV) worldwide, approximately 70% live in sub-Saharan Africa (UNAIDS, 2016). An estimated 6.4 million people are currently living with HIV in South Africa, more than in any other single country in the world. Within South Africa itself, KwaZulu-Natal (KZN) has the highest HIV prevalence of all the nine provinces, with 16.9% of the province's inhabitants living with HIV (Shisana et al., 2014). Antiretroviral therapy (ART) has dramatically improved life expectancy by altering the features and complications of the disease, effectively converting HIV into a chronic disease (Chu & Selwyn, 2011; Worthington, Myers, O'Brien, Nixon, & Cockerill, 2005). South Africa has the world's largest ART programme in the world, with nearly 3.4 million PLHIV now on treatment. The number of people dying annually from HIV-related causes worldwide declined from 1.5 million in 2010 to 1.1 million in 2015, with ART estimated to have averted 6.6 million deaths globally, including 5.5 million deaths in low- and middle-income countries. Encouragingly, the number of annual new HIV infections also continues to decrease. In 2015 there were an estimated 2.1 million new infections as compared to 3.4 million new infections in 2001, a decrease of approximately 40% (UNAIDS, 2016). While the incidence (number of new infections per year) is decreasing, the fact remains that the HIV prevalence (total number of people infected) continues to increase, as less and less people die from HIV-related illnesses (UNAIDS, 2016).

HIV infection has a wide range of effects on the entire human body (Hoffmann & Rockstroh, 2012), resulting in a number of opportunistic infections (OIs) due to the body's depleted immune system . A number of bodily systems, including the cardiorespiratory, neurological and musculoskeletal systems are commonly affected by HIV and result in disorders that are frequently treated by rehabilitation professionals (Myezwa, Stewart, Musenge, & Nesara, 2009) . Rehabilitation is seen as a crucial means of ensuring that PLHIV have an improved quality of life to complement the added life years made likely by ART(Nixon et al., 2011). Rehabilitation programmes commonly include different forms of exercise. A number of studies, in resource-rich settings, have investigated the effects of various types of exercise prescribed for PLHIV. These are well summarised by four systematic reviews (Gomes-Neto, Conceicao, Carvalho, & Brites, 2013; Gomes-Neto, Conceição, Carvalho, & Brites, 2015; O'Brien, Tynan, Nixon, & Glazier, 2016, 2008) designed to investigate the effects of exercise on PLHIV. These reviews provide evidence that both aerobic exercise and progressive resistance exercise interventions are safe and may confer a wide range of health benefits to PLHIV, including improved cardiopulmonary fitness, body composition, muscle strength and psychological status. While these reviews are important in highlighting the benefits of exercise for PLHIV, they focused on otherwise healthy PLHIV. The level of disability of participants was either an excluding factor in the selected studies or was not known.

With the advent of increased ART provision, the annual number of AIDS-related deaths in South Africa has decreased from almost 400 000 in 2005 to less than 200 000 in 2013, a reduction of 48% (UNAIDS, 2014). This increased survival amongst PLHIV has, however, been matched by an increased prevalence of disability in this population (Hanass-Hancock, Regondi, & Nixon, 2013), with 35.5% of over 1000 PLHIV on ART reporting functional limitations, suggesting the onset of disability, in a recent cohort study conducted in KZN province (Hanass-Hancock, Myezwa, & Carpenter, 2015). The focus of HIV care in South Africa to the present date has focused mainly on the acute medical management and drug prescription related to HIV and its related opportunistic infections. Far fewer services and resources are available for the physical rehabilitation of PLHIV. The current model prevalent in the South African public health system favours the rehabilitation of patients in hospitals or clinics, with a low provision of community-based rehabilitation (CBR) or home-based rehabilitation (HBR) services. This shortfall of CBR and HBR provision is contrary to the South African Department of Health's vision of public healthcare delivery in South Africa moving towards these models. According to the National Guidelines on home-base care/community-based care, these services promote the rehabilitation of people in or near their homes and encourage participation by people, respond to the needs of people and encourage traditional community life (Department of Health, 2001).

The DOH call for improved CBR and HBR delivery is echoed by the World Confederation for Physical Therapy (WCPT), who announced their commitment to delivering accessible and appropriate rehabilitation services to persons living with disability (Bury, 2005). Despite the high prevalence of HIV and disability in South Africa, there are relatively few trained physiotherapists working in this country, compared to countries in the developed world. WHO statistics (World Health Organisation, 2011) reveal that there are more than 20 physiotherapists per 10 000 population in Finland, as compared to less than two physiotherapists per 10 000 population in South Africa. With regard to another rehabilitation profession, occupational therapy, Denmark has approximately 11 occupational therapists per 10 000 population, compared to less than one occupational therapist in South Africa, per 10 000 population. CBR and HBR delivery is challenged by the relative scarcity of rehabilitation professionals in South Africa as well as the difficulty of and expense of getting professionals, such as physiotherapists, to work in the community. Chappell & Johannsmeier (2009) investigated the impact of CBR on people living with disabilities and their families. Their study describes how a number of CBR programmes in South Africa employed mid-level rehabilitation workers (also known as community rehabilitation facilitators or CRFs), for this very reason. Unfortunately, this CRF programme has since been discontinued.

Functional limitations are experienced by a large proportion of people on ART (Hanass-Hancock et al., 2015) and may also have a negative impact on PLHIV building livelihoods (Myezwa, Hanass-Hancock, Pautz, Smith, & Carpenter, 2016). Not only are the rehabilitation services for PLHIV and disability in the South African public health service often inadequate, but these individuals have great difficulty in accessing the limited services that are available in district public health hospitals. These obstacles to accessing rehabilitation services include physical, financial and institutional barriers (Cobbing, Hanass-Hancock, & Deane, 2014). It is vital, therefore that alternative rehabilitation options are investigated and implemented for this vulnerable population (Chetty & Hanass-Hancock, 2015). HBR is one such option, which may address some of the barriers described above. While HBR is proven to be an effective strategy for a number of chronic disease populations, including stroke (Chaiyawat & Kulkantrakorn, 2012), heart disease (Munro, Corrigall, Angus, Thompson, & Leslie, 2011) and chronic obstructive pulmonary disorder (Pradella et al., 2015), there is a dearth of evidence related to HBR interventions for PLHIV, particularly in sub-Saharan Africa where HIV infection is endemic.

1.3. Problem statement

The literature reviewed above describes the high prevalence of HIV in sub-Saharan Africa, and particularly in the province of KwaZulu-Natal, South Africa. With more PLHIV receiving ART, the disease is now being viewed as chronic in nature rather than a terminal illness. However, more and more PLHIV are experiencing physical disability as a result of their infection. Despite this close interrelationship between HIV and disability, there is a shortage of rehabilitation services in the South African public healthcare sector, when compared to Western countries, which have far lower rates of HIV prevalence. This paucity of rehabilitation services is exacerbated by the difficulty that PLHIV and disability have in accessing the few services that are available. Rehabilitation services in South Africa are primarily institution-based and offered by trained rehabilitation professionals. There are far less services available in rural communities, despite the DOH’s commitment to move towards home-based models of care. Furthermore, there is a dearth of literature describing Southern African HBR interventions and, prior to this study, no articles that investigated HBR programmes designed specifically for adult PLHIV and disability.

1.4. Research question

What is the effect of a disability-inclusive HBR intervention on PLHIVs' perceived disability, quality of life, functional mobility and functional capacity?

1.5. Research aim and objectives

The aim of this research was to determine the effect of a disability-inclusive HBR intervention on PLHIVs' perceived disability, quality of life, functional mobility and functional capacity. The specific objectives were as follows:

1.5.1. To design a specifically tailored disability-inclusive HBR intervention for adult PLHIV.
1.5.2. To determine the effects of the HBR intervention on participants' perceived disability.
1.5.3. To determine the effects of the HBR intervention on participants' quality of life.
1.5.4. To determine the effects of the HBR intervention on participants' functional mobility.
1.5.5. To determine the effects of the HBR intervention on participants' functional capacity.
1.5.6. To explore community care workers' experiences of being involved in carrying out the HBR intervention.
1.5.7. To describe how the HBR intervention adhered to the fundamental principles of a theoretical model of integrated care developed for this study setting.

1.6. Conceptual framework

The International Classification of Functioning, Disability and Health (ICF) offers a useful framework for studying disability and health-related consequences of disease based on the following three concepts: impairments, activity limitations and participation restrictions (World Health Organization, 2001). According to Van As, Myezwa, Stewart, Maleka, & Musenge (2009) the ICF adopts a bio-psychosocial approach, allowing disability to be defined in broader terms than a mechanistic, purely medical model and places the experience of disability in a socially constructed realm dependent on interrelated social, environmental and personal factors. Impairments are understood to be problems with physiological functioning or anatomical (for example organs, limbs) structure of the body. Activity limitations are defined as difficulties in executing a task or action, such as walking or dressing. Finally, participation restrictions are problems relating to involvement in life situations (World Health Organization, 2001). For example, a female patient diagnosed with HIV may present with impairments such as weak lower limbs or pain in her hands and feet. These impairments may negatively affect activities such as walking or lifting objects which may further limit her participation in work, social and recreational environments. Her experience of disability may further be shaped by her own personal traits as well as the physical and social environment in which she lives and works. This interrelationship between impairments, activity limitations and participation restrictions with environmental and personal contextual factors is well illustrated in Figure 1.

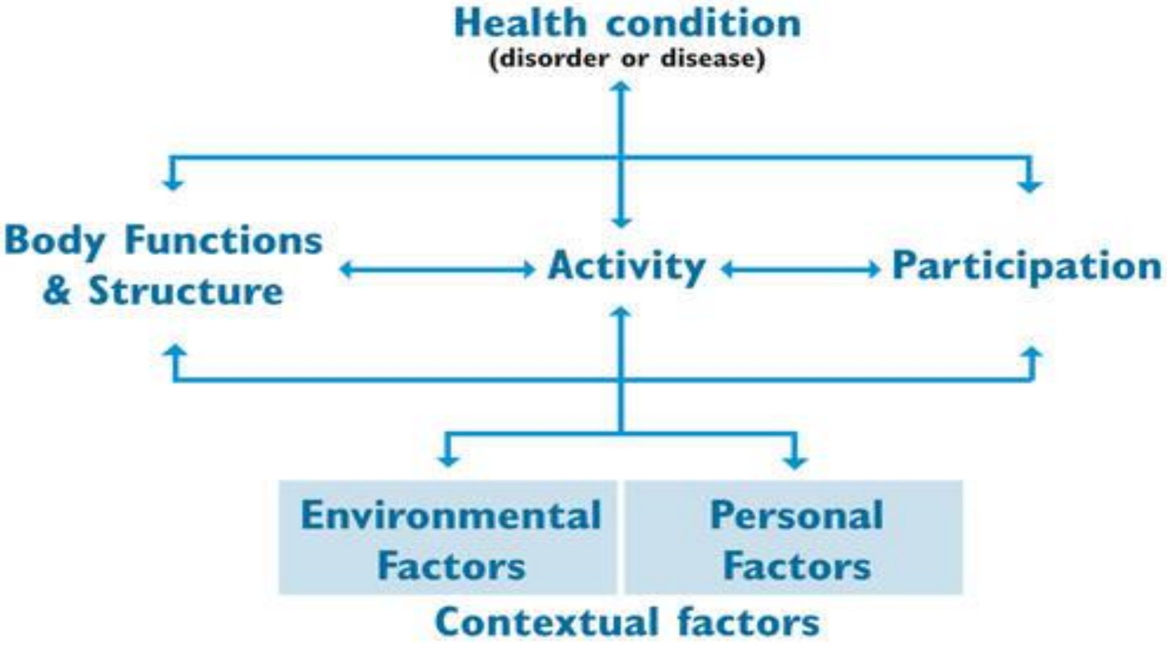

Figure 1: Graphic representation of the ICF framework (World Health Organization, 2001)

Myezwa et al. (2009) conducted an assessment of eighty HIV in-patients at the Chris Hani Baragwanath Hospital in Gauteng province, South Africa. In this study the ICF short-version checklist (WHO, 2003) was employed to assess the impairments, activity limitations and participation restrictions experienced by these patients. Over 70% of the participants in this study reported impairments related to digestive, neuromuscular, respiratory and sensory function as well as emotional and mental problems. These impairments led to activity limitations such as decreased mobility and problems with self-care as well as participation restrictions, including difficulty engaging fully in community, social and civil life. The researchers also analysed specific associations found among impairments, activity limitations and participation restrictions. For example, patients with cardiovascular, haematological, immunological and respiratory system problems were 14-times more likely to have problems with execution of general tasks. An appreciation of the interrelationship between these factors may allow rehabilitation professionals to develop more appropriate rehabilitation interventions for PLHIV.

1.7. Overview of the study methodology and location

This research employed a mixed methods approach, utilising both quantitative and qualitative methods in the overall research design. A quantitative approach, specifically a randomised controlled trial (RCT) design, was employed in the development and analysis of the HBR intervention that formed the primary emphasis of this thesis. The design of this RCT is described in the published article in Chapter 3, while the published results of the study intervention are presented in Chapter 4. When reporting the results of a RCT it is important to consider the issue of methodological quality. A well designed trial is more likely to produce unbiased results that can be replicated in practice (Maher, Sherrington, Herbert, Moseley, & Elkins, 2003). The Physiotherapy Evidence Database (PEDro) Scale is commonly employed to assess the quality of RCTs, particularly trials that involve physiotherapy interventions. It has been proven to be both a reliable (Maher et al., 2003) and valid (de Morton, 2009) measure of the methodological quality of clinical trials. An assessment of the quality of the study RCT is not included in Chapter 4 due to the word limitations common to all peer-reviewed publications. It is of interest, however to note, that the RCT in this study scored 8 out of a possible 10 points on the PEDro scale. This represents a study of high methodological quality, with an average total PEDro score from over 25 000 trials of 5.0, with a standard deviation of 1.6 (PEDro, 2016). Table 1 shows how the study RCT scored for each item of the PEDro Scale. Blinding of subjects and therapists was not possible due to the nature of this RCT. The explanation for each item can be viewed in Appendix 2.

Table 1: Assessment of study RCT on the PEDro Scale

Item	Yes	No
Subjects were randomly allocated	✓	
Allocation was concealed	✓	
Study groups were similar at baseline	✓	
Blinding of all subjects		✓
Blinding of therapists who administered the therapy		✓
Blinding of all assessors	✓	
85% of participants followed up for at least one outcome measure	✓	
An intention-to-treat analysis was employed	✓	
Between-group statistical comparison for at least one outcome measure	✓	
Provision of point and variability measures for at least one key outcome	✓	

A qualitative enquiry, using semi-structured interviews, was employed to assess the research assistants' experiences of being involved in this HBR intervention (see Chapter 5). Hussein (2009) argues that combining qualitative and quantitative methods (triangulation) can increase the credibility of research by enhancing the generalisability and internal consistency of study findings. In this way, a more holistic account of the benefits and challenges of rehabilitative interventions can be communicated, increasing the likelihood of healthcare workers successfully translating this research into practice. Ethical approval from the UKZN Biomedical Research Ethics Committee (BFC052/15) was received in September 2014 (see Appendix 3). The full ethical considerations for this research are described in Chapters 3, 4 and 5.

The study was located at a public-funded hospital situated in the eThekwini district in the province of KwaZulu-Natal, South Africa. It is a 200 bed hospital serving a population of 750 000 people in an impoverished semi-rural area. The hospital provides medication and healthcare services for over 4500 PLHIV. The HBR intervention was conducted in, or near to, participants' homes. These homes all fall within the hospital catchment area, and a map of the location of these homes are shown in the articles in Chapters 4 and 5.

1.8. Philosophical assumptions

It is impossible to completely divorce oneself, as an individual, from the research process. Ontology refers to the researcher's view of the nature of reality (Creswell, 2013). In outlining my ontological position, I acknowledge that I adopted a pragmatic approach to this PhD study, choosing the most rigorous method (an RCT) to answer the overall research question. The choice of research question arose from my interest in the rehabilitation of PLHIV. This interest, in turn, had its genesis in my practical experiences working as a physiotherapist in a palliative care facility for PLHIV at a time when ART was just beginning to be made available to South Africans infected with the virus, who met very stringent criteria. These experiences, together with my move into the tertiary academic environment, resulted in me being the lead author in a position paper that provided recommendations to researchers, academics and clinicians aimed at improving the quality of care available to PLHIV in South Africa (see Appendix 16). The choice of research setting was not coincidental either, allowing me to continue the work begun in my Masters research (see Appendix 17) and add value to the important work being done by my fellow researchers in this area. While every effort was made to maintain study rigour and limit bias, it is important that readers of this thesis understand the nature of the candidate's embeddedness and interest in the research community.

CHAPTER 2: SCOPING REVIEW

After all, the ultimate goal of all research is not objectivity, but truth.

Helene Deutsch (1884-1982)

2.1. Summary of findings

This chapter is presented in the form of a published study, which employed a scoping review methodology to summarise and assess the available evidence on home-based rehabilitation interventions for adults living with HIV. Only six articles were identified that met this review's inclusion criteria. Apart from highlighting the dearth of evidence on this topic, this article recommends that more research of this nature be conducted in sub-Saharan Africa and that a wider range of measures be utilised when assessing the efficacy of home-based rehabilitation interventions for people living with HIV. The results of this scoping review informed the development of the study protocol for the primary intervention employed in this PhD research (described in Chapter 3).

2.2. Publication details

Title	Home-based rehabilitation interventions for adults living with HIV: a scoping review
Authors	Saul Cobbing, Jill Hanass-Hancock and Hellen Myezwa
Journal	African Journal of AIDS Research (AJAR)
Year	2016
Volume (number)	15(1)
Pages	77-88
DOI number	10.2989/16085906.2016.1159968

2.3. Journal details

The African Journal of AIDS Research (AJAR) is a peer-reviewed Institute for Scientific Information (ISI) - listed journal. It publishes papers that make an original contribution to the understanding of social dimensions of HIV/AIDS in African contexts. AJAR includes articles from, amongst others, the disciplines of sociology, epidemiology, health communication, public health, education, nursing science and social work. Papers relating to impact, care, prevention and social planning, as well as articles covering social theory and the history and politics of HIV/AIDS, are considered for publication in AJAR. It has an impact factor of 0.790 (as at October 2016).

2.4. Publication timeline

The first draft of this article was submitted to the African Journal of AIDS Research (AJAR) on the 14 September 2015. Favourable reviews with minor revisions were received from the journal's editorial office on the 25 January 2016. The article (with notated amendments) was re-submitted to AJAR on the 28 January 2016. The final article was published on-line on 22 March 2016.

2.5. Contribution details

The candidate conceptualised, developed and wrote the paper. Professors Myezwa and Hanass-Hancock provided key input in assisting the candidate with the scoping review methodology, interpreting the results and editing the draft manuscript. Professor Aimee Stewart (University of the Witwatersrand) is also acknowledged for her assistance in conceptualising the initial parameters of this scoping review.

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Home-based rehabilitation interventions for adults living with HIV: a scoping review

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Home-based rehabilitation (HBR) has been shown to improve the lives of people living with a wide range of chronic diseases in resource-rich settings. This may also be a particularly effective strategy in resource-poor settings, where access to institution-based rehabilitation is limited. This review aimed to summarise and discuss the evidence related to the effectiveness of home-based rehabilitation (HBR) interventions designed specifically for adults living with HIV. A scoping review methodology was employed, involving systematic search techniques and appraisal of appropriate evidence. English-language journal articles that assessed the quality of life or functional ability outcomes of HBR interventions for adults living with HIV were considered for this review. Out of an initial 1 135 publications retrieved from the search of databases, six articles met this review's inclusion criteria. While this review highlights the scarcity of empirical evidence related to HBR interventions for adults living with HIV, the findings of these six articles are that HBR is a safe management option that may confer a number of physical and psychological benefits for this population. Future research on HBR interventions should include a wider range of assessment measures, including cost-benefit analyses and specific tools designed to assess the functional ability and participation in activities of daily living of participants involved in these programmes. In particular, more research on HBR is required in resource-poor environments, such as sub-Saharan Africa where HIV is endemic, to assess whether this is a feasible strategy that is both effective and practical in the areas that may need it most.

Keywords: disability, HIV, home-based rehabilitation, multidisciplinary, quality of life, scoping review

Introduction

Since the advent of highly active antiretroviral therapy (HAART), people living with HIV (PLHIV) are living for longer with a variety of impairments and disabilities that are amenable to rehabilitation interventions (Solomon and Jung 2006). The 2013 UNAIDS report on the global AIDS epidemic estimates that 35.3 (32.2–38.8) million people are living with HIV, with 25.0 (23.5–26.6) million PLHIV in sub-Saharan Africa. The number of AIDS deaths has declined from 2.3 (2.1–2.6) million in 2005 to 1.6 (1.4–1.9) million deaths in 2012 (UNAIDS 2013). As HIV has shifted from an acute disease requiring palliative care to an illness that is more chronic and episodic in nature (Beauregard and Solomon 2005), it is crucial that rehabilitation is employed as a key component of HIV care (Nixon et al. 2011a). Although PLHIV in sub-Saharan Africa are also expected to live longer lives in the HAART era, two recent systematic reviews (Hanass-Hancock et al. 2013; Banks et al. 2015) have revealed that PLHIV in these hyper-endemic sub-Saharan countries, including those on HAART, experience a wide variety of physical and cognitive disabling conditions that may require rehabilitation interventions. A recent more in-depth study of over 1 000 PLHIV on HAART in South Africa revealed that an alarmingly high proportion of the study cohort (35.5%) experienced the onset of disability, with very few being exposed to any rehabilitation interventions (Hanass-Hancock et al. 2015). Considering the vast numbers of people living with HIV in sub-Saharan Africa who are in need of HAART and potentially rehabilitation, it is crucial that we explore the rehabilitation options and chronic healthcare services for this population (Van As et al. 2009; Nixon et al. 2011b).

Stucki et al. (2007, 39) propose a broad definition of rehabilitation, based on the International Classification of Functioning, Disability and Health (ICF) framework, describing is as a strategy that "aims to enable people with health conditions experiencing or likely to experience disability to achieve optimal functioning in interaction with the environment". Rehabilitation services for PLHIV can be provided by a wide range of health professionals and may include strategies designed to manage pain, reduce fatigue, enhance function, strengthen muscles (via resistance exercises) and improve exercise tolerance, via aerobic exercises (Canadian Working Group on HIV and Rehabilitation 2011). Both resistance and aerobic exercise interventions have been shown, by a number of studies, to be safe and to confer a number of benefits to PLHIV. These benefits include improved quality of life, as well as a number of physical benefits such as increased muscle strength and enhanced exercise tolerance. These studies are well summarised by two systematic reviews on resistance and aerobic exercise respectively (O'Brien et al. 2008; O'Brien et al. 2010).

While the majority of studies investigating the effects of exercise on PLHIV have been conducted in developed countries, in recent years there have been isolated studies of this type emanating from the developing world, conducted in low and middle-income countries (LMICs) (Mutimura et al. 2008a; Mutimura et al. 2008b; Ley et al. 2014;). Globally, most published studies on exercise for PLHIV have focused on interventions conducted in health care institutions or recreational facilities (for example hospitals or gymnasiums). This work, while valuable, has been conducted primarily in highly-controlled environments, rather than in real world settings where most PLHIV live and work. Due to difficulties in accessing institution-based services, particularly in developing countries, it has been suggested by a variety of authors that alternative rehabilitation approaches, including home-based rehabilitation (HBR) interventions, should be implemented and assessed (Hanass-Hancock et al. 2013; Gona et al. 2013; Cobbing et al. 2014)

The terms home-based rehabilitation (HBR) and community based rehabilitation (CBR) are often mistakenly used interchangeably. HBR specifically refers to rehabilitation carried out in an individual's own home, and is just one component of the broader CBR process. CBR entails a far wider scope and is defined by the World Health Organisation (WHO) as "a strategy within general community development for the rehabilitation, poverty reduction, equalisation of opportunities and social inclusion of all people with disabilities" (World Health Organisation 2010, 11).The implementation of full CBR services does present a number of challenges, however. With specific reference to providing CBR services to PLHIV in an under-resourced township in South Africa, Harris (2011) reports that it is unlikely that CBR programmes can be implemented and sustained without a willing participant pool, leadership of local health managers and access to exercise venues and equipment. In a qualitative study designed to assess the impact of CBR as implemented by mid-level rehabilitation workers for people with disabilities (PWD), Chappell and Johannsmeier (2009) found that these workers had a greater impact on individual PWD rather than the community at large. The gaps in service delivery described in this study, conducted in six of the nine South African provinces, included inadequate community interventions related to disability awareness, employment of PWD, schooling, housing and transport. These challenges, along with many other resource, knowledge and time constraints, may result in rehabilitation providers opting to implement specific HBR interventions, rather than full-scale CBR programmes. The challenge of implementing CBR interventions appears to be reflected by the fact that the majority of the literature relating to CBR consists of theoretical and review articles rather than empirical descriptions of CBR interventions (Finkenflügel et al. 2005).

In contrast to this, there is a growing body of evidence supporting the implementation of HBR programmes as an alternative to institution-based rehabilitation programmes, for an array of chronic and acute conditions, including stroke (Geddes and Chamberlain 2001; Outpatient Service Trialists 2003; Chaiyawat and Kulkantrakorn 2012), traumatic brain injury (Powell et al. 2002; Hopman et al. 2012;), coronary artery disease (Munro et al. 2011; Clark et al. 2013), chronic respiratory conditions (Regiane Resqueti et al. 2007; Maltais et al. 2008; Pradella et al. 2014) and hip fracture (Donohue et al. 2013; Salpakoski et al. 2014). In these studies, HBR programmes have been shown to be not only safe for individuals with a wide range of impairments, but to confer benefits of equivalent or greater magnitude than institution-based interventions. These benefits include a variety of physical (strength and endurance) gains, improved daily functioning, enhanced social interaction and better quality of life. The recommendations from these studies include the early supported discharge of patients into HBR programmes as an alternative to hospital-based rehabilitation (Geddes and Chamberlain 2001) while making sure that comprehensive discharge plans are in place before patients leave hospital, ensuring that they can access available health services should they need to (Clark et al. 2013).

Not only has HBR been shown to be an effective means of improving physical and psychosocial functioning, it is also proposed that HBR programmes may counter the multitude of obstacles faced by patients attending institution-based interventions (Taylor et al. 2015), including cost and distance of travel. Of significant interest to policy-makers and funders of rehabilitation programmes, it further appears that HBR may be a more cost-effective means of delivering rehabilitation services than traditional hospital or gymnasium-based programmes (Collins et al. 2001; Salvetti et al. 2008; Munro et al. 2011). While there are various potential benefits of HBR programmes, the challenges to implementing these interventions should also be noted. These challenges include convincing policy makers and service managers to actually implement these programmes (Lang 2011), the provision of appropriate training to grassroots workers (Wirz 2000) and the possibility that patients may stop prescribed home-based exercises once direct supervision has ceased (Regiane Resqueti et al. 2007). It should also be noted that the vast majority of these studies and reviews describing the benefits of HBR reflect interventions and programmes that have been implemented in the developed world, in high-income countries. Caution should thus be taken in extrapolating these findings to LMICs in the developing world, where socio-economic conditions may be markedly different.

HBR interventions may be implemented and supervised by a wide range of health care professionals, including doctors, nurses, occupational therapists and physiotherapists. Mid-level workers and grassroots workers, who are trained by health professionals and other professionals including social and development workers, can also be involved in the delivery of services directly to communities (Wirz 2000). These interventions may involve only one health care worker or may be conducted by a multidisciplinary team of health care workers. Two systematic reviews on the effectiveness of multidisciplinary rehabilitation for adults with multiple sclerosis (Khan et al. 2007) and after primary brain tumour treatment (Khan et al. 2013), demonstrate some evidence that multidisciplinary HBR interventions may improve the participation, quality of life and vocational involvement of individuals offered these services. However, multidisciplinary treatment programmes necessarily require more staff and may therefore place an increased financial burden on health care systems (Karjalainen et al. 2003).

While the various evidence-based benefits of HBR for a wide range of acute and chronic impairments have been discussed above, there is limited evidence related to HBR interventions for PLHIV. The need for research on HBR services for PLHIV is not, however, a recent request. As far back as the early 1990s, Levinson and O'Connell (1991) and O'Dell and Dillon (1992) predicted that rehabilitation professionals could expect an increased number of referrals for the management of disability in PLHIV. In 1993, in a report on the physiotherapy rehabilitation of ten PLHIV seen in their own home or a friend's home, Lang (1993) concluded that while HBR services are appropriate for PLHIV, more studies with larger samples needed to be conducted. Over twenty years later, there remains a dearth of literature focusing on HBR for PLHIV and no systematic analysis of the existing evidence. A number of professionals and researchers working in this field, including the authors of this review, have expressed concern at the lack of inclusion of rehabilitation interventions in HIV care (Cobbing et al. 2013; Chetty and Hanass-Hancock 2015), particularly for people living with HIV and disability (UNAIDS 2014). This phenomenon appears to be true for regions across the globe, but more particularly in resource-poor sub-Saharan African settings where HIV is endemic. The purpose of this review is to present the results of a scoping review assessing the empirical evidence related to the effectiveness of HBR interventions on the functional ability and quality of life of adults living with HIV.

Methods

Study design

This scoping study used specific review techniques and methodology as outlined by Arksey and O'Malley (2005) and further developed by Levac et al. (2010). This methodology guided the development of a search strategy and criteria to identify and appraise articles that focused on HBR for PLHIV. This appraisal allowed the authors to highlight any gaps in the evidence, thus satisfying a key component of this methodology, namely the requirement to make recommendations for future research (Daudt et al. 2013) in an indicative rather than prescriptive manner (Anderson et al. 2008).

Identifying relevant studies

This review identified peer-reviewed journal articles on HBR interventions for PLHIV published up until March 2015. The databases searched were the Cochrane Library, EBSCOhost (including Academic Search Complete, Health Source – consumer and nursing editions, Medline, PsycARTICLES and PsycINFO), PEDro, Pubmed and Science Direct. For this purpose a search string was developed. This included a combination of the following keywords and their synonyms (expressed in Boolean logic): Home-based rehabilitation OR HBR OR community-based rehabilitation OR CBR OR rehabilitation OR *therapy AND HIV. Thorough searches of Google Scholar and appraisals of citation and reference lists were undertaken to find appropriate studies for this review.

Article selection

The procedure for selecting articles consisted of four steps: identification of relevant literature; screening of abstract for inclusion and exclusion criteria (see Table 1); assessing eligibility on the basis of full text; and, final inclusion of articles. It should be noted here that an HBR intervention was defined for the purpose of this review as one in which some or all of the intervention was conducted in or near to the participants' homes. See Figure 1 for the number of records retrieved and included in each of these steps.

Extraction of data

A data extraction sheet was developed and used to extract and summarise the data from the six articles included in this scoping review. The data extracted included general information about the article (title, author, journal and year of publication of each article), as well as information on the study design, study setting, participant demographics and study outcome measures. This extraction sheet also captured a brief summary of the results, limitations and recommendations of the studies.

Results

Characteristics of included studies

The rigorous search process (illustrated in Figure 1) resulted in the selection of five articles (Lang 1993; Baigis et al. 2002; Dolan et al. 2006; Maharaj and Chetty 2011; Pullen et al. 2014) that were eligible for this scoping review. One further article (Roos et al. 2014) was added following communication with a wide range of experts in the field of HIV rehabilitation, thus resulting in a final sample of six articles. These individuals, representing regions across the world, are involved in HIV education and research and their knowledge of articles that were eligible for this review (written by themselves or other researchers) was solicited via e-mail. Details of the six articles included for final analysis and discussion are shown in Table 2. Four of the six studies used a randomised controlled trial (RCT) method, while the other two studies employed a case study design. All six of the studies were conducted in urban

Table 1: Inclusion/exclusion criteria

Inclusion	Exclusion
The article involved a HBR intervention for PLHIV	Non-peer reviewed articles (e.g. books, magazines, policy briefs, etc.)
The article assessed quality of life and/or functional ability outcomes	Articles not written in English
Peer-reviewed journal articles involving primary research	Literature reviews and commentaries
All articles were written in English	
Study participants were adult (over 18 years of age) PLHIV	

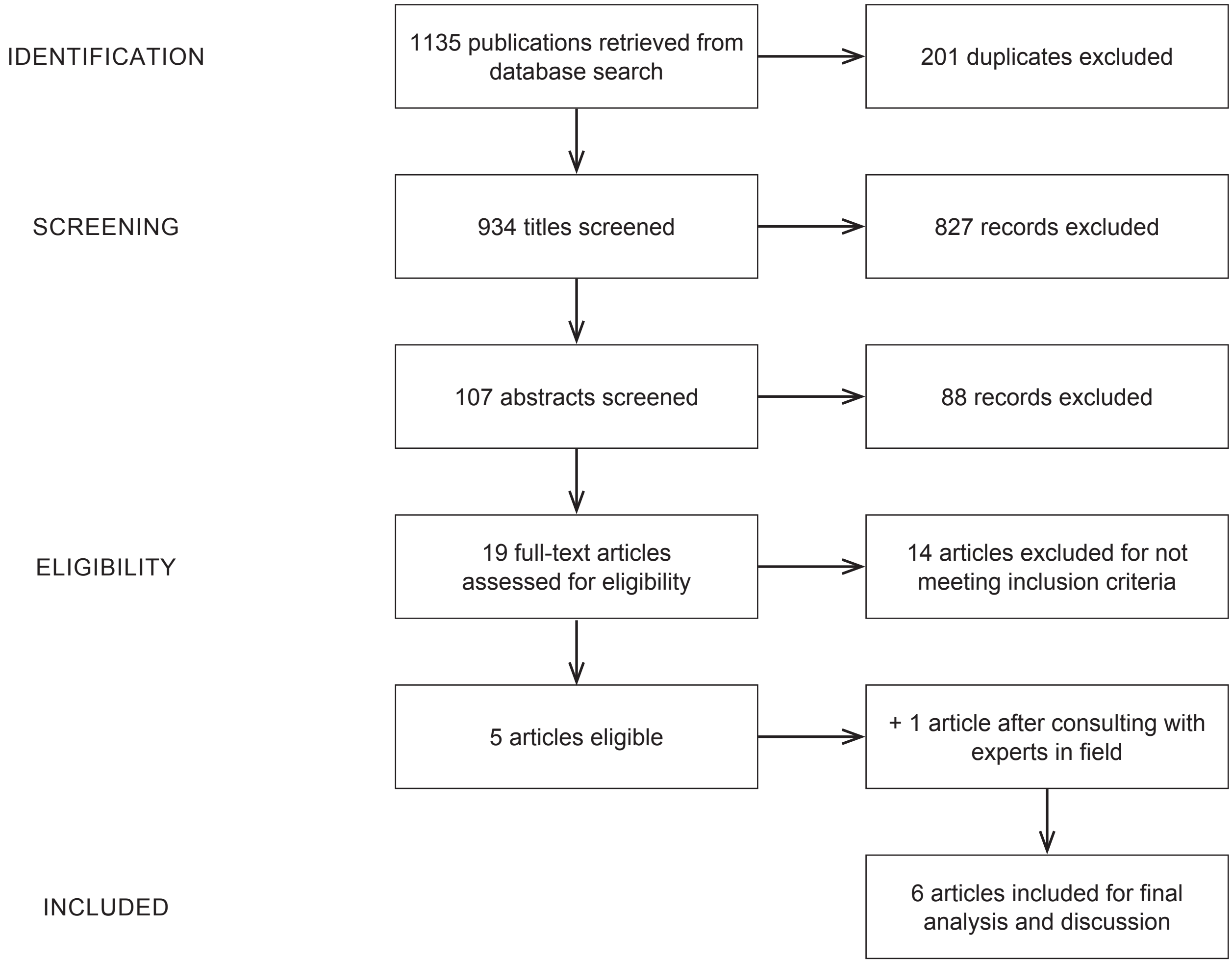

Figure 1: Article selection process

settings, three of them in the developed world (the United Kingdom and the United States of America) and three of them in the developing world (Nigeria and South Africa). All the studies included adult PLHIV as participants, with the sole exception of the study conducted by Lang (1993), which included one child among the total of ten participants. Outcome measures that were utilised in the six studies included measures of aerobic fitness, muscle strength, immune function, cardiovascular risk and quality of life (see Table 3).

Description of interventions

Four of the exercise interventions were implemented by physiotherapists, one by nurse/trainers and one by several members of a multi-disciplinary research team, including physiotherapists and a nurse. Three of the interventions were conducted exclusively in the participants' homes, one within the vicinity of the participants' homes and their community, while the other two interventions included both home-based and clinic-based exercise. The study by Dolan et al. (2006) included a standardised exercise protocol focusing on flexibility, aerobic conditioning and resistance training, while the Baigis et al. (2002) study included flexibility and aerobic exercises. Both of these studies involved the use of exercise equipment, including a stationary bicycle, resistance equipment and a ski machine.

Two of the physiotherapy-led studies involved the combined use of a number of common rehabilitative techniques employed by physiotherapists, including massage, relaxation training, breathing exercises, as well as resistance and aerobic exercises. The third physiotherapy-led study employed a standardised aerobic and resistance training protocol, while the fourth physiotherapy-led study implemented a home-based walking programme. It should be noted that the walking programme also included monthly contact over a five month period and education sessions between participants and researchers during the course of the intervention. Minimal equipment was utilised in the Lang (1993) study, while the study by Roos et al. (2014) also required no equipment other than pedometers, which were used both as a measurement of the number of steps taken by participants and as motivational tools for the participants. A treadmill, cycle ergometer and a multigym were used in the clinic-based exercise sessions of the studies by Pullen et al. (2014) and Maharaj and Chetty (2011).

Table 2: Study characteristics

Author	Title	Study design	Study setting	Participants	Intervention
Baigis et al. (2002)	Effectiveness of a Home-Based Exercise Intervention for HIV-Infected Adults: A Randomized Trial	Randomised controlled trial	U.S.A. (urban setting)	99 adults (80% male) aged 24 to 61 (I = 52, C = 47)	I = Home-based aerobic and stretching programme, conducted by nurse/trainer, 3 x weekly for 15 weeks; C = no exercise
Dolan et al. (2006)	Effects of a Supervised Home-Based Aerobic and Progressive Resistance Training Regimen in Women Infected With Human Immunodeficiency Virus	Randomised controlled trial	U.S.A. (urban setting)	40 female adults with self-reported fat re-distribution aged 18 to 60 (I = 20, C = 20)	I = Home-based aerobic and resistance programme, conducted by MDT, 3 x weekly for 16 weeks; C = no exercise
Lang (1993)	Community Physiotherapy for People with HIV/AIDS	Case study design	U.K. (urban setting)	Nine adults (male and female) aged 20 to 70, one child of 10 No control group	Home-based and needs-based physiotherapy rehabilitation and relaxation training (of varying duration)
Maharaj and Chetty (2011)	Rehabilitation program for the quality of life for individuals on highly active antiretroviral therapy in KwaZulu-Natal, South Africa: a short report	Randomized controlled trial	South Africa (urban setting)	52 adults (male and female) aged 22 to 58 (I =26, C = 26)	Clinic and home-based physiotherapy rehabilitation (12 weeks duration)
Pullen et al. (2014)	Physiotherapy intervention as a complementary treatment for people living with HIV/AIDS	Case study design	Nigeria (urban setting)	One adult female aged 43 No control	Clinic and home-based physiotherapy rehabilitation (12 weeks duration)
Roos et al. (2014)	Effects of an Education and Home-Based Pedometer Walking Program on Ischemic Heart Disease Risk Factors in People Infected with HIV: A Randomized Trial	Randomized controlled trial	South Africa (urban setting)	84 adults (79% female) Aged 20 to 65 (I =42, C = 42)	Home-based walking programme

I = intervention group; C = control group

The frequency and duration of exercise sessions for the six studies were as follows: 40-minute sessions, three times weekly for 15 weeks (Baigis et al. 2002); two-hour sessions, three times weekly for 16 weeks (Dolan et al. 2006) ; a one-hour clinic-based session and three half-hour home-based sessions, weekly for 12 weeks (Maharaj and Chetty 2011); 30-minute sessions, three times weekly for 12 weeks (Pullen et al. 2014); 1 000 (going up to 3 000) steps daily from baseline measure, three (going up to five) times weekly for 6 months (Roos et al. 2014); and 37 appointments (ten missed) for the ten participants in the Lang (1993) study. While the specific length and frequency of individual sessions are not described in the latter study, it is stated that four of the participants were seen over a three-month period and five of the participants were seen over a one-month period.

Individual study outcomes

The results and drop-out rates for each individual study are summarised in Table 3. None of the studies showed any adverse effects of rehabilitation interventions, with all outcome measures either improving or remaining unchanged. Baigis et al. (2002) found that while exercise was safe for PLHIV and had no negative effect on participants' immune function, the intervention group did not shown significant improvements in any of the study outcome measures. The authors pointed out, however, that this study was conducted in the pre-HAART era and that the study sample comprised mainly well-educated African American men who had sex with men. The study by Dolan et al. (2006), with a similar protocol to that used by Baigis et al. (2002) found opposing results to those outlined above. In this study, significant improvements in the exercise group's strength, cardiorespiratory fitness, endurance, and body composition were demonstrated. All forty participants in the intervention and control groups were adult women, which may again limit the generalisability of this study's findings. The only validated outcome measure used in the Maharaj and Chetty (2011) study was the SF-36, which demonstrated a significant improvement in all quality of life (QoL) domains among the participants in the intervention group. The fourth of the RCT studies (Roos et al. 2014), demonstrated significant between-group effects in a six-minute walk test distance, waist to hip ratio, as well as glucose and high-density lipoprotein levels over a 12-month period. Drop-out rates ranged from 5% to 38% for these four studies and were higher in the control groups than in the intervention groups.

Discussion

Scarcity of available evidence

This is the first review that systematically describes and analyses evidence-based, published HBR interventions for adult PLHIV. What is immediately apparent from the final

Table 3: Individual study outcomes

Author	Outcome measures	No change	Improvement	Drop-out rate
Baigis et al.	VO2max	*		17% (I) 25% (C)
(2002)	CD4+ count	*		
	CD4+ %	*		
	DASI	*		
	SIP	*		
	MOS-HIV	*		
Dolan et al.	CD4+ count	✓		5% (I) 5% (C)
(2006)	Aerobic measures		✓	
	6MWT		✓	
	Muscle strength		✓	
	Body composition		✓	
	Biochemical measures	✓		
	Dietary intake	✓		
Lang	Motor assessment	*		N/A (case study)
(1993)	Respiratory assessment	*		
Maharaj and Chetty (2011)	SF-36		*	23% (I) 38% (C)
Pullen et al.	CD4+ count		*	N/A (case study)
(2014)	Aerobic measures		*	
	Muscle strength		*	
	Body composition		*	
	SF-36		*	
Roos et al.	PSS-10	✓		17% (I) 24% (C)
(2014)	6MWT		✓	
	Blood Pressure	✓		
	Body composition		✓	
	Biochemical measures		✓	
	FRS	✓		

I = intervention group; C = control group; DASI = Duke Activity Status Index; SIP = Sickness Impact Profile; MOS-HIV = Medical Outcomes Study-HIV; SF-36 = Short Form (36) Health Survey; PSS-10 = Cohen's Perceived Stress Scale-10; 6MWT = 6-minute walk test; FRS = Framingham Risk Score
*Outcome measures not assessed post-intervention

article selection is the relatively low number of published articles (six) that report on this type of intervention, with two of the studies employing simple case study designs. The first of the case study design articles (Lang 1993) is to these authors' knowledge, the first empirical account of a physiotherapy rehabilitation intervention for PLHIV. This study had a number of limitations, including a small sample size of ten participants (nine adults and one child) and no control group. This study, however, was perhaps the first to confirm that PLHIV are affected by conditions which can be treated by physiotherapists and that home-based rehabilitation is appropriate for this patient population. The second case study design article (Pullen et al. 2014) was conducted on only one adult female, and is thus not generalisable to other PLHIV. It did, however, consider a number of outcome measures related to function and quality of life and was thus deemed suitable for this review. To make a comparison to other chronic disease populations, a systematic review of HBR interventions for stroke patients (published more than ten years ago), found 14 eligible studies, all of them RCTs (Outpatient Service Trialists 2003), while a systematic review of HBR interventions for coronary artery disease identified 22 eligible studies (Munro et al. 2011).

There may be a number of reasons for this apparent discrepancy between these disease populations. It has been argued that the response to HIV has been largely medical in nature, focusing on diagnosis and disease-level issues rather than on the rehabilitation of PLHIV (Hanass-Hancock and Nixon 2009; Hanass-Hancock et al. 2013). However, anti-retroviral medications have been widely available in the West for almost two decades and since 2005 in South Africa (the country with the highest HIV prevalence worldwide), thus changing the lived experience of PLHIV. Furthermore, rehabilitation workers such as occupational therapists and physiotherapists have been treating PLHIV at home for over two decades, as evidenced by Lang (1993) who even then, made a call for more research on HBR for PLHIV. For this reason, one may have expected (by 2015) for there to be more peer-reviewed articles published about HBR interventions. Another possible reason for this relatively low number of articles compared to evidence-based articles published on stroke and coronary artery disease is that these diseases are far more prevalent in the high-income countries (HICs) of the Western world. Not only are most articles in peer-reviewed journals submitted by researchers from HICs, but these researchers also have a significantly better chance of having their work published than their counterparts from LMICs (Singh 2006).This phenomenon also appears to be true in disciplines other than health care, raising the question of whether findings from HICs are always relevant to local practice and policies in LMICs (Das et al. 2009). In sub-Saharan Africa, despite being the global region where HIV prevalence is the highest and community-based work is widely practiced, there may be relatively fewer researchers writing up the results of ongoing HBR interventions for PLHIV. With three of the six articles in this review describing interventions conducted in Africa, it is hoped that more sub-Saharan African-based researchers and rehabilitation practitioners begin to publish the findings of their work in this area.

Effectiveness of HBR interventions on physical ability of PLHIV

As with hospital or institution-based exercise interventions, HBR for PLHIV appears to be safe and confers minimal risk to individuals participating in these interventions. It is difficult to compare the results from the articles included in this review as a variety of different outcome measures were employed. However, the physiological and quality of life parameters that were measured either improved or stayed the same, with no negative results reported across the six articles. These improvements in physiological measures included increased cardiorespiratory fitness (as measured by VO2max), improved endurance (as measured by 6MWT), upper and lower limb muscle strength, lower resting heart rate and reduced waist circumference and waist/hip ratio. Immune function (as measured by CD4 count and CD4%) remained significantly unchanged in two of the three studies that measured this variable, while the case study by Pullen et al. (2014), with only one participant, demonstrated a 12.5% improvement in CD4 count following the 12-week exercise programme.

These improvements in aerobic fitness and strength, together with an unchanged immune status are supported by the findings of two reviews on aerobic and strength exercise for PLHIV (O'Brien et al. 2008; O'Brien et al. 2010). A systematic review on concurrent training (strength and aerobic exercise performed in the same session) for PLHIV also demonstrated that this form of training is safe and confers cardiovascular benefits (Gomes-Neto et al. 2013a). A further systematic review on different exercise strategies reported that aerobic, strength and concurrent training for PLHIV are all safe and that the gains conferred are specific to the type of exercise prescribed. This review concluded that concurrent training is the best form of exercise for individuals living with disabilities resulting from HIV, as it results in significant improvements in all assessed outcomes (Gomes-Neto et al. 2013b).

While it could be argued that the 6MWT is a functional measure of an individual's walking ability, it is interesting to note that apart from the use of the Duke Activity Status Index in the Baigis et al. (2002) study (which showed no improvement in the intervention group), none of the other five studies in this review used specific measures assessing participant's overall functional ability or activities of daily living. By employing functional measures, these studies could have completed a more holistic investigation and description of the functional ability of the study participants to participate fully in their individual life pursuits. Measures such as the Functional Independence Measure (FIM) or Rivermead Mobility Index (RMI) can be employed to assess whether physical improvements brought about by a specific intervention are actually matched by a real improvement in an individual's ability to carry out daily activities at home and at work. It should be pointed out, however, that the FIM assesses a general degree of disability (Linacre et al. 1994) while the RMI was originally designed for individuals who had sustained a head injury or stroke (Collen et al. 1991). While quality of life measures that have been designed for PLHIV, such as the WHOQOL-HIV and the Functional Assessment of HIV Infection (FAHI) (Cella 1996) do include questions related to function, there are no specific functional measures designed for this population.

Effectiveness of HBR interventions on quality of life and pain of PLHIV

Four of the six studies (with the exception of Lang 1993, and Dolan et al. 2006) in this review employed psychological measures assessing the quality of life or level of perceived stress of the participants before and after the chosen intervention. In these four studies, all quality of life domains either stayed the same or improved in participants exposed to the HBR interventions, while the level of perceived stress in the intervention group was inversely associated with interaction over the six-month period of the prescribed walking programme in the Roos et al. (2014) study. These improvements in psychological parameters following a period of HBR mirror the reported psychological benefits of exercise in previous systematic reviews on the effects of resistance, aerobic and concurrent exercise training for PLHIV. It is interesting to note, however, that none of the studies that assessed quality of life, used measurement tools designed specifically for PLHIV (such as the WHOQOL-HIV or the FAHI), which was their target population.

Four of the studies in this review assessed or enquired about participants' pain before and after the prescribed HBR intervention. Both studies that used the SF-36 scale (Maharaj and Chetty 2011 and Pullen et al. 2014), showed a significant reduction in participants' pain following the HBR intervention, while one of the patients in the Lang (1993) case study reported a significant reduction in head and neck pain following HBR. The results of the Baigis et al. (2002) study, using the MOS-HIV survey, demonstrated no change in participants' pain levels following the HBR programme. It would have been of interest to have used specific assessment measures to ascertain how these improvements in quality of life and reduction in pain had influenced participants' participation in functional activities of daily living, which is an important end point in terms of a patient's health outcomes. While it can be argued that this was not the focus of these individual studies, more holistic assessment measures may have provided greater depth and insight into the relationships between quality of life measures and the daily functional ability of study participants.

Implications and recommendations

If HBR is indeed beneficial for PLHIV, as the evidence from the six articles in this scoping review suggests, the question one may ask is why there is so little published research available on HBR interventions for PLHIV, particularly in resource-poor settings? As HIV has become viewed as more a chronic than a terminal disease, in both the developed and developing world, it is crucial that a range of alternative rehabilitation options, including HBR interventions, are made available to PLHIV. Patients, particularly in resource-poor settings, often face a number of barriers to accessing institution-based care and they would stand to benefit greatly from the option of a health care worker visiting their home to supervise their rehabilitation or exercise programme. Rather than being seen as an additional strain on finances resources, it has been shown, in other disease populations, that HBR interventions can actually reduce the use of medication and the number of exacerbations and hospitalisations. Crotty et al. (2008) quantify this phenomenon, in a study of 229 patients referred for ambulatory rehabilitation, finding that patients receiving hospital-based rehabilitation were at twice the risk of readmission compared to those receiving home-based rehabilitation. In South African public hospitals, up to 80% of beds may be occupied by PLHIV (Harding and Higginson 2005), resulting in a large economic burden to the state. Home-based care (HBC) and HBR treatment options could not only serve to reduce this cost, but may also offer a more culturally acceptable form of care to PLHIV while at the same time removing the costly requirement for families to attend hospital. While the challenge of developing and implementing novel and varied rehabilitation interventions for PLHIV falls mainly upon healthcare workers and policy makers, it is vital that this is done in collaboration with researchers in this field in order to continually assess and improve these programmes, via comprehensive evidence-based enquiry.

This scoping review has revealed a number of areas that practitioners and researchers in the field of HIV rehabilitation should consider. Firstly, there is not enough evidence to support an unequivocal call for the widespread implementation of HBR for PLHIV. Six articles in over 20 years, two of which use simple case-study designs, represent a very small body of evidence when compared to the high number of articles assessing HBR in other chronic disease patient populations. However, this evidence on HBR for other population groups can be used to inform the design of studies HBR for PLHIV. Where it is not already happening, CBR and HBR programmes that exist for other chronic condition populations should also be enhanced and adapted to include PLHIV. Similarly, community-based programmes that already exist for PLHIV can be expanded, via multidisciplinary collaboration and task-shifting approaches, to include rehabilitation. By recruiting and training a cadre of community-based care workers to provide basic rehabilitation services to PLHIV, as well as people living with other chronic diseases, health care providers can simultaneously address the high burden of disease and relative lack of resources common to many HIV-endemic countries.

Secondly, it is vital that researchers and healthcare workers currently working with PLHIV should endeavour to assess the effectiveness of existing HBR programmes. This will assist in a move away from anecdotal reports of programme success towards a strengthening of the evidence base in this field, a key element in engaging stakeholders and funders and advocating for more rehabilitative services for PLHIV. Only three of these articles described HBR interventions conducted in sub-Saharan Africa, the global region with by far the highest HIV burden. It is vital, therefore, that new evidence in this field focuses on the specific challenges faced by PLHIV in resource-poor African countries. Thirdly, researchers should identify and, where necessary, develop assessment measures designed specifically to examine the impact of disability on function and quality of life of PLHIV, when planning studies in this field. Focusing on physical and psychological impairments alone does not fully reflect the lived experience of PLHIV. The use of more comprehensive assessment measures focusing on participants' function and participation in daily living, as well as the inclusion of qualitative methodologies may provide a more accurate depiction of the effectiveness of HBR interventions for PLHIV. This is essential to highlight the significance of rehabilitation on individual livelihood, productivity and communities. Future research may consider use of the ICF as a useful conceptual framework to investigate these relationships as well as a means of comparing and synthesising data across different contexts. The ICF, endorsed by all 191 WHO member states in 2001, is a conceptual framework that views an individual's level of functioning and disability as a result of the dynamic interaction between their health conditions and environmental and personal factors (World Health Organisation 2001). Soon after the development of this framework, Hwang and Nochajski (2003) concluded that the ICF can be effectively applied to programmes targeted at PLHIV. The WHO has developed a number of tools that employ the ICF framework to assess individuals' levels of functioning and disability and the impact of these factors on their activity levels and participation in domestic, occupational and social life. These include the comprehensive ICF checklist, which although not validated is a useful guide to the interaction between impairment, activity and participation (World Health Organisation 2003), and the WHO Disability Assessment Schedule (WHODAS 2.0), which is available in versions of varying brevity (World Health Organisation 2009). Myezwa et al. (2009) utilised the ICF checklist in a South African hospital setting to assess 80 PLHIV, demonstrating a clear association among a number of impairments, activity limitations and participation restrictions. The Washington Group Extended Question Set on Functioning (Centers for Disease Control and Prevention 2010) is a further useful tool for examine the relationship between disability and function. Although five of the six articles in this review were published post-2001, it would appear that they mainly concentrate on the physical and psychological ability of the participants, without interrogating how these factors influenced the participants' full participation in daily living in the home and work environment, via the use of one of these assessment tools or qualitative methodological approaches.

Finally, researchers need to include measures related to cost-effectiveness of HBR interventions in comparison to institution-based rehabilitation. Such evidence is needed to initiate a shift in thinking that sees rehabilitation as a crucial component of care for HIV as a chronic disease rather than a "nice to have" luxury. If HBR interventions for

PLHIV can be proven to be cost-effective when compared to institution-based rehabilitation, as demonstrated in other chronic disease populations, this research will strengthen advocacy efforts to influence policy-makers in health departments to include HBR options for PLHIV, particularly in resource-poor communities where HIV is endemic. However, it must be stressed that, even if HBR for PLHIV is proven to be equivalent in cost or costlier than institution-based interventions, this should not obscure the fact that access to quality rehabilitation is a fundamental human right (United Nations 2006) that should be available to all individuals at risk of the disabling effects of HIV. It is vital, therefore for researchers and health professionals to heed the call of Elliott et al. (2009) underlying a range of human rights violations and hindering access to prevention, care, treatment and support. There is some existing protection against HIV-based discrimination under international law, but the extent of states' obligations to address such discrimination has not been comprehensively addressed in an international instrument.The United Nations Convention on the Rights of Persons with Disabilities entered into force in May 2008. As countries ratify the convention, they are required to amend national laws and policies to give greater protection to the human rights of people with disabilities, including abolishing disability-based discrimination by the state and protecting persons against such discrimination by others. The Disability Convention addresses many of the issues faced by people living with HIV (PLHIV and advocate for a human rights-based response in advocating for improved services for PLHIV.

Limitations

This scoping review only included articles published in English in order to avoid the bias of attempting to accurately represent evidence published in languages other than the lead author's first language. It is possible that, in so doing, articles written in other languages that may have met this review's inclusion criteria, were excluded in the search strategy. In an attempt to counter this limitation, the authors consulted experts in the field of HIV rehabilitation from around the world – although it should be noted that the majority of these individuals are also English-speaking. A second limitation of this review was the inclusion of two studies with case study designs (one of which only reported on one participant) as well as two studies with interventions that included institution-based rehabilitation. However, as a scoping review method was chosen for this paper, rather than a systematic review method, it is valid to include studies with designs of lesser quality in order to fully "map" the available evidence related to the topic (Levac et al. 2010). Although the available evidence is clearly limited in this area, the use of a scoping review methodology resulted in the inclusion of studies with a range of methodologies, thus broadening the level of evidence for analysis and discussion. This analysis could possibly have been broadened further by including grey literature in this review as opposed to the stated inclusion criteria of limiting the search to journal articles.

Conclusion

This scoping review indicates that HBR is a promising approach that is both a safe and effective treatment option for PLHIV, and may confer a number of physical and psychological benefits for participants in these programmes. However it also reveals that there is a dearth of evidence on HBR in the context of HIV. Hence more research on HBR for PLHIV is urgently needed in order to inform the design and implementation of improved rehabilitation options for PLHIV. Researchers in this field need to go beyond the medical paradigm and seek to demonstrate the holistic benefits that rehabilitation can provide PLHIV in addition to the increasing years of life made possible by improved HAART regiments. In order to achieve this goal, studies should involve a wide range of assessment measures, including tools that investigate PLHIVs' full participation in daily life and cost-effectiveness analyses of HBR interventions compared to existing institution-based programmes. This is particularly important in resource-poor communities, such as sub-Saharan Africa, where PLHIV face significant challenges in accessing institution-based rehabilitation. Larger multidisciplinary studies should also be conducted, to better reflect the multiple challenges faced by PLHIV. It is hoped that research of this description will then be matched by a variety of novel cost-effective rehabilitation interventions that improve the quality of life and functional ability of PLHIV that can be included into national responses to HIV management and care. Studies of this type, together with appropriate HBR interventions based on the research findings, can assist in ensuring that PLHIV have the enhanced quality and opportunities of life to match the added years of life that medical treatment has made possible.

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References

Anderson, S., Allen, P., Peckham, S., & Goodwin, N. (2008). Asking the right questions: Scoping studies in the commissioning of research on the organisation and delivery of health services. *Health Research Policy and Systems, 6*(7), 1–12.

Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology, 8*(1), 19–32. http://dx.doi.org/10.1080/1364557032000119616

Baigis, J., Korniewicz, D. M., Chase, G., Butz, A., Jacobson, D., & Wu, A. W. (2002). Effectiveness of a home-based exercise intervention for HIV-infected adults: A randomized trial. *The Journal of the Association of Nurses in AIDS Care, 13*(2), 33–45. http://dx.doi.org/10.1016/S1055-3290(06)60199-4

Banks, L. M., Zuurmond, M., Ferrand, R., & Kuper, H. (2015). The relationship between HIV and prevalence of disabilities in sub-Saharan Africa: Systematic review. *Tropical Medicine & International Health, 20*(4), 411–429. http://dx.doi.org/10.1111/tmi.12449

Beauregard, C., & Solomon, P. (2005). Understanding the experience of HIV/AIDS for women: Implications for occupational therapists. *Canadian Journal of Occupational Therapy, 72*(2), 113–120. http://dx.doi.org/10.1177/000841740507200206

Canadian Working Group on HIV and Rehabilitation. 2011. E-Module for Evidence-Informed HIV Rehabilitation. http://www.hivandrehab.ca/wp-content/uploads/CWGHR_E-moduleEvidence-InformedHIVRehabilitationfinal-2015.pdf

Cella, D. F., & Bonomi A. E. (1996). The Functional Assessment of Cancer Therapy (FACT) and Functional Assessment of HIV Infection (FAHI) quality of life measurement system. In Bert Spilker (ed.), *Quality of life and pharmacoeconomics in clinical trials* (pp. 203–214). New York: Lippincott-Raven Publishers.

Centers for Disease Control and Prevention (CDC). (2010). Washington Group Extended Question Set on Functioning. http://www.cdc.gov/nchs/data/washington_group/WG_Extended_Question_Set_on_Functioning.pdf

Chaiyawat, P., & Kulkantrakorn, K. (2012). Effectiveness of home rehabilitation program for ischemic stroke upon disability and quality of life: A randomized controlled trial. *Clinical Neurology and Neurosurgery, 114*(7), 866–870. http://dx.doi.org/10.1016/j.clineuro.2012.01.018

Chappell, P., & Johannsmeier, C. (2009). The impact of community based rehabilitation as implemented by community rehabilitation facilitators on people with disabilities, their families and communities within South Africa. *Disability and Rehabilitation, 31*(1), 7–13. http://dx.doi.org/10.1080/09638280802280429

Chetty, V., & Hanass-Hancock, J. (2015). The need for a rehabilitation model to address the disparities of public healthcare for people living with HIV in South Africa. *African Journal of Disability, 4*(1), 1–6. http://dx.doi.org/10.4102/ajod.v4i1.137

Clark, R. A., Conway, A., Poulsen, V., Keech, W., Tirimacco, R., & Tideman, P. (2013). Alternative models of cardiac rehabilitation: A systematic review. *European Journal of Preventive Cardiology,* 22(1), 35–74. http://dx.doi.org/10.1177/2047487313501093

Cobbing. S., Chetty, V., Hanass-Hancock, J., Jelsma, J., Myezwa, H., & Nixon, S. (2013). The essential role of physiotherapists in providing rehabilitation services to people living with HIV in South Africa. *South African Journal of Physiotherapy 69*(1), 22–25.

Cobbing, S., Hanass-Hancock, J., Deane, M. (2014). Physiotherapy rehabilitation in the context of HIV and disability in KwaZulu-Natal, South Africa. *Disability and Rehabilitation, 36*(20), 1687–1694. http://dx.doi.org/10.3109/09638288.2013.872199

Collen, F., Wade, D., Robb, G., & Bradshaw, C. (1991). The Rivermead mobility index: A further development of the Rivermead motor assessment. *Disability and Rehabilitation, 13*(2), 50–54. http://dx.doi.org/10.3109/03790799109166684

Collins, L., Scuffham, P., Gargett, S. (2001). Cost-analysis of gym-based versus home-based cardiac rehabilitation programs. *Australian Health Review, 24*(1), 51–61. http://dx.doi.org/10.1071/AH010051

Crotty, M., Giles, L. C., Ha bert, J., Harding, J., & Miller, M. (2008). Home versus day rehabilitation: A randomised controlled trial. *Age and Ageing, 37*(6), 628–633. http://dx.doi.org/10.1093/ageing/afn141

Das, J., Do, Q. T., Shaines, K., Srinivasan, S. (2009). U.S. and them: the geography of academic research. World Bank Policy Research Working Paper Series. http://dx.doi.org/10.1596/1813-9450-5152

Daudt, H. M., Van Mossel, C., & Scott, S. J. (2013). Enhancing the scoping study methodology: A large, inter-professional team's experience with Arksey and O'Malley's framework. *BMC Medical Research Methodology, 13*(1), 48. http://dx.doi.org/10.1186/1471-2288-13-48

Dolan, S. E., Frontera, W., Librizzi, J., Ljungquist, K., Juan, S., Dorman, R., … Grinspoon, S. (2006). Effects of a supervised home-based aerobic and progressive resistance training regimen in women infected with human immunodeficiency virus: A randomized trial. *Archives of Internal Medicine, 166*(11), 1225–1231. http://dx.doi.org/10.1001/archinte.166.11.1225

Donohue, K., Hoevenaars, R., McEachern, J., Zeman, E., & Mehta, S. (2013). Home-based multidisciplinary rehabilitation following hip fracture surgery: What is the evidence? *Rehabilitation Research and Practice, 2013*, 1–10. http://dx.doi.org/10.1155/2013/875968

Elliott, R., Utyasheva, L., & Zack, E. (2009). HIV, disability and discrimination: Making the links in international and domestic human rights law. *Journal of the International AIDS Society, 12*(1), 29. http://dx.doi.org/10.1186/1758-2652-12-29

Finkenflügel, H., Wolffers, I., & Huijsman, R. (2005). The evidence base for community-based rehabilitation: A literature review. *International Journal of Rehabilitation Research, 28*(3), 187–201. http://dx.doi.org/10.1097/00004356-200509000-00001

Geddes, J. M., & Chamberlain, M. A. (2001). Home-based rehabilitation for people with stroke: A comparative study of six community services providing co-ordinated, multidisciplinary treatment. *Clinical Rehabilitation, 15*(6), 589–599. http://dx.doi.org/10.1191/0269215501cr452oa

Gomes Neto, M., Conceicao, C. S., Carvalho, V. O., & Brites, C. (2013). A systematic review of the effects of different types of therapeutic exercise on physiologic and functional measurements in patients with HIV/AIDS. *Clinics, 68*(8), 1157–1167. http://dx.doi.org/10.6061/clinics/2013(08)16

Gomes Neto, M., Ogalha, C., Andrade, A. M., & Brites, C. (2013). A systematic review of effects of concurrent strength and endurance training on the health-related quality of life and cardiopulmonary status in patients with HIV/AIDS. *BioMed Research International, 2013*, 1–8. http://dx.doi.org/10.1155/2013/319524

Hanass-Hancock, J., & Nixon, S. A. (2009). The fields of HIV and disability: Past, present and future. *Journal of the International AIDS Society, 12:*28. http://dx.doi.org/10.1186/1758-2652-12-28

Hanass-Hancock, J., Regondi, I., van Egeraat, L., & Nixon, S. (2013). HIV-related disability in HIV hyper-endemic countries: A scoping review. *World Journal of AIDS, 3,* 257–279. http://dx.doi.org/10.4236/wja.2013.33034

Hanass-Hancock, J., Myezwa, H., & Carpenter, B. (2015). Disability and living with HIV: Baseline from a cohort of people on long term ART in South Africa. *PLoS One, 10*(12), e0143936. http://dx.doi.org/10.1371/journal.pone.0143936

Harding, R., & Higginson, I. J. (2005). Palliative care in sub-Saharan Africa. *Lancet, 365*(9475), 1971–1977. http://dx.doi.org/10.1016/S0140-6736(05)66666-4

Harris, M. (2011). Exercise in HIV infection: The value, the difficulties in community-based implementation. (Poster) *Archives of Physical Medicine and Rehabilitation, 92*(10), 1734. http://dx.doi.org/10.1016/j.apmr.2011.07.175

Hopman, K., Tate, R. L., & McCluskey, A. (2012). Community-based rehabilitation following brain injury: comparison of a transitional living program and a home-based program. *Brain Impairment, 13*(1), 44–61. http://dx.doi.org/10.1017/BrImp.2012.6

Hwang, J. L., & Nochajski, S. M. (2003). The international classification of function, disability and health (ICF) and its application with AIDS. *Journal of Rehabilitation, 69*(4), 4–12.

Karjalainen, K., Malmivaara, A., van Tulder, M., Roine, R., Jauhiainen, M., Hurri, H., & Koes, B. (2003). Multidisciplinary biopsychosocial rehabilitation for subacute low back pain among working age adults. *Cochrane Database of Systematic Reviews, 2.* http://dx.doi.org/10.1002/14651858.CD002193

Khan, F., Turner-Stokes, L., Ng, L., & Kilpatrick, T. (2007). Multidisciplinary rehabilitation for adults with multiple sclerosis. *Cochrane Database of Systematic Reviews, 2.* http://dx.doi.org/10.1002/14651858.CD006036.pub2.

Khan, F., Amatya, B., Ng, L., Drummond, K., & Olver, J. (2013). Multidisciplinary rehabilitation after primary brain tumour treatment. *Cochrane Database of Systematic Reviews,* 8. http://dx.doi.org/10.1002/14651858.CD009509.pub3.

Lang, C. (1993). Community physiotherapy for people with HIV/AIDS. *Physiotherapy, 79*(3), 163–167. http://dx.doi.org/10.1016/S0031-9406(10)60657-8

Lang, R. (2011). Community-based rehabilitation and health professional practice: Developmental opportunities and challenges in the global North and South. *Disability and Rehabilitation, 33*(2), 165–173. http://dx.doi.org/10.3109/09638288.2010.487923

Levac, D., Colquhoun, H., & O'Brien, K. K. (2010). Scoping studies: Advancing the methodology. *Implementation Science; 5*, 69. http://dx.doi.org/10.1186/1748-5908-5-69

Levinson, S. F., & O'Connell, P. G. (1991). Rehabilitation dimensions of AIDS: A review. *Archives of Physical Medicine and Rehabilitation, 72*(9), 690–696.

Ley, C., Leach, L., Barrio, M. R., & Bassett, S. (2014). Effects of an exercise programme with people living with HIV: Research in a disadvantaged setting. *African Journal of AIDS Research, 13*(4), 313–319. http://dx.doi.org/10.2989/16085906.2014.961937

Linacre, J. M., Heinemann, A. W., Wright, B. D., Granger, C. V., & Hamilton, B. B. (1994). The structure and stability of the Functional Independence Measure. *Archives of Physical Medicine and Rehabilitation, 75*(2), 127–132.

Maharaj, S. S., & Chetty, V. (2011). Rehabilitation program for the quality of life for individuals on highly active antiretroviral therapy in KwaZulu-Natal, South Africa. *International Journal of Rehabilitation Research, 34*(4), 360–365. http://dx.doi.org/10.1097/MRR.0b013e32834d2bab

Maltais, F., Bourbeau, J., Shapiro, S., Lacasse, Y., Perrault, H., Baltzan, M., & Bernard, S. (2008). Effects of home-based pulmonary rehabilitation in patients with chronic obstructive pulmonary disease. *Annals of Internal Medicine, 149*(12), 869–878. http://dx.doi.org/10.7326/0003-4819-149-12-200812160-00006

Munro, J., Corrigall, H., Angus, N. J., Thompson, D., & Leslie, S. (2011). Home versus hospital-based cardiac rehabilitation: A systematic review. *Rural and Remote Health, 11*(2), 1532.

Mutimura, E., Crowther, N. J., Cade, T. W., Yarasheski, K. E., & Stewart, A. (2008a). Exercise training reduces central adiposity and improves metabolic indices in HAART-treated HIV-positive subjects in Rwanda: A randomized controlled trial. *AIDS Research and Human Retroviruses, 24*(1), 15–23. http://dx.doi.org/10.1089/aid.2007.0023

Mutimura, E., Stewart, A., Crowther, N. J., Yarasheski, K. E., & Cade, W. T. (2008b). The effects of exercise training on quality of life in HAART-treated HIV-positive Rwandan subjects with body fat redistribution. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation, 17*(3), 377–385. http://dx.doi.org/10.1007/s11136-008-9319-4

Myezwa, H., Stewart, A., Musenge, E., & Nesara, P. (2009). Assessment of HIV-positive in-patients using the International Classification of Functioning, Disability and Health (ICF) at Chris Hani Baragwanath Hospital, Johannesburg. *African Journal of AIDS Research, 8*(1), 93–105. http://dx.doi.org/10.2989/AJAR.2009.8.1.10.723

Nixon, S., Forman, L., Hanass-Hancock, J., Mac-Seing, M., Munyanukato, N., Myezwa, H., & Retis, C. (2011a). Rehabilitation : a crucial component in the future of HIV care and support : opinion. *Southern African Journal of HIV Medicine, 12*(2), 12–17.

Nixon, S., Hanass-Hancock, J., Whiteside, A., & Barnett, T. (2011a). The increasing chronicity of HIV in sub-Saharan Africa: Re-thinking "HIV as a long-wave event" in the era of widespread access to ART. *Globalization and Health, 7*(1), 41. http://dx.doi.org/10.1186/1744-8603-7-41

O'Brien, K., Nixon, S., Tynan, A. M., & Glazier, R. (2010). Aerobic exercise interventions for adults living with HIV/AIDS. Cochrane Database of Systematic Reviews, 8. http://dx.doi.org/10.1002/14651858.CD001796.pub3.

O'Brien, K., Tynan, A. M., Nixon, S., & Glazier, R. (2008). Effects of progressive resistive exercise in adults living with HIV/AIDS: Systematic review and meta-analysis of randomized trials. *AIDS Care, 20*(6), 631–653. http://dx.doi.org/10.1080/09540120701661708

O'Dell, M. W., & Dillon, M. E. (1992). Rehabilitation in adults with human immunodeficiency virus-related diseases. *American Journal of Physical Medicine & Rehabilitation, 71*(3), 183–190. http://dx.doi.org/10.1097/00002060-199206000-00010

Outpatient Service Trialists. (2003). Therapy-based rehabilitation services for stroke patients at home. *Cochrane Database of Systematic Reviews,* 1. http://dx.doi.org/10.1002/14651858.CD002925.

Powell, J., Heslin, J., & Greenwood, R. (2002). Community based rehabilitation after severe traumatic brain injury: A randomised controlled trial. *Journal of Neurology, Neurosurgery, and Psychiatry, 72*(2), 193–202. http://dx.doi.org/10.1136/jnnp.72.2.193

Pradella, C. O., Belmonte, G. M., Maia, M. N., Delgado, C. S., Luise, A. P. T., Nascimento, O. A., & Jardim, J. R. (2014). Home-based pulmonary rehabilitation for subjects with COPD: a randomized study. *Respiratory Care*. http://dx.doi.org/10.4187/respcare.02994

Pullen, S. D., Chigbo, N. N., Nwigwe, E. C., Chukwuka, C. J., Amah, C. C., & Idu, S. C. (2014). Physiotherapy intervention as a complementary treatment for people living with HIV/AIDS. *HIV/AIDS (Auckland, N.Z.), 6*, 99–107. http://dx.doi.org/10.2147/HIV.S62121

Regiane Resqueti, V., Gorostiza, A., Gáldiz, J. B., López de Santa María, E., Casan Clarà, P., & Güell Rous, R. (2007). Benefits of a home-based pulmonary rehabilitation program for patients with severe chronic obstructive pulmonary disease. *Archivos de Bronconeumologia, 43*(11), 599–604. http://dx.doi.org/10.1016/S1579-2129(07)60136-0

Roos, R., Myezwa, H., Van Aswegen, H., & Musenge, E. (2014). Effects of an education and home-based pedometer walking program on ischemic heart disease risk factors in people infected with hHIV: a randomized trial. *Journal of Acquired Immune Deficiency Syndromes, 67*(3), 268–276. http://dx.doi.org/10.1097/QAI.0000000000000299

Salpakoski, A., Törmäkangas, T., Edgren, J., Kallinen, M., Sihvonen, S. E., Pesola, . . ., Sipilä, S. (2014). Effects of a Multicomponent Home-Based Physical Rehabilitation Program on Mobility Recovery After Hip Fracture: A Randomized Controlled Trial. *Journal of the American Medical Directors Association, 15*(5), 361–368. http://dx.doi.org/10.1016/j.jamda.2013.12.083

Salvetti, X. M., Oliveira, J. A., Servantes, D. M., & Vincenzo de Paola, A. A. (2008). How much do the benefits cost? Effects of a home-based training programme on cardiovascular fitness, quality of life, programme cost and adherence for patients with coronary disease. *Clinical Rehabilitation, 22*(10-11), 987–996. http://dx.doi.org/10.1177/0269215508093331

Singh, D. (2006). Publication bias-a reason for the decreased research output in developing countries. *The African Journal of Psychiatry, 9*(3), 153–155. http://dx.doi.org/10.4314/ajpsy.v9i3.30216

Solomon, P., & Jung, B. (2006). An interprofessional role-emerging placement in HIV rehabilitation. *International Journal of Therapy and Rehabilitation, 13*(2), 59–65. http://dx.doi.org/10.12968/ijtr.2006.13.2.21354

Stucki, G., Cieza, A., & Melvin, J. (2007). The international classification of functioning, disability and health: A unifying model for the conceptual description of the rehabilitation strategy. *Journal of Rehabilitation Medicine, 39*(4), 279–285. http://dx.doi.org/10.2340/16501977-0041

Taylor, R. S., Dalal, H., Jolly, K., Zawada, A., Dean, S. G., Cowie, A., & Norton, R. J. (2015). Home-based versus centre-based cardiac rehabilitation. Cochrane Database Syst Rev, 8.

United Nations. (2006). Convention on the Rights of Persons with Disabilities. http://www.un.org/disabilities/convention/conventionfull.shtml.

UNAIDS. (2013). UNAIDS Report on the Global AIDS Epidemic. www.unaids.org/sites/default/.../UNAIDS_Global_Report_2013_en_1.pdf

UNAIDS. (2014). Executive Director's report: Down to the details: Fast-Tracking the response to end the AIDS epidemic by 2030. http://www.unaids.org/sites/default/files/media_asset/20141209_SP_EXD_PCB-35_en.pdf

Van As, M., Myezwa, H., Stewart, A., Maleka, D., & Musenge, E. (2009). The International Classification of Function Disability and Health (ICF) in adults visiting the HIV outpatient clinic at a regional hospital in Johannesburg, South Africa. *AIDS Care, 21*(1), 50–58. http://dx.doi.org/10.1080/09540120802068829

Wirz, S. (2000). Training of CBR personnel. *Asia Pacific Disability Rehabilitation Journal*. 100–112.

World Health Organisation. (2001). International Classification of Functioning, Disability and Health (ICF). http://www.who.int/classifications/icf/en/

World Health Organisation. (2003). ICF CHECKLIST, Version 2.1a. http://www.who.int/classifications/icf/icfchecklist.pdf?ua=1

World Health Organisation. (2009). WHO Disability Assessment Schedule 2.0 (WHODAS 2.0). http://www.who.int/classifications/icf/whodasii/en/

World Health Organisation. (2010). Community-based Rehabilitation Guidelines: Introductory Booklet. http://whqlibdoc.who.int/publications/2010/9789241548052_introductory_eng.pdf?ua=1

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CHAPTER 3: STUDY DESIGN

A goal without a plan is just a wish.

Antoine de Saint-Exupéry (1900-1944)

3.1. Summary of findings

This chapter is presented in the form of a published study, outlining the methodology for the primary intervention of this PhD research. The article describes in detail the study protocol of a randomised controlled trial which aimed to evaluate the effectiveness of a novel needs-based home-based rehabilitation intervention designed specifically for people living with HIV. This methodology was, in part, informed by the scoping review presented in the previous chapter as well as a broader review of literature on home-based rehabilitation interventions for individuals living with a wide range of chronic conditions. A table with the empirical evidence for the rehabilitation techniques used throughout this HBR intervention has now been compiled and included in appendix 4.

3.2. Publication details

Title	A home-based rehabilitation intervention for people living with HIV and disability in a resource-poor community, KwaZulu-Natal: study protocol for a randomised controlled trial
Authors	Saul Cobbing, Jill Hanass-Hancock and Hellen Myezwa
Journal	Trials
Year	2015
Volume	16 (1)
Pages	491-499
DOI number	10.1186/s13063-015-1025-2

3.3. Journal details

Trials is an open access, peer-reviewed, ISI-listed journal that encompasses all aspects of the performance and findings of randomised controlled trials in health. The journal publishes articles on general trial methodology as well as protocols, commentaries and traditional results papers. It has an impact factor of 1.859 (as at October 2016).

3.4. Publication timeline

The first draft of this article was submitted to Trials on the 12 June 2015. The reviewers replied with minimal comments and revisions on the 15 October 2015. These revisions were made and the manuscript was re-submitted on the 16 October. The final article was published on 2 November 2015.

3.5. Contribution details

The candidate conceptualised, developed and wrote the paper. Professors Myezwa and Hanass-Hancock advised the candidate on the methodology for a randomised controlled trial (RCT) and provided assistance with editing the draft manuscript. A qualified statistician, employed by the UKZN School of Health Sciences, was consulted with regard to planning the statistical analysis of the collected data.

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DOI 10.1186/s13063 015 1025 2

TRIALS

STUDY PROTOCOL **Open Access**

A home-based rehabilitation intervention for people living with HIV and disability in a resource-poor community, KwaZulu-Natal: study protocol for a randomised controlled trial

Saul Cobbing[1*], Jill Hanass Hancock[2] and Hellen Myezwa[3]

Abstract

Background: In the era of highly active antiretroviral therapy HIV is now viewed as a chronic disease. Although people living with HIV are living longer lives, they are prone to a number of disabilities. Home based rehabilitation has been shown to be an effective means of improving quality of life and function for people with a wide range of chronic diseases. There is a dearth of evidence, however, related to home based rehabilitation interventions for people living with HIV, particularly in sub Saharan Africa — the region with the highest global prevalence of HIV.

Methods: A randomised controlled trial design will be employed. Adults living with HIV who have been on antiretroviral therapy for at least six months and with defined limited mobility will be randomly allocated to either an intervention group or the control group. Pre and post intervention testing will be conducted at a public hospital in KwaZulu Natal, South Africa in order to assess the participants' quality of life, perceived level of disability, functional ability and endurance. Individuals randomly allocated to the intervention group will participate in a four month home based rehabilitation programme, conducted once a week in their homes. This programme will be implemented by community workers who will be trained and supervised by a qualified physiotherapist. The participants in the control group will continue with the standard clinic management offered to them. On completion of the intervention, all participants will be re assessed using the same outcome measures. Analysis of results will be carried out on intention to treat basis in order to identify any changes between intervention and control groups.

Discussion: The researchers aim to employ a novel task shifting approach to implement a needs based home based rehabilitation programme for people living with HIV in order to improve their quality of life and functional ability. It is hoped that this study will provide rehabilitation professionals and researchers with evidence that can be utilised to improve existing rehabilitation interventions for people living with HIV.

Trial registration: South African National Clinical Trials Register: NHREC#4094 (Date of registration: 21 July 2015).

Keywords: HIV, Home based rehabilitation, ICF, Task shifting

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Background

Globally, it is estimated that there are 35.3 million people living with HIV (PLHIV) with 25 million PLHIV in sub-Saharan Africa. An estimated 6.1 million people are currently living with HIV in South Africa [1], more than in any other single country in the world. Within South Africa itself, KwaZulu-Natal (KZN) has the highest HIV prevalence of all the country's nine provinces, with 14.8 % of its inhabitants living with HIV. With improved treatment options for PLHIV, specifically the advent of highly active antiretroviral treatment (HAART), HIV is now viewed as a chronic disease rather than a terminal illness [2]. As an illustration of this, life expectancy in 2011 in KZN province was 11.3 years higher than in 2003, when the scale-up of HAART for PLHIV was in its infancy [1].

Although they are now living longer due to HAART, PLHIV are also more prone to a number of impairments and disabilities that may require rehabilitation. These disabilities may be permanent (such as blindness) or episodic in nature, with the extent of an individual's impairments (and their experience of these impairments) fluctuating over time, depending on a number of interrelated factors [3]. A recent qualitative paper on the experiences of disability in PLHIV concludes that future HIV research needs to consider the new health care needs of PLHIV beyond a focus on clinical conditions and address the activity and participation restrictions that come with a life on HAART [4]. Rehabilitation services can help PLHIV address the life-related consequences of their medical condition [2] and can enhance their daily functioning via a number of strategies, including exercise [5].

Exercise and rehabilitation have been shown to be beneficial for PLHIV in a number of different settings [6, 7]. However, there is a great disparity in access to rehabilitation for PLHIV between developed and developing countries [8]. The current model prevalent in the South African public health system favours rehabilitation of patients in hospitals or clinics, despite evidence of the urgency to raise the profile of community-based rehabilitation (CBR) in South Africa at national, provincial and district levels [9]. This shortfall of widespread CBR provision is contrary to the South African Department of Health's [10] vision of public health care delivery in South Africa moving towards a model that provides rehabilitation services in or near to patients' homes. There is extensive evidence supporting the effectiveness of home-based rehabilitation (HBR) interventions for other chronic disease populations, including stroke [11–13] and coronary artery disease [14, 15]. However, there is a dearth of literature describing sub-Saharan African HBR interventions in general and no studies that have investigated HBR programmes designed specifically for PLHIV and disability in South Africa.

In the resource-poor community where this research is being conducted, PLHIV have identified a number of barriers to accessing the traditional institution-based physiotherapy rehabilitation available to them. These barriers include cost of rehabilitation, transport and accessibility issues [16]. This preliminary research has demonstrated the need for alternative evidence-based rehabilitation interventions for PLHIV in South Africa, particularly those living in resource-poor environments. The authors hypothesise that this HBR programme designed specifically for PLHIV and disability will have a positive effect on participants' perceived disability, quality of life, functional mobility and functional capacity and will thus offer an effective alternative to institution-based rehabilitation for this patient population.

Research question

What is the effect of a needs-based HBR intervention on PLHIVs' perceived disability, quality of life, functional mobility and functional capacity?

Aim

To determine the effect of a needs-based HBR intervention on PLHIVs' perceived disability, quality of life, functional mobility and functional capacity.

Objectives

1. To design a needs-based HBR intervention for adult PLHIV in a resource-poor setting using a task shifting approach.
2. To determine the effects of the HBR intervention on participants' perceived disability.
3. To determine the effects of the HBR intervention on participants' quality of life.
4. To determine the effects of the HBR intervention on participants' functional mobility.
5. To determine the effects of the HBR intervention on participants' functional capacity.

Conceptual framework

This study uses the International Classification of Functioning, Disability and Health (ICF) as a guiding framework. The ICF [17] offers a useful framework for studying disability and health-related consequences of disease such as HIV [18]. This framework is based on three concepts: body function and structure, activity levels and participation. Changes in body function or structure (also named impairments) are understood to be problems with physiological functioning or anatomical (for example organs, limbs) structures of the body. Similarly, activity limitations are defined as difficulties in executing a task or action, such as walking or dressing. Finally, participation restrictions are problems relating to involvement in life situations [17]. Disability can be experienced at any of these levels and further influenced by inter-related environmental and personal factors (see Fig. 1). Thus, two individuals with the same impairment (for example, pain secondary to an HIV-related opportunistic infection) may experience markedly different activity limitations and participation restrictions, due to their respective socio-economic environments and specific personal characteristics. The authors of this study have utilised this framework in the design of this study in order to better reflect the overall lived experience of the participants who are exposed to the rehabilitation intervention.

Methods

Study design

A randomised controlled trial (RCT) design will be used in this study in order to assess the effectiveness of a 16-week HBR intervention designed specifically for PLHIV and disability. The RCT is considered the highest level of evidence when attempting to establish the effectiveness of a chosen intervention [19].

Study area

The study is located at a public hospital in the eThekwini district of the province of KwaZulu-Natal, South Africa. This hospital serves a population of 750,000 people in Mariannhill, which is an impoverished rural and peri-urban area on the outskirts of Durban. The hospital and its outlying clinics provide a service for more than 4,500 PLHIV [20]. The eThekwini district is one of the ten municipal districts in South Africa with the highest HIV prevalence, with an HIV prevalence of 38 % amongst expectant mothers [21]. While the assessment of patients pre- and post-intervention will be conducted on the hospital premises, the intervention itself will be conducted in, or near to, participants' homes. These communities fall within the hospital catchment area, which is defined as including individuals living within the Inner and Outer West Operational Entities of the Durban Metropolitan Area, a large geographical area spanning approximately 40 kilometres [20].

Study population

Participants for the proposed study will be recruited from the HIV-LIVE study, a large cohort study that included 1,043 PLHIV who receive HAART from clinics that fall under the study hospital described above. The HIV-LIVE study is an ongoing collaboration between the Health Economics in HIV/AIDS Research Division (HEARD) and the University of the Witwatersrand's Department of Physiotherapy, which aims to determine the extent and impact of HIV-related disability on PLHIV in South Africa. It is a cohort study that employed a cross-sectional design and includes, as one of many assessment measures, the short form of the World Health Organisation Disability Assessment Schedule (WHODAS 2.0) assessment tool, a self-reported measure of disability [22].

Study sample and recruitment

Individuals from the study population who meet the inclusion and exclusion criteria (see Table 1) will be contacted by telephone and invited to the study hospital. On their arrival, the study will be described in detail to each individual (in their home language—most of the study population speak isiZulu), each prospective participant will be given a study information sheet and they will be asked to sign an informed consent form, should they agree to participate in the study. Baseline blood pressure and heart rate measures will also be taken to ensure that each individual is fit to complete the pre-intervention testing. General questions about their current health will also be asked to ensure that individuals with acute illnesses are not exposed to further risk of testing. On agreeing to participate, all participants will continue to complete the four study outcome measures. Ethical approval for both the main HIV-LIVE study and

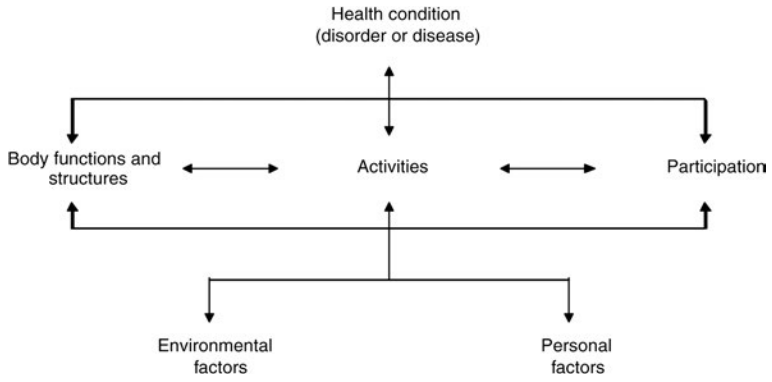

Fig. 1 Graphic representation of the ICF framework

Table 1 Study inclusion and exclusion criteria

Inclusion criteria
Males and females living with HIV attending an outpatient HIV clinic of the study hospital
Individuals who have received HAART for six months or longer, specifically one of the national HAART regimens for adults, as outlined by the South African Department of Health.
Individuals over the age of 18
Individuals who scored for limitation in the mobility domain according to the WHODAS 2.0 (12 item version) assessment tool.
Exclusion criteria
Pregnant or breast feeding women.
Any individual with an acute AIDS defining opportunistic infection.
Any individual with a complete spinal cord injury with no possibility of being able to walk.
Unstable angina, recent myocardial infarction and elevated blood pressure (as per contraindications for the Six Minute Walk Test)

this RCT has been given by the South African Department of Health, University of KwaZulu-Natal (UKZN) and the University of Witwatersrand.

Sample size

The sample size for this study has been calculated based on the group of participants from the HIV-LIVE cohort study who scored for limitation in the mobility-related questions (S1 and S7) of the WHODAS 2.0 (12 item version) tool. The effect size was chosen for these parameters. This was set at an alpha level 0.05 and allowed for a 40 % drop-out rate as indicated in previous studies (power of 80 %). A sample size of 80 participants is required, based on these parameters.

Testing procedure

Five lay health workers, currently working in the study area for a non-governmental organisation, will conduct the pre-intervention testing, over a period of one week, at the study hospital. They will explain the nature and requirements of the study and provide each prospective participant with an additional study information sheet. Each individual will then be invited to participate in the study and, if they agree, asked to sign the consent form, in the full understanding that they be permitted to withdraw from the study at any point. Thereafter participants will undergo the pre-intervention testing. The four baseline outcome measures will each be conducted by a separate individual. The participants will be interviewed in their first language using a questionnaire including the short version of the World Health Organisation Quality of Life assessment tool (WHOQOL-HIV BREF) [23] and the short form of the World Health Organisation Disability Assessment Schedule (WHODAS 2.0). All interviews will be conducted in a private location, ensuring confidentiality and comfort for the participants. Following the interviews, the individual participant's functional ability will be assessed using the Rivermead Mobility Index (RMI). After a five minute rest, the participant will then be invited to complete the Six Minute Walk Test (6MWT). Participants' heart rate and blood pressure will be assessed before and after the test using an ambulatory wrist sphygmomanometer. Following the test, participants will be instructed to sit and rest for five minutes and offered water, after which time they will return home.

Outcome measures

The WHOQOL-HIV BREF contains brief demographic questions, followed by 31 questions related to the individual's perceived quality of life. The short form of the WHODAS 2.0 tool consists of 12 core questions assessing an individual's perceived level of difficulty in carrying out certain day-to-day activities and participating in social, occupational and educational environments. The RMI is a 15-item assessment tool involving a combination of self-reported and directly observed measures of function, such as transferring from a bed to a chair and walking up and down four steps. Although initially designed to assess the functional ability of stroke patients, it is appropriate for populations with a range of physical disabilities [24]. The 6MWT is a test designed to assess distance walked over six minutes as a submaximal test of aerobic capacity/endurance [25]. The 6MWT will be performed, according to the test standards, indoors along a flat, hard surface in a hall on the study hospital's premises. The walking course will be 20 metres in length, marked at every one metre. The turnaround points will be marked with cones. Absolute contraindications for the 6MWT include the following: unstable angina during the previous month and myocardial infarction during the previous month. Relative contraindications include a resting heart rate of more than 120, a systolic blood pressure of more than 180 mm Hg, and a diastolic blood pressure of more than 100 mm Hg [26]. Individuals who report absolute contraindications for the trial will not be considered for the trial. Individuals who present with any of the relative contraindications will have these measures taken twice more at 15-minute intervals, and if all of these readings are below the accepted limits, they will be able to continue with the trial. The four outcome measures employed in this study are described in more detail in Table 2.

Randomisation and follow-up of participants

Following the pre-intervention assessments, participants will be randomly assigned to either the intervention group or a control group (standard care). Computerised randomisation and stratification (according to gender)

Table 2 Study outcome measures

Measure	Description
RMI	Assesses functional mobility in gait, balance and transfers. Consists of 14 self reported items and one direct observation item, with items progressing in difficulty.
6MWT	This test measures the distance that a patient can quickly walk on a flat, hard surface in a period of 6 minutes. It evaluates the global and integrated responses of all the systems involved during exercise.
WHODAS 2.0 (12 item)	This is a self reported assessment instrument for health and disability, directly linked to the ICF, used across all diseases. This 12 item version focuses primarily on activities of daily living and participation.
WHOQOL HIV BREF	This self reported instrument, adapted for PLHIV, examines an individual's perceptions of his/her quality of life across six domains: physical, psychological, independence, social, environment and spirituality.

will be employed in order to ensure homogeneity between intervention and control groups. This will be achieved using the randomise list [RAND()] function in the Microsoft Excel (2013) software package [27]. This will also satisfy allocation concealment, thus ensuring that the investigators will be unaware of to which group each participant will be allocated [28]. In the week immediately following the 16-week HBR intervention, participants from both intervention and control groups will return to the study hospital. The same four outcome measures will be assessed at this follow-up visit in order to ascertain the change from the pre-intervention measures.

HBR intervention

The lead author (SC), a qualified physiotherapist, has conducted the training of four lay health workers who were selected from a pool of people who currently live in the area and volunteer as home-based carers for a non-governmental organisation in the study community. The training was conducted over a one-month period and was designed to equip these four individuals with the theoretical and practical skills to conduct the exercise and rehabilitation intervention at the homes of the participants randomised to the study intervention group. The HBR intervention will begin two weeks after the pre-intervention assessments to allow for the randomisation of participants and communication with each participant in the intervention group in order to set up a time for the first visit. The four health workers will work in pairs, with each pair being responsible for the rehabilitation of half of the participants in the intervention group. The justification for working in pairs is to ensure that participants will continue to be seen throughout the 16-week intervention, even if one of the health workers should be unavailable. Furthermore, it is often necessary for two individuals to assist a participant, particularly with mobility exercises such as learning to walk with crutches.

On the first home visit, SC will assess each participant and teach them strength and stretching exercises suitable for each individual. Upper limb and lower limb strength exercises will primarily be performed using MSD-Band [29] resistive bands (lightweight latex bands of varying resistance), which will be provided for each participant. Stretching exercises for the upper and lower limbs, trunk and neck will also be taught. Functional exercises, such as sitting to standing and bridging, will also be demonstrated where appropriate. All participants will also be encouraged, if able, to carry out a progressive walking programme over the 16-week period. Following this first visit, SC will fulfil a supervisory role, advising and helping the lay health workers if they have particular concerns or difficulty with any specific participant.

Following the first assessment week, when participants will begin their individualised HBR programmes, each participant will be seen in their own home once a week by their designated pair of health workers. Each appointment will be made by mobile phone call, and participants will be seen on a day and at a time convenient to them. While the majority of the participants in the intervention group are unemployed, home visits will also be scheduled for Saturdays to accommodate those participants who do work full-time. The stretching exercises will be performed at each visit, while the volume and resistance of the strengthening exercises will be progressively increased, as will the distance walked at each visit. Where possible, walking will be performed on the streets surrounding the participants' homes, with each participant being accompanied by at least one health worker in order to ensure safety. Walking aids in the form of walking frames, elbow crutches and walking sticks will be provided to those participants who require them, following thorough assessment and instruction in their use by SC. Each participant will also be instructed on the specific home exercises they should do for the days between each weekly visit.

At each weekly visit, the health workers will complete a comprehensive entry into each participant's individual diary, including information on the rehabilitation completed on that visit. The exercises done over the previous week, any equipment issued (such as resistive bands or walking aids) and any illness or problems that the participant may have had in the previous week will also be recorded. Should a participant not have been available to be seen at home on any given week, the reason for this will be noted in the diary and the above information will be elicited via telephone conversation and recorded in the diary. At the halfway mark of the intervention (after 8 weeks) the participants will be requested to select a date and time for their post-intervention assessment at the study hospital. They will be reminded of this follow-up appointment in the last (16th) week of the HBR intervention.

Control group

The participants randomised to the control group will receive the standard of care treatment offered by the specific clinic where they receive their HAART medication. They will be given a two-page information sheet on healthy living for PLHIV and encouraged to follow this advice. In the event that they are referred for rehabilitation by their clinic nurse or doctor, this will be conducted by a qualified physiotherapist at the study hospital's physiotherapy department. Participants in the control group will receive a monthly phone call from one of the four lay health workers involved in the HBR intervention. These phone calls will serve to determine their health status and whether their contact/address details have changed. The phone call in the last month will also be utilised to set up a date and time for their post-intervention assessment at the study hospital. On completion of this study, should the HBR intervention be found to be effective, participants in the control group will be offered the opportunity to receive this intervention, at no cost to themselves.

Blinding

The four lay health workers who will be involved in the HBR intervention are different individuals than the five lay health workers who are employed to conduct the pre- and post-intervention assessment. These latter five individuals will be blinded (at the post-intervention assessment) to the group allocation of participants in order to limit bias. Due to the nature of the intervention, double blinding was impossible, as participants will know whether they are receiving the intervention or are in the control group.

Ethical considerations

1. Permission to conduct the study was obtained from the chief executive officer of the study hospital.
2. Ethical approval from the University of Kwazulu-Natal's Biomedical Research Ethics Committee (BFC052/15) was received on 11 September 2014.
3. This study is registered with the South African National Clinical Trial Register (SANCTR); registration number: NHREC# 4094 as well as the South African Department of Health (DOH number: DOH-27-0715-5094).
4. Participants will be given an information sheet outlining the nature and requirements of the study and their completely voluntary participation, with the right to withdraw at any point during the study. Following this, they will be required to sign a consent form to participate in the study.
5. During all assessments requiring verbal discussion, participants will be interviewed in private locations at the study hospital in order to maintain privacy and confidentiality.
6. A physician at the study hospital must be informed of when the Six Minute Walk Test assessments will be performed and immediately called should participants suffer any adverse response during or after the walk.
7. Any participants who require any medical assistance directly related to the rehabilitation intervention will be immediately referred to the study hospital for assessment and treatment.
8. Participants in the control group will be offered the HBR intervention, should it prove to be beneficial.
9. While no inducements will be offered to participants, their transport costs to and from the study hospital will be covered. A small allowance for food will also be provided to participants for each of their two visits to the study hospital.
10. Participants will be assigned codes in order to maintain their anonymity. No information regarding their involvement in this study will be divulged at any point.
11. All information obtained from participants will be kept under lock and key and electronically on a password protected computer at the UKZN department of physiotherapy for 5 years, after which time all study data will be destroyed or deleted.

Data analysis

Statistical analysis of collected data will be performed with the assistance of a qualified statistician, employed by the UKZN School of Health Sciences. This statistical analysis will be performed on an intention-to-treat basis. This form of analysis requires participants to be included even if they did not fully adhere to the protocol. The rationale for this approach is that, in this study, it is important to estimate the effects of allocating an intervention in practice, not only the effects in the subgroup of the participants who adhere to it. Descriptive statistics, such as mean and mode, will be used to evaluate baseline demographic data. Analysis of changes between the intervention and control groups will be compared using analysis of variance (ANOVA) and/or analysis of covariance (ANCOVA), determined by the consulting statistician. Level of significance will be set at $P \leq 0.05$ with confidence intervals set at 95 %. The Statistical

Package for the Social Sciences (SPSS) version 22 will be employed to record and analyse the study data.

Discussion

HIV is now viewed globally as a chronic disease rather than a terminal illness [30]. However, it was important that the lay health workers involved in the testing and implementation of this HBR intervention were cognisant of the specific challenges facing both PLHIV and those working with PLHIV. This is particularly important when considering the ethical issues around implementing an intervention designed for PLHIV. Despite the improvements in HIV treatment and care, HIV has always presented specific ethical challenges to scientists, patients and caregivers [31]. Using ethnographic material collected from five HIV clinics in South Africa, Uganda and Thailand, Heimar (2013) distinguishes between what is understood as official ethics (including the universal principles of autonomy, beneficence, non-maleficence and justice) and "ethics on the ground" [31]. This study has ensured that official ethical principles were followed (see the above 11 ethical considerations). However, the question remains: If participants have been fully informed and subsequently sign a consent form, have we done enough to meet our ethical obligations? We would argue that we need to do more and this is why, in addition to the considerations outlined above, the lay health workers underwent thorough ethical training before the pre-assessments and HBR intervention began. Research conducted across five South African samples from township, urban and clinic settings showed that stigmatisation of PLHIV in South Africa is widespread. For example, between 33 % and 56 % of respondents believed that PLHIV should expect some restrictions on their freedom [32]. In extreme cases, people in South Africa who have revealed their HIV status have been assaulted and killed [33]. It would be naïve, therefore, to assume that PLHIV in this study's community will necessarily be treated the same as people who suffer from other chronic diseases, such as diabetes or asthma. In this respect, as part of their training, the lay health workers involved in this study have been requested to inform other community members, if asked, that the trial is investigating the benefits of home-based exercise for people living in the community. At no point will participants' HIV status be divulged to anybody outside of the study. Furthermore, should any participant feel that the attendance of the lead author or the lay health workers at their homes may cause them any harm or distress, every effort will be made to continue to see them in an alternate location where they feel more at ease. In addition to this, we will strongly support the right of any participant to withdraw from the study at any time and for any reason.

Despite the ethical challenges of this particular study, it is important that a study of this nature is conducted in this community, an area with such a high prevalence of PLHIV. This HBR intervention is novel for a number of reasons. While two systematic reviews have shown that both resistance and aerobic exercise are safe and beneficial for PLHIV, most of the articles included in these reviews investigated exercise conducted at health institutions or public exercise facilities [6, 7]. A thorough review of the literature by the authors identified only six peer-reviewed publications that have investigated the effectiveness of home-based exercise programmes for PLHIV [34–39]. Of these studies, two employed case study designs [36, 38] and two included a combination of home and institution-based exercise [37, 38]. Furthermore, only three of these studies [37–39] were conducted in sub-Saharan Africa and none in KZN, the province with the highest HIV prevalence in South Africa, the country with the highest HIV prevalence in the world [1]. Of the three sub-Saharan African-based studies, only one [39] exclusively employed a home-based protocol, and this study specifically investigated the effects of a walking programme on PLHIV, without the inclusion of broader rehabilitation elements. Thus this study is, to the authors' knowledge, the first RCT conducted in sub-Saharan Africa that is exclusively home-based in nature and designed to provide needs-based rehabilitation for PLHIV and disability.

The distinction between exercise and rehabilitation is an important one. The majority of published articles on RCT exercise interventions for PLHIV involve a set programme of strength (for example, dumbbell curls) and/or resistance exercises (for example, treadmill walking) over a set period of time that is strictly implemented regardless of the differing needs of each individual participant [6, 7]. Rehabilitation, although generally including exercise components, involves more than just exercise. Worthington et al. [30] define rehabilitation as a dynamic process involving all prevention and treatment activities or services that address physical impairments, activity limitations and participation restrictions for an individual. This implies that rehabilitation must be adapted to the specific needs of the individual and should further be refined and adjusted as the period of rehabilitation continues. This study again demonstrates its novelty by investigating a needs-based HBR intervention, where the activities and exercises performed by each participant will be suited to their individual needs and progressed at a pace specific to their ability and adaptation to the demands of the programme. Each participant's rehabilitation programme will be based on the study pre-assessment period, which focuses on functional measures, the presentation of the participant at the first home visit, as well as ongoing assessment of the participant's progress. While this type of intervention may be more difficult to describe and replicate, it will more closely mirror the interventions performed by therapists working in the field of rehabilitation of PLHIV. It is hoped that this will ensure that the results of this study are more applicable and translatable to therapists working with PLHIV in community settings, particularly in sub-Saharan Africa.

Another novel aspect of this study is the fact that it employs a task shifting approach in the design and application of this HBR intervention for PLHIV. Despite the high prevalence of HIV and disability in South Africa, there are relatively few trained physiotherapists working in this country (per capita population), compared to countries in the developed world. Recent WHO statistics [8] reveal that there are more than 20 physiotherapists per 10,000 population in Finland, as compared to less than two physiotherapists per 10,000 population in South Africa. With regard to another rehabilitation profession, occupational therapy, Denmark has approximately 11 occupational therapists per 10,000 population, compared to less than one occupational therapist in South Africa, per 10,000 population. This relative paucity of rehabilitation professionals requires alternative approaches, particularly in a country with such a high prevalence of PLHIV. One such alternative is to employ a task shifting approach, which can be defined as a "process whereby specific tasks are moved, where appropriate, to health workers with shorter training and fewer qualifications" [40], for example (as in this case), from physiotherapists to lay community care workers. This has been shown to be an effective strategy for addressing shortages of human healthcare resources in a number of areas of HIV care and treatment, including HAART management by nurses rather than doctors [41] and the provision of basic clinical tasks by lay health care workers [42]. A study conducted by one of the authors of this paper (in the same community) showed the potential for appropriately trained lay HIV counselors to carry out group-based counseling interventions for PLHIV and depression [43]. The success of this study has now been integrated in a current larger RCT trial in South Africa [44]. Additional opportunities related to task shifting for PLHIV include potential cost advantages, enhancing the role of the community and improving the efficiency of existing health systems [45]. For these reasons, and despite the ethical challenges inherent in this type of research, it is anticipated that this study will add new data and understanding to the field of rehabilitation for PLHIV and disability. It is hoped that this information will be of interest to a wide range of rehabilitation professionals and researchers, particularly those working in resource-poor communities, and that it will contribute to the design and implementation of improved rehabilitation options for this vulnerable population.

Trial status

This trial is currently ongoing. Ethical approval from the UKZN Biomedical Research Ethics Committee, the South African National Clinical Trial Register (registration number: NHREC# 4094) as well as the South African Department of Health (DOH number: DOH-27-0715-5094) has been obtained. Recruitment of potential participants from the study population has begun.

Abbreviations

6MWT: Six Minute Walk Test; AIDS: acquired immune deficiency syndrome; CBR: community based rehabilitation; HAART: highly active antiretroviral treatment; HBR: home based rehabilitation; HIV: human immunodeficiency virus; ICF: International Classification of Functioning, Disability and Health; KZN: KwaZulu Natal; PLHIV: people living with HIV; RCT: randomised controlled trial; RMI: Rivermead Mobility Index; UKZN: University of KwaZulu Natal; WHODAS 2.0: World Health Organisation Disability Assessment Schedule (version 2.0); WHOQOL HIV BREF: World Health Organisation Quality of Life (HIV) tool.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

SC is the principal investigator, conceptualised and designed this study and was the lead author compiling this manuscript. He will also be responsible for the training and supervision of the lay health workers involved in the assessment and rehabilitation of the study participants. JH and HM were involved in the conceptualisation of the study and provided theoretical input and editing of this manuscript. All authors read and approved the final manuscript prior to submission to the Trials journal.

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References

1. UNAIDS. UNAIDS report on the global AIDS epidemic 2013. 2013. http://www.unaids.org/sites/default/files/en/media/unaids/contentassets/documents/epidemiology/2013/gr2013/UNAIDS Global Report 2013 en.pdf. Accessed 15 May 2015.
2. Nixon S, Forman L, Hanass Hancock J, Mac Seing M, Munyanukato N, Myezwa H, et al. Rehabilitation: a crucial component in the future of HIV care and support. South Afr J HIV Med. 2011;12(2):12 7.
3. O'Brien KK, Davis AM, Strike C, Young NL, Bayoumi AM. Putting episodic disability into context: a qualitative study exploring factors that influence disability experienced by adults living with HIV/AIDS. J Int AIDS Soc. 2009;12(1):30.
4. Hanass Hancock J, Myezwa H, Nixon SA, Gibbs A. "When I was no longer able to see and walk, that is when I was affected most": experiences of disability in people living with HIV in South Africa. Disabil Rehabil. 2014;0:1 11.
5. Canadian Working Group on HIV and Rehabilitation. E Module for Evidence Informed HIV Rehabilitation. 2011. http://www.hivandrehab.ca/EN/information/care providers/documents/CWGHR E moduleEvidence InformedHIVRehabilitationfinal.pdf. Accessed 18 May 2015.

6. O'Brien K, Tynan A M, Nixon S, Glazier R. Effects of progressive resistive exercise in adults living with HIV/AIDS: systematic review and meta analysis of randomized trials. AIDS Care. 2008;20(6):631 53.
7. O'Brien K, Nixon S, Tynan AM, Glazier R. Aerobic exercise interventions for adults living with HIV/AIDS. Cochrane Database Syst Rev. 2010. doi:10.1002/14651858.CD001796.pub3.
8. World Health Organisation. World Report on Disability. 2011. http://apps.who.int/iris/handle/10665/44575. Accessed 15 May 2015.
9. Rule S, Lorenzo T, Wolmarans M, Watermeyer B, Swartz L, Lorenzo T, et al. Community based rehabilitation: new challenges. Disability and social change: a South African Agenda. 2006:273 90
10. Department of Health. National guideline on home base care/community based care. 2001. http://www.npi connect.net/documents/592341/749044/R1+%26+2+SOTA+ +National+Guidelines+for+Home Based+%26 +Community Based+Care. Accessed 21 May 2015.
11. Cochrane Collaboration. Outpatient Service Trialists. Therapy based rehabilitation services for stroke patients at home. Cochrane Database Syst Rev. 2003; CD002925.
12. Chaiyawat P, Kulkantrakorn K. Effectiveness of home rehabilitation program for ischemic stroke upon disability and quality of life: a randomized controlled trial. Clin Neurol Neurosurg. 2012;114(7):866 70.
13. Geddes JM, Chamberlain MA. Home based rehabilitation for people with stroke: a comparative study of six community services providing co ordinated, multidisciplinary treatment. Clin Rehabil. 2001;15(6):589 99.
14. Clark RA, Conway A, Poulsen V, Keech W, Tirimacco R, Tideman P. Alternative models of cardiac rehabilitation: a systematic review. Eur J Prev Cardiol. 2015;22(1):35 74.
15. Blair J, Corrigall H, Angus NJ, Thompson DR, Leslie S. Home versus hospital based cardiac rehabilitation: a systematic review. Rural Rem Health. 2011;11(2):1532.
16. Cobbing S, Hanass Hancock J, Deane M. Physiotherapy rehabilitation in the context of HIV and disability in KwaZulu Natal, South Africa. Disabil and Rehabil. 2014. doi:10.3109/09638288.2013.872199.
17. WHO. International Classification of Functioning Disability and Health. 2001. http://www.who.int/classifications/icf/en/. Accessed 15 May 2015.
18. Hanass Hancock J, Nixon SA. The fields of HIV and disability: past, present and future. J Int AIDS Soc. 2009;12(1):28.
19. Polgar S, Thomas SA. Introduction to research in the health sciences (5th edition). Edinburgh: Churchill Livingstone; 2008.
20. St Mary's Hospital. About us. 2015. http://www.stmarys.co.za/about us/. Accessed 23 June 2015.
21. Department of Health. The 2011 National Antenatal Sentinel HIV & Syphilis Prevalence Survey in South Africa. 2012. http://www.hst.org.za/publications/2011 national antenatal sentinel hiv syphilis prevalence survey south africa. Accessed 12 June 2015.
22. World Health Organisation. WHO Disability Assessment Schedule 2.0 (WHODAS 2.0). 2009. http://www.who.int/classifications/icf/whodasii/en/. Accessed 10 May 2015.
23. WHO. The World Health Organization Quality of Life (WHOQOL) BREF. 2004. http://www.who.int/substance abuse/research tools/en/english whoqol.pdf. Accessed 23 July 2013.
24. Wade D. The Rivermead Mobility Index. 1991. Accessed 10 May 2015. http://www.rehabmeasures.org/PDF%20Library/Rivermead%20Mobility%20Index.pdf.
25. Balke B. A simple field test for assessment of physical fitness. Civil Aeromed Res Inst. 1963;53:1 8.
26. American Thoracic Society. ATS Statement: Guidelines for the Six Minute Walk Test. Am J Respir Crit Care Med. 2002;166:111 7.
27. Microsoft. Microsoft Excel 2013. 2015. http://microsoft excel.en.softonic.com/. Accessed 28 May 2015.
28. Physiotherapy Evidence Database. PEDro scale. 2015. http://www.pedro.org.au/english/downloads/pedro scale/. Accessed 28 May 2015.
29. MSD. MSD Band Resistive Exercise System. 2015. http://www.msd band.com/nl/msd band.html. Accessed 30 May 2015.
30. Worthington C, Myers T, O'Brien K, Nixon S, Cockerill R. Rehabilitation in HIV/AIDS: development of an expanded conceptual framework. AIDS Patient Care STDS. 2005;19(4):258 71.
31. Heimer CA. 'Wicked' ethics: compliance work and the practice of ethics in HIV research. Soc Sci Med. 2013;98:371 8.
32. Kalichman SC, Simbayi LC, Jooste S, Toefy Y, Cain D, Cherry C, et al. Development of a brief scale to measure AIDS related stigma in South Africa. AIDS Behav. 2005;9(2):135 43.
33. Skinner D, Mfecane S. Stigma, discrimination and the implications for people living with HIV/AIDS in South Africa: Original article. SAHARA J. 2004;1(3):157 64.
34. Baigis J, Korniewicz DM, Chase G, Butz A, Jacobson D, Wu AW. Effectiveness of a home based exercise intervention for HIV infected adults: a randomized trial. J Assoc Nurses AIDS Care. 2002;13(2):33 45.
35. Dolan SE, Frontera W, Librizzi J, Ljungquist K, Juan S, Dorman R, et al. Effects of a supervised home based aerobic and progressive resistance training regimen in women infected with human immunodeficiency virus: a randomized trial. Arch Intern Med. 2006;166(11):1225 31.
36. Lang C. Community physiotherapy for people with HIV/AIDS. Physiotherapy. 1993;79(3):163 6.
37. Maharaj SS, Chetty V. Rehabilitation program for the quality of life for individuals on highly active antiretroviral therapy in KwaZulu Natal, South Africa: a short report. Int J Rehabil Res. 2011;34(4):360 5.
38. Pullen SD, Chigbo NN, Nwigwe E, Chukwuka C, Amah C, Idu S. Physiotherapy intervention as a complementary treatment for people living with HIV/AIDS. HIV/AIDS (Auckland, NZ). 2014;6:99.
39. Roos R, Myezwa H, Van Aswegen H, Musenge E. Effects of an education and home based pedometer walking program on ischemic heart disease risk factors in people infected with HIV: a randomized trial. J Acquir Immune Defic Syndr. 2014;67(3):268 74.
40. World Health Organisation. Task shifting. Global recommendations and guidelines. 2008. http://www.who.int/healthsystems/TTR TaskShifting.pdf. Accessed 15 May 2015.
41. Sanne I, Orrell C, Fox MP, Conradie F, Ive P, Zeinecker J, et al. Nurse versus doctor management of HIV infected patients receiving antiretroviral therapy (CIPRA SA): a randomised non inferiority trial. Lancet. 2010;376(9734):33 40.
42. Callaghan M, Ford N, Schneider H. A systematic review of task shifting for HIV treatment and care in Africa. Hum Resour Health. 2010;8:8 16.
43. Petersen I, Hancock JH, Bhana A, Govender K. A group based counselling intervention for depression comorbid with HIV/AIDS using a task shifting approach in South Africa: a randomized controlled pilot study. J Affect Disord. 2014;158:78 84.
44. Centre for Global Mental Health. COBALT: Comorbid Affective Disorders, AIDS/HIV, and Long Term Health. 2015. http://www.centreforglobalmentalhealth.org/projects research/cobalt comorbid affective disorders aidshiv and long term health. Accessed 30 May 2015.
45. Zachariah R, Ford N, Philips M, Lynch S, Massaquoi M, Janssens V, et al. Task shifting in HIV/AIDS: opportunities, challenges and proposed actions for sub Saharan Africa. Trans R Soc Trop Med Hyg. 2009;103(6):549 58.

CHAPTER 4: HBR INTERVENTION

Whereas medicine adds years to life, it is rehabilitation that aims to add life to years.

Stephanie Nixon et al (2011)

4.1. Summary

This chapter is presented in the form of a published study, presenting and discussing the results of the randomised controlled trial that was central to of this PhD research. These results demonstrate that a HBR intervention can be safely delivered to PLHIV and disability by trained community healthcare workers, trained and supervised by a qualified physiotherapist. Furthermore, it appears that HBR may improve the quality of life of PLHIV, while at the same time minimising some of the obstacles they face accessing institution-based rehabilitation. The authors outline the value of alternative rehabilitation options for PLHIV, using task-shifting approaches, and propose recommendations for further research in this area. Appendices 11 and 12 have been added to show individual participants' pre and post-intervention scores for the main study outcome measures.

4.2. Publication details

Title	A home-based rehabilitation intervention for adults living with HIV: A randomized controlled trial
Authors	Saul Cobbing, Jill Hanass-Hancock and Hellen Myezwa
Journal	Journal of the Association of Nurses in Aids Care (JANAC)
Year	2017
Volume	28 (1)
Pages	105-117
DOI number	10.1016/j.jana.2016.08.008

4.3. Journal details

The Journal of the Association of Nurses in AIDS Care (JANAC) is a peer-reviewed, ISI-listed nursing journal that covers the full spectrum of the global HIV epidemic, focusing on prevention, evidence-based care management, interdisciplinary clinical care, research, advocacy, policy, education, social determinants of health, epidemiology, and program development. It accepts original research from a wide range of disciplines, including one of the few published accounts of a randomised controlled trial home-based exercise intervention for PLHIV (Baigis et al, 2002). JANAC has an impact factor of 1.398 (as at October 2016).

4.4. Publication timeline

The first draft of this article was submitted to JANAC on the 7 April 2016. Reviewers' and editorial feedback was received on the 12 July and 10 August, with all comments and queries responded to on the 14 July and 26 August respectively. The final manuscript was accepted and slated for publication on the 29 August 2016 and was published on-line on 6 September 2016. The final journal copy appeared in JANAC in the January/February 2017 edition.

4.5. Contribution details

The candidate conceptualised, developed and wrote the paper. Professors Myezwa and Hanass-Hancock provided assistance with conceptualizing the reported intervention and contributed significant editing of the draft manuscript. A qualified statistician, from an external tertiary institution, was consulted and employed to provide input for the statistical analysis contained within this article.

A Home-Based Rehabilitation Intervention for Adults Living With HIV: A Randomized Controlled Trial

Saul Cobbing, MSc*
Jill Hanass-Hancock, PhD
Hellen Myezwa, PhD

A randomized controlled trial was conducted to investigate the effects of a 16-week home-based rehabilitation (HBR) intervention on the quality of life, functional mobility, and functional capacity of adult people living with HIV (PLWH) on antiretroviral therapy in KwaZulu-Natal, South Africa. The intervention was carried out by community health care workers under the supervision of a qualified physical therapist. Participants in the control group received the standard of care as well as written health advice. While participants in the intervention group showed greater improvements across all outcome measures, between-group differences were nonsignificant. HBR for PLWH is a safe means of addressing the functional deficits experienced by PLWH and appears likely to improve quality of life. A task-shifting approach may be a feasible method of meeting the varied needs of PLWH, while at the same time potentially minimizing costs to already overburdened health care systems.

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Key words: *disability, home-based care, people living with HIV infection, quality of life, rehabilitation, task-shifting*

More than 35 million people live with HIV globally, 24.7 million of whom live in sub-Saharan Africa (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2013). South Africa has 6.4 million people living with HIV (PLWH), while KwaZulu-Natal (KZN) province has the highest HIV prevalence of all of South Africa's nine provinces (Shisana et al., 2014) and can thus be considered the epicenter of the global HIV epidemic. In the last decade, South Africa has seen a marked increase in the number of PLWH receiving antiretroviral therapy (ART). This has resulted in a reduction in deaths attributable to HIV and an increase in life expectancy, with KZN seeing an 11.3-year increase in life expectancy between 2003 and 2011 (UNAIDS, 2013). Following an analysis of 37,740 South African PLWH on ART, Johnson and colleagues (2013) concluded that South African HIV-infected adults who started ART before their CD4+ T cell count fell below 200 cells/mm^3 could expect to enjoy near-normal life expectancy. What is less clear, however, is what quality of life these patients can expect to have.

HIV is now increasingly being viewed as a chronic disease (Deeks, Lewin, & Havlir, 2013), and like other chronic diseases, it presents PLWH with a number of physical, mental, and cognitive challenges. In a recent study of a cohort of 1,041 PLWH in KZN, Hanass-Hancock, Myezwa, and Carpenter (2015) found that 35.5% of the cohort experienced

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functional limitations, which could also be understood as the onset of disability. Few participants in that cohort reported any access to rehabilitation aimed at addressing these disabilities. The relationship between HIV and disability is well established (Hanass-Hancock & Nixon, 2009; Nixon et al., 2014; Van As, Myezwa, Stewart, Maleka, & Musenge, 2009), with two systematic reviews revealing that PLWH in hyper-endemic sub-Saharan African countries were prone to a wide range of physical and cognitive disabling conditions (Banks, Zuurmond, Ferrand, & Kuper, 2014; Hanass-Hancock, Regondi, van Egeraat, & Nixon, 2013).

HIV infection is associated with reduced physical performance, with both of these factors increasing mortality (Greene et al., 2014). According to the findings of Nixon and colleagues (2011), rehabilitation was crucial in ensuring that quality of life was added to the increased years of life that ART may provide to PLWH. Exercise forms an integral component of any physical rehabilitation program. Resistance and aerobic exercise interventions have been shown, via a number of systematic reviews (Gomes-Neto, Conceicao, Carvalho, & Brites, 2013; Gomes-Neto, Ogalha, Andrade, & Brites, 2013; O'Brien, Nixon, Tynan, & Glazier, 2010; O'Brien, Tynan, Nixon, & Glazier, 2008), to be both safe and beneficial for PLWH. Exercise and rehabilitation interventions are often offered by rehabilitation professionals working within hospitals or other centralized facilities. In resource-poor environments, PLWH experience a number of challenges related to accessing institution-based rehabilitation (Cobbing, Hanass-Hancock, & Deane, 2014) and there has been a call for alternative rehabilitation options for PLWH in these communities (Chetty & Hanass-Hancock, 2015). Chu and Selwyn (2011) proposed that health care systems need to reinvent themselves as the HIV epidemic evolves, with a particular focus on patient-centered community-based practice.

Home-based rehabilitation (HBR) is a key component of a wider community-based rehabilitation approach and has been proven to be an effective strategy to improve the quality of lives and the physical and mental well-being of individuals living with a wide range of chronic conditions, including stroke (Chaiyawat & Kulkantrakorn, 2012; Geddes & Chamberlain, 2001; Outpatient Service Trialists, 2009), traumatic brain injury (Hopman, Tate, & McCluskey, 2012; Powell, Heslin, & Greenwood, 2002), coronary artery disease (Blair, Corrigall, Angus, Thompson, & Leslie, 2011; Clark et al., 2015), and chronic respiratory conditions (Maltais et al., 2008; Pradella et al., 2015; Resqueti et al., 2007). A scoping review of the literature (Cobbing, Hanass-Hancock, & Myezwa, 2016) revealed only six articles that had investigated HBR interventions for adult PLWH (Baigis et al., 2002; Dolan et al., 2006; Lang, 1993; Maharaj & Chetty, 2011; Pullen et al., 2014; Roos, Myezwa, van Aswegen, & Musenge, 2014). Three of these interventions were situated in sub-Saharan Africa, and none offered rehabilitation tailored to individual participants' specific needs.

With specific reference to health care services available in South Africa, rehabilitation remains primarily institution based, despite commitment by the country's Department of Health (2001) to promote access to rehabilitative services closer to patients' homes, as stated more than 15 years ago. This lack of home-based services is exacerbated by the relative shortage of rehabilitation professionals in South Africa when compared to resource-rich countries in the North. World Health Organization statistics highlight this disparity, with Finland having more than 10 times more qualified physical therapists than South Africa (World Health Organization [WHO], 2011). These shortages were even more marked in poorer sub-Saharan countries such as Kenya, Namibia, and Zimbabwe, which all have considerably fewer than one physical therapist and occupational therapist per 10,000 population (WHO, 2011). The shortage of trained rehabilitation professionals has suggested the need for alternative approaches to the provision of rehabilitation, particularly in countries with a high prevalence of PLWH and disability. A task-shifting approach could counter this human resources challenge by training less-qualified personnel to conduct more complex tasks (Zachariah et al., 2009). This strategy has already shown promise in other areas of HIV care in Africa, such as ART provision (Callaghan, Ford, & Schneider, 2010) and counseling for depression (Petersen, Hanass-Hancock, Bhana, & Govender, 2014).

In summary, little evidence has been published on HBR programs developed for PLWH who are also affected by disabilities, and even less related to

PLWH in sub-Saharan Africa. Nixon and colleagues (2011) argued that, despite the fact that so many PLWH experienced disability, rehabilitation had not been adequately incorporated into HIV care. Following widespread engagement with health professionals and PLWH in this study setting, Chetty, Hanass-Hancock, and Myezwa (2016) concluded that evidence-based HBR interventions were essential elements in an optimal model of care for PLWH in HIV-endemic countries. Our study aimed to assess the impact of a 16-week disability-inclusive HBR program on the quality of life, perceived disability, functional capacity, and mobility of adult PLWH.

Methods

Study Design

We employed a single-blinded randomized controlled trial (RCT) design. Ethical approval was obtained from the Biomedical Research Ethics Committee at the University of KwaZulu-Natal (BFC052/15), and the study was also registered with the South African Department of Health (DOH-27-0715-5094) and the South African National Clinical Trial Register (NHREC# 4094). A more detailed account of the study method has been published elsewhere (Cobbing, Hanass-Hancock, & Myezwa, 2015).

Study Location

Our study was conducted at a state hospital and in participants' homes in a peri-urban area of the eThekwini district in KwaZulu-Natal province, South Africa. This area has had one of the highest rates of HIV infection in South Africa, with more than one in three pregnant women testing positive for HIV (Department of Health, 2012). Pre- and postintervention testing took place on the hospital premises, while all components of the HBR intervention were conducted in, or around, the homes of the study participants. The locations of the homes of the 38 participants in the intervention group in relation to the study hospital are shown in Figure 1.

Study Population, Sample, and Randomization

Study participants were recruited from an observational cohort study that included 1,041 adult PLWH who obtained ART from clinics in the study district (Hanass-Hancock et al., 2015). A statistical power of 80% was selected for the study, allowing for a loss to follow-up rate of between 20% and 50%, as indicated in previous studies that had recruited PLWH in South Africa (Cornell et al., 2012; Petersen et al., 2014). Based on these parameters, a sample of 80 participants was sought for our study. Participants from the study population were considered for recruitment if they were older than 18 years of age, had been on ART for more than 6 months, and scored for mobility limitations, according to the WHO Disability Assessment Schedule (WHODAS 2.0) questions S1 and S7. Participants were excluded if they were pregnant, had a complete spinal cord injury, had an acute opportunistic infection, had a recent myocardial infarction, or had unstable angina at the time of recruitment. Individuals who met the inclusion criteria were contacted by telephone and invited to the study hospital. Of 141 individuals who met study inclusion criteria, 76 were able to attend, consented to, and were deemed fit to participate in the preintervention assessments. Following these assessments, stratified randomization was employed using a computerized method, to ensure an even number of male and female participants in the intervention and control groups.

Pre- and Postintervention Assessments

Participants were assessed before and after the HBR intervention by five trained research assistants at the study hospital. After signing full voluntary informed consent, participants were assessed using the following outcome measures: the WHO Quality of Life–short version (WHOQOL-HIV BREF; WHO, 2004); the WHODAS 2.0 – short version (WHO, 2009); the Rivermead Mobility Index (RMI; Collen, Wade, Robb, & Bradshaw, 1991); and the Six Minute Walk Test (6MWT; American Thoracic Society, 2002). All information sheets, consent forms, and outcome measures were translated and conducted in isiZulu, the home language of all 76 participants. Four participants were lost to follow-up from each study group, resulting in 68 of 76 participants attending the postintervention testing, conducted in the week after the conclusion of the intervention. Participant transport costs and a small

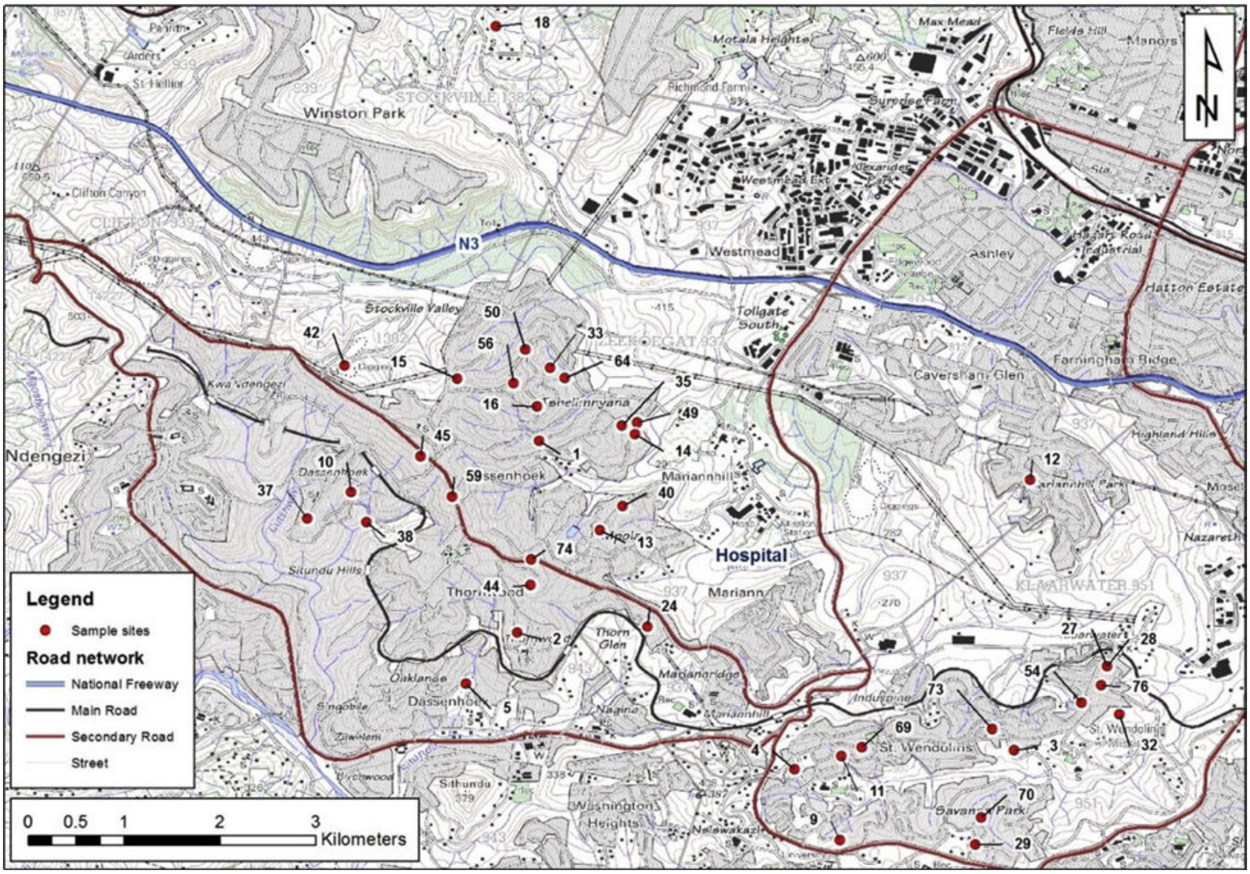

Figure 1. Map of location of participants' homes.

food allowance for each of the 2 testing days were covered. No other inducements were made to participants. The research assistants conducting the postintervention testing were blinded to the group allocation of participants. Figure 2 illustrates the study selection and testing process.

Study Intervention

The HBR intervention was conducted by four community health care workers who lived in the study area and volunteered their services for a local nongovernmental organization, performing basic home-based care for people living in the community. For the duration of the 4-month intervention they were paid from a research grant awarded to the lead author. None of these individuals had a background in formal health or rehabilitation provision. They were trained as rehabilitation assistants for our study by the lead author, a registered physical therapist, who also fulfilled a supervisory role throughout the study. Training took place for more than 1 month and included theory on research ethics and the study method. Practical sessions covered aerobic exercise, resistance exercise, and functional rehabilitation. The rehabilitation assistants worked in pairs, both for safety reasons and to ensure that participants who needed extra assistance received appropriate care. Each pair of assistants was responsible for the rehabilitation of 19 participants in the intervention group. A novelty of this intervention, compared with other published exercise interventions for PLWH, was the fact that it was a needs-based rehabilitation intervention. This meant that rather than each participant doing the same exercises as other participants, each individual's program was structured and progressed according to her/his own specific physical impairments. On the first home visit, each participant was assessed by the lead author and taught a

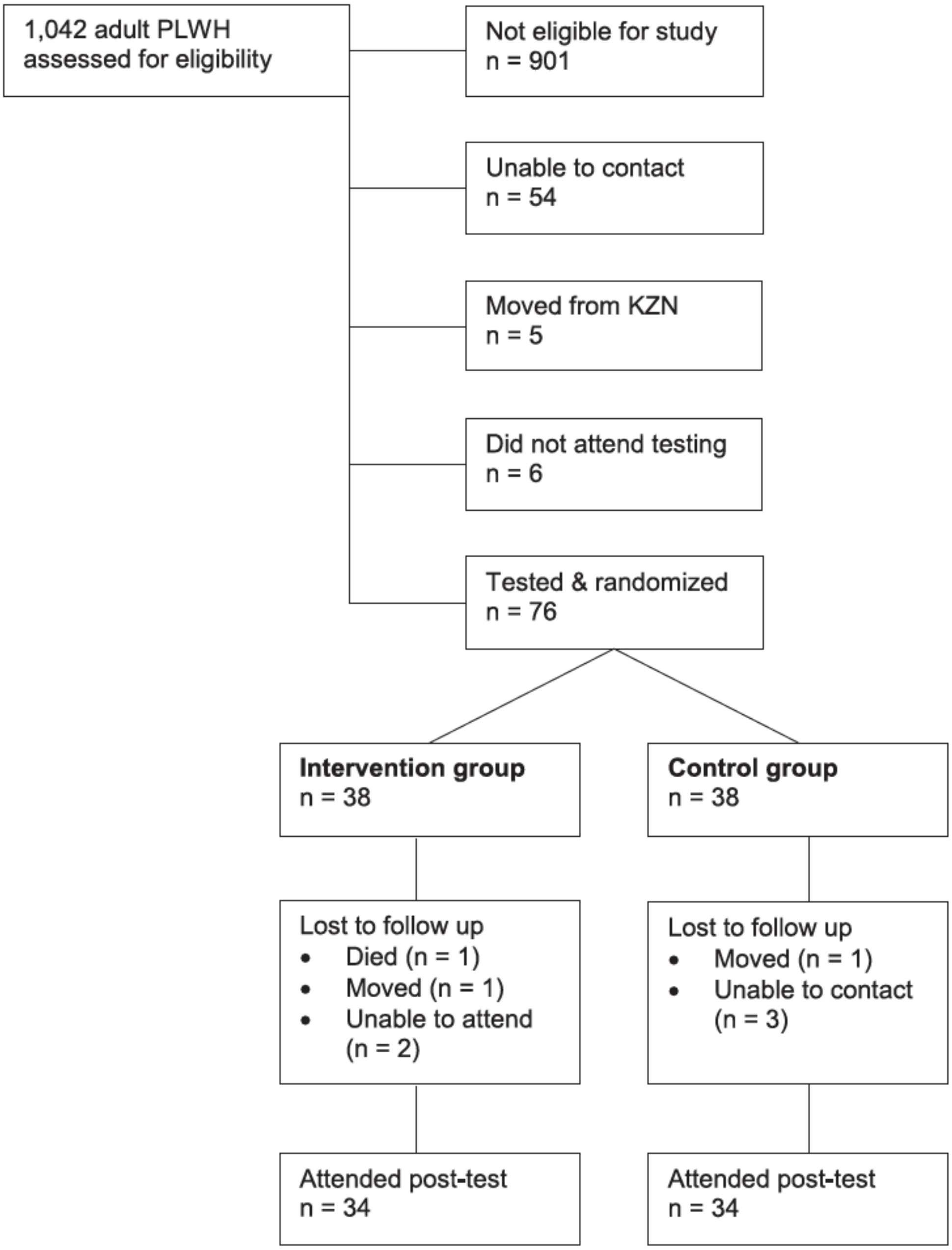

Figure 2. Selection and testing process. ***Note.*** **PLWH = people living with HIV; KZN = Kwazulu-Natal.**

variety of strength, stretching, and functional exercises suitable for his/her condition and level of ability. Upper limb and lower limb strength exercises were primarily performed using lightweight latex bands of varying resistance, which were given to each participant. The exercises included bicep curls; shoulder raises; tricep push-downs; and hip, knee, and ankle flexion and extension. Training volume increased weekly from one set of 10 repetitions of each exercise to three sets of 10 repetitions, after which intensity was increased by increasing the distance from where the band was attached, therefore increasing the band resistance. Participants were encouraged to work at an intensity where they felt effort but no pain. Functional exercises, such as sitting to standing and bridging were also taught where appropriate. All participants were also encouraged, if able, to walk outside at every visit, gradually increasing the distance covered. Participants were encouraged to work at a pace where they felt an increase in heart rate and breathing but were still able to talk.

Participants were seen once weekly, in their own homes. Appointments were made by telephone and participants were able to select times and dates most suitable for them, including Saturdays, to cater to participants who worked on weekdays. Stretching exercises were followed by progressive strengthening exercises, functional exercises, and a graded walking program, performed outdoors. Where necessary, participants were provided with walking sticks, walking frames, or elbow crutches and instructed in their use. At each visit, the rehabilitation assistants updated the participants' individual diaries, recording which activities were completed and any reasons for a participant being unable to attend or complete a session.

Control Group

Participants in the control group received the standard of care offered to PLWH in the South African public sector. They were also provided with written advice by the researchers discussing general tips on healthy living for people receiving ART. Control participants were contacted by telephone once a month to check on their health status, confirm their contact details, and remind them of their allocated date for postintervention testing.

Data Analysis

Data were analyzed using SPSS version 23.0 (IBM, Armonk, NY). An intention-to-treat analysis was performed, requiring all participants to be included. Intention-to-treat is seen as the gold standard for analyzing the results of clinical trials (Armijo-Olivo, Warren, & Magee, 2009) and allowed for a more accurate account of this intervention in practice, rather than only reporting the outcomes of participants who adhered to the intervention and returned for posttesting. Mean values were entered for participants who did not return for postintervention testing. Descriptive statistics were used to summarize baseline demographic data. Data sets were tested for normality using the Kolmogorov-Smirnov test. These results indicated that most of the variables were not normally distributed, resulting in the use of nonparametric methods of analysis. Within-group changes were compared using the Wilcoxon test, while the Mann-Whitney test assessed between-group effects. Significance for all analyses was considered when *p*-values of less than .05 were recorded.

Results

Participant Characteristics at Baseline

All participants in our study were Black isiZulu-speaking adults living with HIV, ranging in age from 25 to 67 years. The majority of the participants in both the intervention and control groups was female, had not completed high school, and had never been married. More than half the participants in both groups were unemployed at the time of baseline testing. Full participant characteristics for both groups are presented in Table 1.

The changes in selected study outcome measures before and after the 16-week HBR intervention (in both study groups as well as the difference between the 2 groups) are shown in Table 2. The results of the first question from the WHOQOL-HIV BREF questionnaire (which asks about overall QOL) and the six QOL domains are shown. The overall weighted WHODAS 2.0 score and the cognition and mobility domain scores are shown. Finally, the totaled RMI score is shown and the overall distance covered in the 6MWT. These specific outcomes were selected to best represent the differences in participants' physical and psychological function before and after the study period. While greater improvements were recorded, on average, in the intervention group across all outcome measures, none of the within-group differences were statistically significant ($p < .05$).

Discussion

Baseline values for the six quality-of-life domains measured by the WHOQOL-HIV BREF for both study groups were similar to those found in 643

Table 1. **Participant Characteristics at Baseline**

Variable	HBR Group (*n* = 38)	Control Group (*n* = 38)
Age, mean (range)	43.4 (29 63)	44.7 (25 67)
Gender, *n* (%)		
Female	29 (76.3)	29 (76.3)
Male	9 (23.7)	9 (23.7)
Education, *n* (%)		
Primary school not completed	7 (18.4)	8 (21.1)
Primary school completed	22 (57.9)	23 (60.5)
High school completed	9 (23.7)	7 (18.4)
Marital status, *n* (%)		
Never married	25 (65.8)	29 (76.3)
Married/cohabiting	11 (28.9)	8 (21.1)
Divorced	0 (0)	1 (2.6)
Widowed	2 (5.3)	0 (0)
Dwelling type, *n* (%)		
Brick house	29 (76.3)	29 (76.3)
Mud hut	5 (13.1)	4 (10.5)
Shack	2 (5.3)	3 (7.9)
Rented room in backyard	2 (5.3)	2 (5.3)
Employment, *n* (%)		
Unemployed	23 (60.5)	14 (36.8)
Part time work	8 (21.1)	13 (34.2)
Full time work	7 (18.4)	9 (23.7)
Retired	0 (0)	2 (5.3)
CD4+ T cell count (cells/mm^3), mean (range)	448 (45 1182)	395 (21 920)

Note. HBR = home based rehabilitation.

symptomatic PLWH in a cross-cultural study conducted across eight countries on five continents (O'Connell & Skevington, 2012). The total WHODAS 2.0 weighted scores, as well as the mobility-related questions, for both study groups indicated the physical challenges faced by the study participants, although the total scores for the RMI showed that the participants were able to carry out the relatively simple functional tasks assessed in this test. The average scores from the 6MWT, however, revealed the marked deficits in functional capacity and endurance experienced by the study participants at baseline. Average distances covered (270 meters in the intervention group and 253 meters in the control group) compared poorly with average distances of 482 meters (intervention) and 474 meters (control) achieved at baseline by a group of 40 American women living with HIV (Dolan et al., 2006), and even more poorly with average distances at baseline of 541 meters (intervention) and 548 meters (control) recorded amongst 84 South African PLWH (Roos et al., 2014). Furthermore, a meta-analysis of data from 13 studies (nine conducted in North America and four in Europe) on the 6MWT collected from 4,809 apparently healthy adults older than 60 years of age reported an overall average walking distance of 499 meters (Bohannon, 2007). Indeed, women in the 80- to 89-year-old category in this meta-

Table 2. **Changes in Selected Study Outcome Measures**

Variable	HBR Pre	HBR Post	Control Pre	Control Post	*p* Value
WHOQOL1: Overall QoL	3.13 (±0.84)	3.62 (±0.70)[a]	3.13 (±0.74)	3.41 (±0.93)	*p* = .642
WHOQOL domain 1: Physical	12.71 (±2.69)	14.09 (±2.62)[a]	12.79 (±2.60)	12.94 (±2.85)	*p* = .308
WHOQOL domain 2: Psychological	13.81 (±2.35)	14.11 (±1.71)	14.11 (±1.71)	14.38 (±1.44)	*p* = .844
WHOQOL domain 3: Independence	12.97 (±2.94)	13.62 (±2.31)	13.00 (±2.13)	13.06 (±1.86)	*p* = .424
WHOQOL domain 4: Relationships	12.32 (±3.47)	13.00 (±2.85)	11.84 (±2.57)	12.79 (±2.70)	*p* = .739
WHOQOL domain 5: Environment	12.30 (±2.19)	12.41 (±1.98)	12.08 (±2.06)	11.87 (±3.09)	*p* = .644
WHOQOL domain 6: Spiritual	13.00 (±2.62)	13.88 (±2.46)	14.05 (±2.54)	14.32 (±2.43)	*p* = .456
WHODAS (Total) Weighted	5.53 (±7.12)	1.24 (±2.18)[a]	3.37 (±3.32)[b]	0.94 (±1.84)	*p* = .800
WHODAS domain 1: Cognition	1.29 (±1.72)	0.24 (±0.55)[a]	0.74 (±1.13)[b]	0.18 (±0.46)	*p* = .570
WHODAS domain 2: Mobility	1.55 (±2.11)	0.18 (±0.56)[a]	0.95 (±1.45)[b]	0.21 (±0.59)	*p* = .463
RMI (Total)	13.89 (±3.01)	14.24 (±1.50)	13.95 (±1.61)	13.82 (±2.33)	*p* = .761
6MWT (distance)	269.66 (±74.55)	327.71 (±73.61)[a]	253.42 (±79.79)[b]	303.29 (±92.48)	*p* = .859

Note. WHOQOL = World Health Organization Quality of Life; QOL = quality of life; WHODAS = World Health Organization Disability Assessment Schedule; RMI = Rivermead Mobility Index; 6MWT = Six Minute Walk Test.

a. Within group significant difference (intervention group).

b. Within group significant difference (control group).

analysis averaged 382 meters, more than 100 meters further than both groups in this study.

The postintervention results for QOL (as assessed by the WHOQOL-HIV BREF), showed statistically significant improvements within the intervention group in both overall QOL and the physical domain, with all other domains showing a nonsignificant increase in average score. The average score in the intervention group for overall quality of life increased from 3.13 to 3.61, markedly higher than the average overall QOL score of 2.8 found among 292 South African PLWH on ART (Peltzer & Phaswana-Mafuya, 2008). The physical domain score for the intervention group (12.71) was lower at baseline than an average score of 13.3 in the Peltzer and Phaswana-Mafuya (2008) sample, but improved significantly to an average score of 14.09 post intervention. While QOL domains also improved in the control group, none of these increases were statistically significant. Although nonsignificant, greater improvements occurred in the intervention group across all WHOQOL-HIV BREF domains. This finding supported the improvements in QOL demonstrated in a number of studies investigating the effects of resistance exercise (Agin et al., 2001; Lox, McAuley, & Tucker, 1996) and aerobic exercise (Baigis et al., 2002; Mutimura, Stewart, Crowther, Yarasheski, & Cade, 2008; Stringer, Berezovskaya, O'Brien, Beck, & Casaburi, 1998) interventions designed for PLWH. The improvement in the physical domain reported by the intervention group may be explained by the general physical improvements in strength and fitness shown by PLWH who have participated in exercise-based studies (O'Brien et al., 2010, 2008). A recent activity-based study conducted in a disadvantaged urban setting in South Africa found that participants who were compliant (i.e., who participated in at least one-third of exercise sessions) performed better in posttest strength assessments than noncompliers (Ley, Leach, Barrio, & Bassett, 2015). This was related to these participants also feeling and looking healthier and thus less likely to experience HIV-related stigma.

The WHODAS 2.0 tool has proven to be reliable and valid for measuring function and disability in different countries, including varied disease types (Üstün et al., 2010). Both intervention and control groups in our study showed statistically significant improvements in overall WHODAS 2.0 scores (both total and weighted scores), as well as in the cognition and mobility domains ($p < .05$). While the improvements were more substantial in the intervention group, statistically significant differences were not found between groups. The participants exposed to the HBR intervention showed an average (weighted) total score of 5.53, which was higher than average total scores of 4.3 for 4,750 Australian participants (with any chronic condition) recorded by Andrews, Kemp, Sunderland, Von Korff, and Ustun (2009), the only normative data available for this tool. Following our intervention, however, the average total score in the intervention group decreased significantly to 1.23, well below the normative scores reported above. This indicated that the participants experienced far fewer functional challenges after the HBR intervention, allowing them to participate more fully in various life activities. As with the WHOQOL-HIV BREF, there were no statistically significant between-group differences recorded. However, greater improvements were evident in the intervention group.

The third outcome measure used in our study was the RMI. Average scores for participants in the intervention group improved from 13.89 to 14.24, while average scores in the control group decreased slightly, with neither reported change being statistically significant. This tool was chosen in anticipation of participants having more serious physical problems, preventing them from performing relatively simple functional tasks such as sitting to standing. While a small number of participants recorded low scores on the RMI, many more participants scored a maximum total of 15 out of 15, thus accounting for the high average scores in both groups. The scoring of either 0 (*unable to do a task*) or 1 (*able to do a task*) did not allow for subtle variations where participants may have been able to report relative difficulties in carrying out tasks they were able to do. In retrospect, the RMI was a poor choice of outcome measure, adding little depth to the understanding of the effects of this study intervention.

Participants in both groups improved significantly ($p < .05$) in the final outcome measure, the 6MWT, with postassessment distances of 328 meters (intervention group) and 303 meters (control) recorded. While these improvements were matched by statistically significant improvements in the mobility domain of the WHODAS 2.0 (with most participants reporting no problems standing or walking), it was interesting to note how low these postassessment distances still were compared to age-respective norms for this test (Bohannon, 2007). This suggests that subjective measures of ability and function (such as the WHODAS 2.0) may be more realistic and applicable to chronic disease populations than objective measures such as the 6MWT or tests of absolute strength and endurance.

While greater improvements were observed in the participants in the intervention group across all four outcome measures, all between-group differences were found to be statistically nonsignificant. One reason for this was that the study did not meet the required power calculation of 80 participants, with 68 of the 76 participants attending postintervention testing. According to Button and colleagues (2013), any study with reduced statistical power has a lesser chance of demonstrating the actual effect resulting from biomedical interventions. Every attempt was made by the researchers to recruit as many participants as possible, with 76 of 141 eligible individuals representing a high recruitment rate, given that 59 of these eligible individuals had either left the province or were uncontactable by the phone numbers in their patient records (see Figure 2). Another potential reason for nonsignificance between the study groups may have been that, for ethical reasons, the participants in the control group were given written advice on healthy living and exercise, in addition to continuing with the standard care offered by the study hospital. This may have motivated participants in the control group to take up some form of exercise, thus resulting in improvements in the study outcome measures. It is vital, according to Heimer (2013), to also see research participants as patients, especially given the ethical challenges inherent in HIV research. While it would have been interesting to have a third group who were given no advice of this nature and exposed to the intervention at a later point, this was outside the scope of our study. Adopting a crossover design should be considered for future research of this nature, where all participants receive all different treatment options, allowing a more efficient comparison of treatment effects while at the same time limiting confounding variables (Wellek & Blettner, 2012). A third possible reason for nonsignificance may have been that the 16-week intervention was not long enough or intensive enough. A 6- or 12-month intervention (with more regular supervised visits) may have resulted in statistically significant improvements in the intervention group, in comparison to the control group. It should be noted, however, that the majority of exercise-based RCTs designed for PLWH report durations of 12 to 16 weeks (Fillipas, Cherry, Cicuttini, Smirneos, & Holland, 2010; O'Brien et al., 2010, 2008), information that was utilized in the design of our study. Finally, a possible reason for the improvements seen in the control group could have been the sharing of knowledge between these participants and those in the intervention group. While there is no evidence that this actually occurred in our study, it cannot be ruled out completely as participants in the control group did live in the same neighborhoods as the participants in the intervention group. Future studies could employ a geographical cluster sampling method in order to ensure that participants in the control group and intervention group are less likely to interact and share knowledge of the trial.

Although there were no statistically significant between-group differences, our study has revealed some important facts that can help to guide future research and practice for this population. First, it has shown that community health care workers, trained and supported by a qualified rehabilitation professional, can successfully implement and supervise an HBR program for PLWH. Task-shifting was identified by health professionals and PLWH as a key element of optimal HIV care in this study setting (Chetty et al., 2016), information that contributed to the design of our study. While task-shifting has been proven to be beneficial in wider HIV care (Callaghan et al., 2010; Petersen et al., 2014), ours was the first study investigating the practice of task-shifting in the physical rehabilitation of PLWH. Not only did most participants in the intervention group improve across most outcome measures, there was also a very low loss to follow-up rate of 10.5% in both study groups. This compared favorably with studies of similar design, with a 20.2% loss to follow-up rate reported by Roos and colleagues (2014) after a 6-month home-based walking program for PLWH (conducted in an urban South African setting) and a 19.5% rate reported by Baigis and colleagues (2002) after a 15-week home-based exercise intervention (conducted in an urban

American setting). An 8-week counseling intervention conducted at the same study hospital (Petersen et al., 2014) recorded a 51% loss to follow-up rate, perhaps explained by the fact that study participants suffered from depression and also attended counseling sessions at local clinics, rather than being seen in their own homes. It appears that conducting an intervention of this nature in participants' own homes (only requiring them to come to the study hospital for pre- and post-testing), successfully addressed some of the challenges related to transport and finance previously described by patients receiving physical therapy rehabilitation at our study setting (Cobbing et al., 2014).

Conclusions and Implications for Health Care Providers

The multi-morbidity experienced by PLWH threatens to overwhelm health care systems, particularly those in resource-limited regions (Deeks et al., 2013). Mahomed, Asmall, and Freeman (2014) asserted that, in order to successfully manage chronic diseases over an extended period of time, innovative, multi-professional services focusing on patient empowerment are required. Our study demonstrated its innovation by presenting the first empirical account of the effects of a needs-based HBR intervention for PLWH with disabilities, conducted in a community where HIV was endemic and resources were limited. The results showed that an HBR intervention was both safe and showed promise in improving the functional ability and QOL of PLWH. The intervention was implemented by community health care workers who lived in the same communities as the study participants, suggesting that a task-shifting approach was a feasible and potentially cost-saving method of providing rehabilitation for PLWH. Where possible, other disciplines should contribute to the training and supervision of community health workers to ensure that PLWH have access to a wider range of rehabilitation services. In resource-poor regions, where HIV is most prevalent, stakeholders in both the health care and education sectors should consider formalizing the training and deployment of general mid-level rehabilitation workers in order to provide essential cost-effective services to PLWH. In locations where resources are extremely limited and rehabilitation workers are not present, medical and nursing personnel should receive specialized training in order to identify any physical problems experienced by PLWH and should be able to provide specific advice on exercise, nutrition, and healthy living to patients attending ART clinics. Researchers in this field should attempt to recruit larger participant samples and ensure the selection of outcome measures that are appropriate to the participants recruited. In order to build on the results of our study, it would be instructive to consider a cross-over design and randomized clustering in any future RCT, ensuring that all participants receive both intervention and control treatments, while at the same time limiting the chance of contact between groups. Further research in this area should also consider investigating the effects of longer, more intensive HBR interventions with PLWH.

Key Considerations

- As people living with HIV (PLWH) live longer, they are more prone to develop disabilities that negatively affect full physical, social, and vocational participation. Medical and nursing care alone are not sufficient to respond to the multiple morbidities faced by this population.
- Home-based rehabilitation has shown promise as an intervention that can address the functional deficits experienced by PLWH. It is also safe and appears likely to improve the quality of life of participants.
- A task-shifting approach, training community health care workers to conduct basic rehabilitation interventions, is a feasible method of meeting the various needs of PLWH, while also minimizing costs to already overburdened health care systems.

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References

Agin, D., Gallagher, D., Wang, J., Heymsfield, S. B., Pierson, R. N., & Kotler, D. P. (2001). Effects of whey protein and resistance exercise on body cell mass, muscle strength, and quality of life in women with HIV. *AIDS*, *15*(18), 2431 2440.

American Thoracic Society. (2002). ATS statement: Guidelines for the six minute walk test. *American Journal of Respiratory and Critical Care Medicine*, *166*(1), 111.

Andrews, G., Kemp, A., Sunderland, M., Von Korff, M., & Ustun, T. B. (2009). Normative data for the 12 item WHO Disability Assessment Schedule 2.0. *PLoS One*, *4*(12), e8343.

Armijo Olivo, S., Warren, S., & Magee, D. (2009). Intention to treat analysis, compliance, drop outs and how to deal with missing data in clinical research: A review. *Physical Therapy Reviews*, *14*(1), 36 49. http://dx.doi.org/10.1179/174328809X405928

Baigis, J., Korniewicz, D. M., Chase, G., Butz, A., Jacobson, D., & Wu, A. W. (2002). Effectiveness of a home based exercise intervention for HIV infected adults: A randomized trial. *Journal of the Association of Nurses in AIDS Care*, *13*(2), 33 45.

Banks, L. M., Zuurmond, M., Ferrand, R., & Kuper, H. (2014). The relationship between HIV and prevalence of disabilities in sub Saharan Africa: Systematic review (FA). *Tropical Medicine & International Health*, *20*(4), 411 429. http://dx.doi.org/10.1111/tmi.12449

Blair, J., Corrigall, H., Angus, N. J., Thompson, D., & Leslie, S. (2011). Home versus hospital based cardiac rehabilitation: A systematic review. *Rural and Remote Health*, *11*(2), 1532.

Bohannon, R. W. (2007). Six Minute Walk Test: A meta analysis of data from apparently healthy elders. *Topics in Geriatric Rehabilitation*, *23*(2), 155 160. http://dx.doi.org/10.1097/01.TGR.0000270184.98402.ef

Button, K. S., Ioannidis, J. P. A., Mokrysz, C., Nosek, B. A., Flint, J., Robinson, E. S. J., & Munafò, M. R. (2013). Power failure: Why small sample size undermines the reliability of neuroscience. *Nature Reviews Neuroscience*, *14*(5), 365 376. http://dx.doi.org/10.1038/nrn3475

Callaghan, M., Ford, N., & Schneider, H. (2010). A systematic review of task shifting for HIV treatment and care in Africa. *Human Resources for Health*, *8*(8), 16. http://dx.doi.org/10.1186/1478 4491 8 8

Chaiyawat, P., & Kulkantrakorn, K. (2012). Effectiveness of home rehabilitation program for ischemic stroke upon disability and quality of life: A randomized controlled trial. *Clinical Neurology and Neurosurgery*, *114*(7), 866 870. http://dx.doi.org/10.1016/j.clineuro.2012.01.018

Chetty, V., & Hanass Hancock, J. (2015). The need for a rehabilitation model to address the disparities of public healthcare for people living with HIV in South Africa. *African Journal of Disability*, *4*(1), 1 6. http://dx.doi.org/10.4102/ajod.v4i1.137

Chetty, V., Hanass Hancock, J., & Myezwa, H. (2016). Expert consensus on the rehabilitation framework guiding a model of care for people living with HIV in a South African setting. *Journal of the Association of Nurses in AIDS Care*, *27*(1), 77 88. http://dx.doi.org/10.1016/j.jana.2015.10.003

Chu, C., & Selwyn, P. A. (2011). An epidemic in evolution: The need for new models of HIV care in the chronic disease era. *Journal of Urban Health*, *88*(3), 556 566.

Clark, R. A., Conway, A., Poulsen, V., Keech, W., Tirimacco, R., & Tideman, P. (2015). Alternative models of cardiac rehabilitation: a systematic review. *European Journal of Preventive Cardiology*, *22*(1), 35 74. http://dx.doi.org/10.1177/2047487313501093

Cobbing, S., Hanass Hancock, J., & Deane, M. (2014). Physiotherapy rehabilitation in the context of HIV and disability in KwaZulu Natal, South Africa. *Disability and Rehabilitation*, *36*(20), 1687 1694. http://dx.doi.org/10.3109/09638288.2013.872199

Cobbing, S., Hanass Hancock, J., & Myezwa, H. (2015). A home based rehabilitation intervention for people living with HIV and disability in a resource poor community, KwaZulu Natal: Study protocol for a randomised controlled trial. *Trials*, *16*(1), 491. http://dx.doi.org/10.1186/s13063 0 15 1025 2

Cobbing, S., Hanass Hancock, J., & Myezwa, H. (2016). Home based rehabilitation interventions for adults living with HIV: A scoping review. *African Journal of AIDS Research*, *15*(1), 77 88. http://dx.doi.org/10.2989/16085906.2016.1159968

Collen, F. M., Wade, D. T., Robb, G. F., & Bradshaw, C. M. (1991). The Rivermead Mobility Index: A further development of the Rivermead Motor Assessment. *International Disability Studies*, *13*(2), 50 54.

Cornell, M., Schomaker, M., Garone, D. B., Giddy, J., Hoffmann, C. J., Lessells, R., … Johnson, L. F. (2012). Gender differences in survival among adult patients starting antiretroviral therapy in South Africa: A multicentre cohort study. *PLoS Medicine*, *9*(9), e1001304. http://dx.doi.org/10.1371/journal.pmed.1001304

Deeks, S. G., Lewin, S. R., & Havlir, D. V. (2013). The end of AIDS: HIV infection as a chronic disease. *Lancet*, *382*(9903), 1525 1533. http://dx.doi.org/10.1016/S0140 6736(13)61809 7

Department of Health. (2001). *National guidelines on home base care/community based care*. Retrieved from https://www.westerncape.gov.za/sites/www.westerncape.gov.za/files/documents/2003/define homebased.pdf

Department of Health. (2012). *The 2011 national antenatal sentinel HIV & syphilis prevalence survey in South Africa*. Retrieved from http://www.health e.org.za/wp content/uploads/2013/05/f0980fb5107a7ce543a8bd5730e52333.pdf

Dolan, S. E., Frontera, W., Librizzi, J., Ljungquist, K., Juan, S., Dorman, R., … Grinspoon, S. (2006). Effects of a supervised home based aerobic and progressive resistance training regimen in women infected with human immunodeficiency virus: A randomized trial. *Archives of Internal Medicine*, *166*, 1225 1231. http://dx.doi.org/10.1001/archinte.166.11.1225

Fillipas, S., Cherry, C. L., Cicuttini, F., Smirneos, L., & Holland, E. (2010). The effects of exercise training on metabolic and morphological outcomes for people living with HIV: A systematic review of randomised controlled trials. *HIV Clinical Trials*, *11*(5), 270 282. http://dx.doi.org/10.1310/hct1105 270

Geddes, J. M. L., & Chamberlain, M. A. (2001). Home based rehabilitation for people with stroke: A comparative study of six community services providing coordinated, multidisciplinary treatment. *Clinical Rehabilitation*, *15*(6), 589 599. http://dx.doi.org/10.1191/0269215501cr452oa

Gomes Neto, M., Conceicao, C. S., Carvalho, V. O., & Brites, C. (2013). A systematic review of the effects of different types of therapeutic exercise on physiologic and functional measurements in patients with HIV/AIDS. *Clinics*, *68*(8), 1157 1167. http://dx.doi.org/10.6061/clinics/2013(08)16

Gomes Neto, M., Ogalha, C., Andrade, A. M., & Brites, C. (2013). A systematic review of effects of concurrent strength and endurance training on the health related quality of life and cardiopulmonary status in patients with HIV/AIDS. *BioMed Research International*, *2013*, 319524. http://dx.doi.org/10.1155/2013/319524

Greene, M., Covinsky, K., Astemborski, J., Piggott, D. A., Brown, T., Leng, S., … Kirk, G. D. (2014). The relationship of physical performance with HIV disease and mortality. *AIDS*, *28*(18), 2711. http://dx.doi.org/10.1097/QAD.0000000000000507

Hanass Hancock, J., Myezwa, H., & Carpenter, B. (2015). Disability and living with HIV: Baseline from a cohort of people on long term ART in South Africa. *PloS One*, *10*(12), e0143936. http://dx.doi.org/10.1371/journal.pone.0143936

Hanass Hancock, J., & Nixon, S. A. (2009). The fields of HIV and disability: Past, present and future. *Journal of the International AIDS Society*, *2*, 3. http://dx.doi.org/10.1186/1758 2652 12 28

Hanass Hancock, J., Regondi, I., van Egeraat, L., & Nixon, S. (2013). HIV related disability in HIV hyper endemic countries: A scoping review. *World Journal of AIDS*, *3*, 257 279. http://dx.doi.org/10.4236/wja.2013.33034

Heimer, C. A. (2013). “Wicked” ethics: Compliance work and the practice of ethics in HIV research. *Social Science and Medicine*, *98*, 371 378. http://dx.doi.org/10.1016/j.socscimed.2012.10.030

Hopman, K., Tate, R. L., & McCluskey, A. (2012). Community based rehabilitation following brain injury: Comparison of a transitional living program and a home based program. *Brain Impairment*, *13*(1), 44 61.

Johnson, L. F., Mossong, J., Dorrington, R. E., Schomaker, M., Hoffmann, C. J., Keiser, O., … Garone, D. B. (2013). Life expectancies of South African adults starting antiretroviral treatment: Collaborative analysis of cohort studies. *PLoS Medicine*, *10*(4), e1001418. http://dx.doi.org/10.1371/journal.pmed.1001418

Joint United Nations Programme on HIV/AIDS. (2013). *Global report: UNAIDS global report on the global AIDS epidemic 2013*. Retrieved from http://www.unaids.org/sites/default/files/media asset/UNAIDS Global Report 2013 en 1.pdf

Lang, C. (1993). Community physiotherapy for people with HIV/AIDS. *Physiotherapy*, *79*(3), 163 167.

Ley, C., Leach, L., Barrio, M. R., & Bassett, S. (2015). Effects of an exercise programme with people living with HIV: Research in a disadvantaged setting. *African Journal of AIDS Research*, *13*(4), 313 319. http://dx.doi.org/10.2989/16085906.2014.961937

Lox, C. L., McAuley, E., & Tucker, R. S. (1996). Aerobic and resistance exercise training effects on body composition, muscular strength, and cardiovascular fitness in an HIV 1 population. *International Journal of Behavioral Medicine*, *3*(1), 55 69.

Maharaj, S. S., & Chetty, V. (2011). Rehabilitation program for the quality of life for individuals on highly active antiretroviral therapy in KwaZulu Natal, South Africa. *International Journal of Rehabilitation Research*, *34*, 360 365. http://dx.doi.org/10.1097/MRR.0b013e32834d2bab

Mahomed, O., Asmall, S., & Freeman, M. (2014). An integrated chronic disease management model: A diagonal approach to health system strengthening in South Africa. *Journal of Health Care for the Poor and Underserved*, *25*(4), 1723 1729. http://dx.doi.org/10.1353/hpu.2014.0176

Maltais, F., Bourbeau, J., Shapiro, S., Lacasse, Y., Perrault, H., Baltzan, M., … Parenteau, S. (2008). Effects of home based pulmonary rehabilitation in patients with chronic obstructive pulmonary disease: A randomized trial. *Annals of Internal Medicine*, *149*(12), 869 878.

Mutimura, E., Stewart, A., Crowther, N. J., Yarasheski, K. E., & Cade, W. T. (2008). The effects of exercise training on quality of life in HAART treated HIV positive Rwandan subjects with body fat redistribution. *Quality of Life Research*, *17*, 377 385. http://dx.doi.org/10.1007/s11136 008 9319 4

Nixon, S., Forman, L., Hanass Hancock, J., Mac Seing, M., Munyanukato, N., Myezwa, H., & Retis, C. (2011). Rehabilitation: A crucial component in the future of HIV care and support. *Southern African Journal of HIV Medicine*, *12*(2), 12 14.

Nixon, S. A., Cameron, C., Hanass Hancock, J., Simwaba, P., Solomon, P. E., Bond, V. A., … Zack, E. (2014). Perceptions of HIV related health services in Zambia for people with disabilities who are HIV positive. *Journal of the International AIDS Society*, *17*(1), 18806. http://dx.doi.org/10.7448/IAS.17.1.18806

O'Brien, K., Nixon, S., Tynan, A., & Glazier, R. (2010). Aerobic exercise interventions for adults living with HIV/AIDS. *Cochrane Database Systemic Review*(8), CD001796. http://dx.doi.org/10.1002/14651858.CD001796.pub3

O'Brien, K., Tynan, A. M., Nixon, S., & Glazier, R. H. (2008). Effects of progressive resistive exercise in adults living with HIV/AIDS: Systematic review and meta analysis of randomized trials. *AIDS Care*, *20*(6), 631 653. http://dx.doi.org/10.1080/09540120701661708

O'Connell, K. A., & Skevington, S. M. (2012). An international quality of life instrument to assess wellbeing in adults who are HIV positive: A short form of the WHOQOL HIV (31 items). *AIDS and Behavior*, *16*(2), 452 460. http://dx.doi.org/10.1007/s10461 010 9863 0

Outpatient Service Trialists. (2009). Therapy based rehabilitation services for stroke patients at home (Review). *Cochrane Database of Systematic Reviews*(1), CD002925.

Peltzer, K., & Phaswana Mafuya, N. (2008). Health related quality of life in a sample of HIV infected South Africans. *African Journal of AIDS Research*, *7*(2), 209 218. http://dx.doi.org/10.2989/AJAR.2008.7.2.6.523

Petersen, I., Hanass Hancock, J., Bhana, A., & Govender, K. (2014). A group based counselling intervention for depression comorbid with HIV/AIDS using a task shifting approach in South Africa: A randomized controlled pilot study. *Journal of Affective Disorders*, *158*, 78 84. http://dx.doi.org/10.1016/j.jad.2014.02.013

Powell, J., Heslin, J., & Greenwood, R. (2002). Community based rehabilitation after severe traumatic brain injury: A randomised controlled trial. *Journal of Neurology, Neurosurgery & Psychiatry*, *72*(2), 193 202. http://dx.doi.org/10.1136/jnnp.72.2.193

Pradella, C. O., Belmonte, G. M., Maia, M. N., Delgado, C. S., Luise, A. P. T., Nascimento, O. A., … Jardim, J. R. (2015). Home based pulmonary rehabilitation for subjects with COPD: A randomized study. *Respiratory Care*, *60*(4), 526 532. http://dx.doi.org/10.4187/respcare.02994

Pullen, S. D., Chigbo, N. N., Nwigwe, E. C., Chukwuka, C. J., Amah, C. C., & Idu, S. C. (2014). Physiotherapy intervention as a complementary treatment for people living with HIV/AIDS. *HIV/AIDS Research and Palliative Care*, *6*, 99 107. http://dx.doi.org/10.2147/HIV.S62121

Resqueti, V. R., Gorostiza, A., Gladis, J. B., de Santa María, E. L., Clarà, P. C., & Rous, R. G. (2007). Benefits of a home based pulmonary rehabilitation program for patients with severe chronic obstructive pulmonary disease. (English Edition). *Archivos de Bronconeumología*, *43*(11), 599 604. http://dx.doi.org/10.1016/S1579 2129(07)60136 0

Roos, R., Myezwa, H., van Aswegen, H., & Musenge, E. (2014). Effects of an education and home based pedometer walking program on ischemic heart disease risk factors in people infected with HIV: A randomized trial. *Journal of Acquired Immune Deficiency Syndromes*, *67*(3), 268 276. http://dx.doi.org/10.1097/QAI.0000000000000299

Shisana, O., Rehle, T., Simbayi, L. C., Onoya, D., Jooste, S., Zungu, N., & Zuma, K. (2014). *South African national HIV prevalence, incidence and behaviour survey, 2012*. Retrieved from http://www.hsrc.ac.za/en/research outputs/view/6871

Stringer, W. W., Berezovskaya, M., O'Brien, W. A., Beck, C. K., & Casaburi, R. (1998). The effect of exercise training on aerobic fitness, immune indices, and quality of life in HIV+ patients. *Medicine & Science in Sports & Exercise*, *30*(1), 11 16.

Üstün, T. B., Chatterji, S., Kostanjsek, N., Rehm, J., Kennedy, C., Epping Jordan, J., … Pull, C. (2010). Developing the World Health Organization disability assessment schedule 2.0. *Bulletin of the World Health Organization*, *88*(11), 815 823. http://dx.doi.org/10.2471/BLT.09.067231

Van As, M., Myezwa, H., Stewart, A., Maleka, D., & Musenge, E. (2009). The International Classification of Function Disability and Health (ICF) in adults visiting the HIV outpatient clinic at a regional hospital in Johannesburg, South Africa. *AIDS Care*, *21*(1), 50 58. http://dx.doi.org/10.1080/09540120802068829

Wellek, S., & Blettner, M. (2012). On the proper use of the crossover design in clinical trials. *Deutsches Arzteblatt Intern*, *109*, 276 281.

World Health Organization. (2004). *The World Health Organization Quality of Life (WHOQOL) BREF*. Retrieved from http://www.who.int/substance abuse/research tools/en/english whoqol.pdf

World Health Organization. (2009). *WHO Disability Assessment Schedule 2.0 (WHODAS 2.0)*. Retrieved from http://www.who.int/classifications/icf/whodasii/en/

World Health Organization. (2011). *World report on disability*. Retrieved from http://www.who.int/disabilities/world report/2011/report.pdf

Zachariah, R., Ford, N., Philips, M., Lynch, S., Massaquoi, M., Janssens, V., & Harries, A. D. (2009). Task shifting in HIV/AIDS: Opportunities, challenges and proposed actions for sub Saharan Africa. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, *103*(6), 549 558. http://dx.doi.org/10.1016/j.trstmh.2008.09.019

CHAPTER 5: RESEARCH ASSISTANTS' EXPERIENCES

There are no facts, only interpretations.
Friedrich *Nietzsche* (1844-1900)

5.1. Summary

This qualitative paper explored the experiences of the four community healthcare workers who were involved in the HBR intervention described in Chapters 3 and 4. Analysis of semi-structured interviews revealed four overarching themes namely; enablers, inhibitors, participants' feelings of empowerment and recommendations for future interventions. While participants felt empowered through their involvement in this trial, they highlighted a number of barriers to their work. The findings described in this paper further support the evidence from Chapter 4 that a task shifting approach can assist the successful implementation of HBR interventions for PLHIV. Appendix 13 outlines the training these individuals received, the information sheet and consent form they received prior to the interviews are shown in Appendix 14, while the interview schedule is presented in Appendix 15.

5.2. Publication details

Title	"Knowing I can be helpful makes me feel good inside, it makes me feel essential": community healthcare workers' experiences of conducting a home-based rehabilitation intervention for people living with HIV in KwaZulu-Natal, South Africa
Authors	Saul Cobbing, Verusia Chetty, Jill Hanass-Hancock and Hellen Myezwa
Journal	Aids Care
Year	2017
Volume	Accepted for publication
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5.3. Journal details

AIDS Care is a peer-reviewed ISI-listed journal that provides an authoritative forum for publishing critical, cutting edge and state of the art research, reviews and reports from the many complementary disciplines involved in the AIDS and HIV field in one key source. This journal reaches a number of disciplines including psychology, sociology, epidemiology, social work and anthropology, social aspects of medicine, nursing, education, health education, law, administration and counselling (including various approaches such as cognitive behavioural therapy (CBT), psychotherapy and family therapy). AIDS Care provides resources for planning of services, prevention and psychosocial aspects of care and treatment. HIV and AIDS affects many echelons of society ranging from individuals, couples and families through to institutions and communities. A particular aim is to publish work emanating from many centers and in so doing address the global impact of AIDS. AIDS Care has an impact factor of 1.902 (as at October 2016).

5.4. Publication timeline

The first draft of this article was submitted to AIDS Care on the 13 April 2016. The reviewers replied with comments and minor revisions on the 12 October 2016. These revisions were made and the manuscript was re-submitted on the 22 October. The final article was accepted, pending minor corrections, in November 2016. The revised article was published on-line on 13 February 2017.

5.5. Contribution details

The candidate conceptualised, developed and wrote the paper. Dr Verusia Chetty conducted the interviews of the research participants, in the presence of an isiZulu-speaking translator, and further assisted with the coding and analysis of the transcribed data. Professor Myezwa, Professor Hanass-Hancock and Dr Chetty were all involved in editing the draft manuscript.

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"Knowing I can be helpful makes me feel good inside, it makes me feel essential": community health care workers' experiences of conducting a home-based rehabilitation intervention for people living with HIV in KwaZulu-Natal, South Africa

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ABSTRACT
People living with HIV (PLHIV) are living longer lives on antiretroviral therapy and are prone to a wide range of disabilities. Innovative strategies are required to meet the rehabilitation needs of PLHIV, particularly in resource-poor communities where HIV is endemic and access to institution-based rehabilitation is limited. Home-based rehabilitation (HBR) is one such approach, but there is a paucity of research related to HBR programmes for PLHIV or the experiences of community care workers (CCWs) involved in these programmes. Following a four month randomised controlled trial of a HBR intervention designed specifically for PLHIV in KwaZulu-Natal, South Africa; four CCWs were interviewed. This study employed a qualitative research design, using semi-structured interviews to explore these workers' experiences of being involved in carrying out this intervention. Participants reported how their personal development, improvement in their own health and increased feelings of self-worth enabled them to successfully implement the intervention. Participants also described a number of inhibitors, including stigma and environmental challenges related to the distances between patients' homes, the steep terrain and the hot climate. Despite this, the participants felt empowered by acquiring knowledge and skills that enabled them to shift roles beyond rehabilitation provision. The findings of this study should be considered when employing a task shifting approach in the development and implementation of HBR interventions for PLHIV. By employing a less specialised cadre of community workers to conduct basic HBR interventions, both the relative lack of qualified rehabilitation professionals and the high levels of disability in HIV-epidemic communities can be simultaneously addressed.

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HIV; home based rehabilitation; community care worker; task shifting

Introduction

While PLHIV are living longer lives on antiretroviral therapy (ART), they are prone to chronic disabling conditions, which affect physical and cognitive function (Banks, Zuurmond, Ferrand, & Kuper, 2015; Hanass-Hancock, 2009). There remains a dearth of literature on home-based rehabilitation interventions (HBR) for PLHIV, particularly in sub-Saharan Africa (Cobbing, Hanass-Hancock, & Myezwa, 2016a). While HBR can provide a more accessible rehabilitation option for PLHIV, it has also been argued that community care workers (CCWs) can be trained to conduct basic rehabilitation with patients' in their homes (Chappell & Johannsmeier, 2009; Rule et al., 2006). This task shifting approach has been shown to be beneficial in the delivery of other HIV services such as ART roll-out (Emdin & Millson, 2012; Iwu & Holzemer, 2014) and psychological counselling (Petersen, Hanass Hancock, Bhana, & Govender, 2014). There is no published evidence, however, of CCWs involvement in HBR programmes designed for PLHIV in sub-Saharan Africa. In order for the findings of community-based research to be implemented into practice, Harris (2006) proposes that the voices of individuals other than the researchers be considered. This study aimed to describe the experiences of CCWs when working as rehabilitation assistants in a randomised controlled trial investigating the effects of a four month HBR intervention on adult PLHIV.

Methods

Data collection and analysis

This study employed a qualitative design. Participants were individually interviewed using a semi-structured guide, allowing reflexive communication between interviewer and interviewee (Louise Barriball & While,

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1994). All interviews were conducted in a private room in the physiotherapy department of a public hospital in a semi-rural district of KwaZulu-Natal (KZN) province, South Africa, an area where up to a third of the population are infected with HIV. The questions interrogated the participants' experiences of being involved in the HBR study. The interviews were conducted in IsiZulu with a translator present. The interviewer and translator were not previously known to the participants.

The interviews were recorded using a Dictaphone and thematic content analysis (Hsieh and Shannon, 2005) was employed to identify common themes emerging from the transcribed data. The participants' responses were coded to ensure anonymity. Member checking which involved verification of findings by participants was also deemed critical to maintain rigour in this study (Creswell & Miller, 2000). To improve the trustworthiness of the findings, two individuals experienced in qualitative methodology analysed the interview data independently before meeting together to identify key themes.

Participant demographics

The four participants were CCWs who were trained to conduct a four month HBR intervention for adult PLHIV (Cobbing, Hanass-Hancock, & Myezwa, 2016b). All participants were isiZulu-speaking women, aged between 38 and 49 years, living within ten kilometres of the study hospital. The participants were selected from a group of CCWs who worked at a local NGO, following interviews which assessed their interest in rehabilitation and the specific area where they lived. They each volunteered for the NGO, working between 20 and 30 hours each week. While they reported great personal satisfaction from helping members of their community, they all expressed a hope that their volunteer work would ultimately translate to paid work. Pseudonyms have been given to the participants to ensure their anonymity. At the time of the interviews, Thembi was 45, had two children and had volunteered for 15 years at the local NGO. Nolwazi was 49, had three children and had also volunteered for 15 years. Hlengiwe was 38, had no children and had volunteered for eight years. Thobeka was 41, had two children and had volunteered for 10 years. None of the participants had post-school qualifications. Funding was secured to pay the participants for the duration of the HBR intervention, but ordinarily they receive no stipends for their NGO work. They worked in pairs during the intervention, with each pair being responsible for 19 study participants. Their duties primarily involved teaching and supervising strength, aerobic and functional exercises.

Study themes

The study themes, sub-themes and pertinent quotes are displayed in Table 1.

Discussion

Enablers

Participants described how working on the HBR intervention developed their communication ability as well as learn technical skills, such as adjusting walking aids to the correct size for patients. This, in turn, resulted in them passing on this knowledge to patients and colleagues. The improved self-worth and personal health benefits they reported further enabled them to provide HBR services to PLHIV. By shifting tasks to less specialised workers, more patients can be cared for and more efficient use can be made of qualified personnel (World Health Organisation, 2007). Chappell and Johannsmeier (2009) found, in a South African context, that mid-level CCWs had a positive impact on people with a wide range of disabilities. As the link between HIV and disability has been clearly established (Banks et al., 2015; Hanass-Hancock, Regondi, & Nixon, 2013), it stands to reason that trained CCWs could assist with the functional deficits often experienced by PLHIV. Rule et al. (2006) has called for greater collaboration between professional therapists, academics and community members in the implementation of effective community-based rehabilitation (CBR) projects in South Africa. This study has demonstrated both the effectiveness and willingness of these CCWs to be involved in collaborations of this nature.

Inhibitors

Participants also described a number of challenges in carrying out the HBR intervention, including difficulties related to the environment in which they had to work. The distances between patients' homes were often far and difficult to reach due to steep terrain. Participants also reported challenges with extreme heat, despite the intervention being conducted during autumn and winter. Participants reflected on the length of the intervention, suggesting that it ended just as they were starting to see positive effects on the patients. Participants also reported stigma as a common concern, with patients worried that the home visits could unintentionally reveal their HIV status. In an earlier qualitative study in South Africa, PLHIV felt that their community would be ashamed of them and would blame them for contracting HIV (Visser, Makin, & Lehobye, 2006). The participants in this study reported similar fears a decade later.

Table 1. Themes, sub-themes and quotes arising from data analysis.

Sub theme	Quotes
Enablers	
Personal development	*"This project has really improved my communication skills." Hlengiwe*
	"I don't do massages only now. I do more due to the skills acquired here." Thobeka
	"I have developed a passion to help the sick." Thembi
	"I now also help other community care workers who are based in my area with advice related to rehabilitation." Thobeka
Health benefits	*"I also started losing weight due to the exercises." Thembi*
	"Even us as staff, we felt our mental health improving." Nolwazi
	"I lost weight and I am feeling so good, it compelled me to start jogging again." Thobeka
Improved self worth	*"Seeing a patient happy and ready when I arrived made me feel so happy." Thobeka*
	"It felt like I brought hope to their predicament." Nolwazi
	"Knowing I can be helpful it makes me feel good inside (laughing) it makes me feel essential." Thobeka
Inhibitors	
Environmental	*"We walked long distances and it was steep." Thobeka*
	"I wondered how the patient got to hospital as the area was so remote." Thembi
	"The weather itself made more it more difficult as it was boiling hot." Thobeka
	"Another challenge I faced was when five dogs attacked me. One of them bit me I had to get medical attention." Thembi
Study length	*"I'm concerned over the fact that the patients are longer receiving help since the project has come to an end." Thembi*
	"My main concern is about follow up now that the project has ended." Hlengiwe
	"People need motivation and now that the project has ended, I wonder if they will all continue to do their exercises." Thobeka
Stigma	*"Most of them know me as we reside on the area so they were afraid I may divulge their secrets to the wrong people." Hlengiwe*
	"I make certain no patient name is divulged or mentioned in order to protect their confidentiality." Thobeka
	"Stigma is big because even amongst us the community workers we won't share our status because we are afraid of what our colleagues will think. If we can't share I don't know how patients will want to share?" Hlengiwe
Empowerment	
Education	*"I learnt that a patient being in a wheelchair doesn't make them disabled forever." Thembi*
	"It was mutual benefit for the patient and us." Nolwazi
	"What I learned from them is growing veggies at home. Now I know growing veggies saves money and it is healthy." Hlengiwe
Shifting roles	*"I eventually became more like a counsellor." Thembi*
	"I provided a patient with seeds, she used it to grow vegetables." Nolwazi
	"Then we would call water guys to come and sort out the water problem." Hlengiwe
	"A lady was abused by a man, I referred her to the social worker." Thobeka
Peer support	*"We would talk about our experiences to release the stress of having to listen to emotional accounts from our patients." Nolwazi*
	"We would share experiences with each other and encourage each other." Hlengiwe

Integrating the rehabilitation of PLHIV into the wider care of people with other chronic diseases, may be one way of addressing this HIV-related stigma, removing the focus on an individual's HIV status. Indeed, recognition of HIV as a chronic disease and its integration with broader services has been proposed as a means of "jumpstarting" ailing health care systems, thereby improving the care available for individuals living with other conditions (Rabkin & El-Sadr, 2011). Participants further raised concerns about hunger among their patients, making it very difficult for them to exercise. The participants suggested that providing food for patients would improve rehabilitation outcomes. This is supported by research stating that adequate nutrition is crucial in ensuring PLHIVs' overall health (Leyes, Martínez, & Forga, 2008) and adherence to ART (Au et al., 2006). Resources, however, cost money and thus it is crucial that economic studies should accompany intervention studies in order to establish their cost-effectiveness, (Lewin et al., 2005).

Empowerment

Despite these challenges, participants felt empowered by their involvement in this intervention. They recounted how their own knowledge related to rehabilitation and definitions of disability had improved as well as how they had learnt other skills from the patients, such as tips on growing vegetables. These accounts are mirrored by the enhanced learning and feelings of personal satisfaction reported by staff working with PLHIV in Canada (Olivier & Dykeman, 2003). Through broadening their knowledge, participants in this study attained the confidence to shift roles beyond providing rehabilitation services. These added roles included counselling patients, referring them to social services and advocating for their broader rights, in one instance ensuring that water services were resumed to the area. These wider roles and responsibilities are consistent with the philosophies espoused by global CBR guidelines, which call on health workers to look beyond physical deficits to ensure that patients are able to fully participate in community life (World Health Organisation, 2010). This can help ensure that communities receive services broader than therapy alone (Rule et al., 2006). The participants in this study were also able to rely on each other for support. This is crucial in an environment where workers are often overwhelmed by the burden of caring for PLHIV (Horsman & Sheeran, 1995) and suggests a need for ongoing support for these community workers. Despite the crucial role lay CCWs play in the functioning of the public health care system, they continue to be excluded from secure paid employment and training opportunities (Schneider & Lehmann, 2010). Well-designed studies that employ quantitative and qualitative methods will allow researchers to better evaluate the significant time and costs borne by these unpaid (predominantly female) workers (Akintola, 2008). This will contribute to strengthening advocacy efforts that ensure that these workers are fairly remunerated and further upskilled, which will in turn address the high burden of disability in HIV-endemic communities.

Conclusion

Meeting the multi-faceted rehabilitation needs of PLHIV in Africa will require innovative evidence-based interventions. CCWs in this study reported that their involvement in a HBR intervention equipped them with the necessary skills to make a significant difference to the lives of PLHIV. They also highlighted a number of barriers that impacted upon the full effective implementation of the intervention, including environmental and resource-related challenges. The design of contextualised training programmes, in collaboration with community members, should focus on developing a new cadre of CCWs who can effectively manage the functional limitations of PLHIV and people living with other chronic diseases. Researchers can contribute to this process by investigating the efficacy and cost-benefit of novel task shifting rehabilitative interventions. These measures can assist in improving the lives of PLHIV as well as facilitate the effective use of resources in countries where HIV is endemic.

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Disclosure statement

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References

Akintola, O. (2008). Unpaid HIV/AIDS care in Southern Africa: Forms, context, and implications. *Feminist Economics*, *14*, 117 147.

Au, J. T., Kayitenkore, K., Shutes, E., Karita, E., Peters, P. J., Tichacek, A., & Allen, S. A. (2006). Access to adequate nutrition is a major potential obstacle to antiretroviral adherence among HIV infected individuals in Rwanda. *AIDS*, *20*, 2116 2118.

Banks, L. M., Zuurmond, M., Ferrand, R., & Kuper, H. (2015). The relationship between HIV and prevalence of disabilities in sub Saharan Africa: Systematic review (FA). *Tropical Medicine & International Health*, *20*, 411 429. doi:10.1111/tmi.12449

Chappell, P., & Johannsmeier, C. (2009). The impact of community based rehabilitation as implemented by community rehabilitation facilitators on people with disabilities, their families and communities within South Africa. *Disability and Rehabilitation*, *31*, 7 13. doi:10.1080/09638280802280429

Cobbing, S., Hanass Hancock, J., & Myezwa, H. (2016a). Home based rehabilitation interventions for adults living with HIV: A scoping review. *African Journal of AIDS Research*, *15*, 77 88.

Cobbing, S., Hanass Hancock, J., & Myezwa, H. (2016b). A home based rehabilitation intervention for adults living with HIV: A randomized controlled trial. *Journal of the Association of Nurses in AIDS Care*.

Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory Into Practice*, *39*, 124 130.

Emdin, C. A., & Millson, P. (2012). A systematic review evaluating the impact of task shifting on access to antiretroviral therapy in sub Saharan Africa. *African Health Sciences*, *12*, 318 324. doi:10.4314/ahs.v12i3.11

Hanass Hancock, J. (2009). Disability and HIV/AIDS a systematic review of literature on Africa. *Journal of the International AIDS Society*, *2*, 9. doi:10.1186/1758 2652 12 34

Hanass Hancock, J., Regondi, I., & Nixon, S. (2013). HIV related disability in HIV hyper endemic countries: A scoping review. *World Journal of AIDS*, *3*, 257 279.

Harris, G. E. (2006). Practicing HIV/AIDS community based research. *AIDS Care*, *18*, 731 738.

Horsman, J. M., & Sheeran, P. (1995). Health care workers and HIV/AIDS: A critical review of the literature. *Social Science & Medicine*, *41*, 1535 1567.

Iwu, E. N., & Holzemer, W. L. (2014). Task shifting of HIV management from doctors to nurses in Africa: Clinical outcomes and evidence on nurse self efficacy and job satisfaction. *AIDS Care*, *26*, 42 52.

Lewin, S. A., Dick, J., Pond, P., Zwarenstein, M., Aja, G., Van Wyk, B., … Patrick, M. (2005). Lay health workers in primary and community health care. *The Cochrane Database of Systematic Reviews*, *1*, CD004015.

Leyes, P., Martínez, E., & Forga, M. d. e. T. (2008). Use of diet, nutritional supplements and exercise in HIV infected patients receiving combination antiretroviral therapies: A systematic review. *Antiviral Therapy*, *13*, 149 159.

Louise Barriball, K., & While, A. (1994). Collecting data using a semi structured interview: A discussion paper. *Journal of Advanced Nursing*, *19*, 328 335.

Olivier, C., & Dykeman, M. (2003). Challenges to HIV service provision: The commonalities for nurses and social workers. *AIDS Care*, *15*, 649 663. doi:10.1080/0954012031000159 5131

Petersen, I., Hanass Hancock, J., Bhana, A., & Govender, K. (2014). A group based counselling intervention for depression comorbid with HIV/AIDS using a task shifting approach in South Africa: A randomized controlled pilot study. *Journal of Affective Disorders*, *158*, 78 84. doi:10.1016/j.jad 2014.02.013

Rabkin, M., & El Sadr, W. M. (2011). Why reinvent the wheel? Leveraging the lessons of HIV scale up to confront non communicable diseases. *Global Public Health*, *6*, 247 256.

Rule, S., Lorenzo, T., Wolmarans, M., Watermeyer, B., Swartz, L., Lorenzo, T., … Priestley, M. (2006). Community based rehabilitation: New challenges. *Disability and Social Change: A South African Agenda*, 273 290.

Schneider, H., & Lehmann, U. (2010). Lay health workers and HIV programmes: Implications for health systems. *AIDS Care*, *22*, 60 67.

Visser, M. J., Makin, J. D., & Lehobye, K. (2006). Stigmatizing attitudes of the community towards people living with HIV/AIDS. *Journal of Community & Applied Social Psychology*, *16*, 42 58. doi:10.1002/casp.836

World Health Organisation. (2007). *Task shifting: Rational redistribution of tasks among health workforce teams: Global recommendations and guidelines*.

World Health Organisation. (2010). *Community based rehabilitation: CBR Guidelines* [WWW Document]. Geneva: Author. Retrieved from http://www.who.int/disabilities/cbr/guidelines/en/

CHAPTER 6: STUDY SYNTHESIS WITH MODEL OF CARE

> *Without a rational public discussion about science, about poverty, about medicine, we cannot advance and do the real work that lies ahead for us in the communities of Stanger, Mariannhill, in the communities around Durban, around KZN and throughout the country.*
>
> Zackie Achmat (co-founder of the Treatment Action Campaign)

6.1. Summary

The final paper included in this PhD study presents a synthesis of the overall findings of the doctoral research in specific relation to a model of care for the rehabilitation of people living with HIV developed in the same study setting. It describes the fundamental principles of this model that the PhD study did address as well as the elements of the model that need further consideration and investigation, in order to ensure that effective and accessible rehabilitation interventions are included in the wider care of PLHIV in resource-poor settings.

6.2. Publication details

Title	Assessing home-based rehabilitation within the development of an integrated model of care for people living with HIV in a resource-poor community
Authors	Saul Cobbing, Jill Hanass-Hancock and Hellen Myezwa
Journal	African Journal of Primary Health Care & Family Medicine
Year	2017
Volume	Under review
Pages	Pending
DOI number	Pending

6.3. Journal details

The African Journal of Primary Health Care & Family Medicine is a peer-reviewed, Department of Higher Education and Training (DHET) approved, open-access journal that encourages scholarly exchange between primary health care researchers and practitioners across Africa and the developing world, whilst providing a contextual and holistic view of family medicine as practised across the continent. The journal is indispensable for primary health care practitioners, family medicine specialists and academics from both the developing and developed worlds, and offers an engaging insight into the growth of these disciplines from a distinctly African and developing world perspective. It seeks to publish innovative research and clinical reviews in all aspects of primary health care and family medicine in the African and developing world context. It has an impact factor of 0.550 (as at October 2016).

6.4. Publication timeline

The first draft of this article was submitted to the African Journal of Primary Health Care & Family Medicine on the 5 November 2016. The journal e-mailed proof of submission on the same day. Reviewers' and editorial comments were received on 27 January 2017. Major revisions were made to the original manuscript and resubmitted to the journal on 23 February 2017.

6.5. Contribution details

The candidate conceptualised, developed and wrote the paper. Professors Myezwa and Hanass-Hancock advised the candidate on the outline and central question of this paper and provided considerable assistance with the editing of the draft manuscript.

Assessing home-based rehabilitation within the development of an integrated model of care for people living with HIV in a resource-poor community

Abstract

Background: People living with HIV (PLHIV) are living longer lives but are at a greater risk of developing disability. South Africa has the largest antiretroviral treatment (ART) programme in the world, shifting HIV from a deadly to a chronic disease. The integration of rehabilitation into chronic care is therefore now crucial to ensure the highest quality of life of PLHIV. **Aim:** To describe how a home-based rehabilitation (HBR) programme adhered to the fundamental principles of a theoretical model of integrated care developed for the study setting in KwaZulu-Natal, South Africa. **Method:** The process and results from the HBR programme were assessed in relation to the model of care to ascertain which principles of the model were addressed with the HBR programme and which elements require further investigation. **Results:** The HBR programme was able to apply a number of principals such as evidence-based practice, task shifting to lay personnel, enabling patient-centered care and maximizing function and independence of PLHIV. Other elements such as the adoption of a multidisciplinary approach, training on the use of disability screening tools and the use of evidence to influence policy development were more difficult to implement. **Conclusion:** It is possible to implement elements of the integrated model of care. Further research is needed to understand how principles, which require further training and collaboration with other stakeholders, can be implemented. The results of this study provides additional evidence towards understanding the feasibility of the theoretical model and what is required to adjust and test the full model.

Background

Following more than a decade of activism by human rights' and civil society organisations (1), 3.4 million people living with HIV (PLHIV) in South Africa have thus far gained access to the largest antiretroviral therapy (ART) programme in the world. The population currently on ART constitutes approximately half of the total number of PLHIV in South Africa (2). Even greater access to ART will be achieved by the recent removal of CD4 criteria from South African ART treatment guidelines (3) which further re-emphasises the approach of universal access to ART. This policy is also promoted thorough the ambitious UNAIDS 90-90-90 targets (4) and the new World Health Organisation (WHO) guidelines on antiretroviral treatment (5). However, activists, healthcare workers (HCWs) and scientists in South Africa are now shifting their attention beyond access to treatment towards increased access to a continuum of care that ensures quality of life for all (6). Lazurus et al (2016) proposes a "fourth 90" target, which should aim to ensure that 90% of PLHIV with viral suppression to have a good health-related quality of life (7) while Hanass-Hancock et al (2016) call for 100% of services for PLHIV to be able to link to mitigating services like rehabilitation (8).

Enhancing the quality of life of PLHIV requires, among other interventions, the integration of rehabilitation in the continuum of care, an aspect of care that has often been neglected in the emergency-type of response to HIV. Improved access to ART has resulted in PLHIV living longer lives but this comes with new health challenges related to chronicity (9,10) and an increased risk of developing physical and cognitive disabilities (11). Recent WHO guidelines (5) recognise this development, calling for the integration of rehabilitation into the continuum of care for PLHIV. In South Africa, Goal 1 of the Framework and Strategy on Disability and Rehabilitation Services (12) explicitly mentions integrating rehabilitation and disability services into priority health programmes, which include HIV care. This framework is supported by the National Strategic Plan for STIs, HIV and TB (13), which focuses on the reduction of disability resulting from HIV and TB (objective 3). The proposed National Health Insurance (14) further promotes the rights of all South Africans to access quality healthcare services that "are affordable without exposing them to financial hardships". Healthcare providers working in South Africa are compelled, by the recently published White Paper on the Rights of Persons with Disabilities (15), to ensure that all HIV programmes are accessible to persons with disabilities. These documents all promote the integration of accessible disability and rehabilitation services into the HIV care. They do not describe, however, how these services can be integrated nor which rehabilitation services may be feasible to address some of the barriers that PLHIV face in accessing holistic health care. The challenge therefore has emerged to understand what kind of model of care can link chronic care and rehabilitation and which rehabilitative approaches are effective and feasible for such a model of care in resource poor settings.

In response to this challenge, a team of South African-based researchers at the University of KwaZulu-Natal and the University of the Witwatersrand developed a larger research project that attempted to describe the needs of rehabilitation for PLHIV and understand which model of care would best integrate chronic HIV and rehabilitation services. The project (with all its sub-studies) was located in in a semi-rural resource-poor area of KwaZulu-Natal province, South Africa. The larger project included an exploratory study (16) a longitudinal cohort-study (11,17), the development of a theoretical model of integrated care (18,19) and a training approach for healthcare workers (20). The theoretical model of care included a thorough review of international rehabilitation policies and consensus with a wide range of key local stakeholders and experts. The need for this new model was driven by the fact that a large number of PLHIV in this area experience functional limitations (11) while they were experiencing obstacles in accessing institutional-based rehabilitation, including physical challenges, high costs and accessibility of healthcare and supporting services (16). The theoretical model (henceforth referred to as the Chetty model) promotes greater collaboration between hospitals and communities. It also supports alternative approaches such as task shifting, a strategy that aims to train community care workers (CCWs) to deliver varied health services to PLHIV experiencing disability. The studies that were located at the project location and contributed to the development of the Chetty model are summarised in Table 1. Figure 1 depicts the Chetty model. It illustrates that the rehabilitation of PLHIV in their own home is seen as central to the implementation of the model. The aim of this paper is to describe how a home-based rehabilitation (HBR) programme designed for PLHIV in this study community adhered to the fundamental principles of the Chetty Model. This HBR intervention was the first attempt to test part of this model in practise.

TABLE 1: Studies contributing to the development of the Chetty model

Author (year)	Objective	Method	Participants	Key outcomes
Cobbing et al (2014) (21)	To describe the experiences of PLHIV who received hospital-based physiotherapy with the aim of informing future rehabilitation interventions	Qualitative (semi-structured interviews)	Adult PLHIV	Hospital-based physiotherapy rehabilitation provides a number of barriers to patients
Hanass-Hancock et al (2014) (20)	To sensitise healthcare workers and people with disabilities on the inter-relationship of HIV and disability	Quantitative (short checklist) and qualitative (semi-structured interviews)	Healthcare workers and people with disabilities	Training presented opportunities to improve services for people with disabilities and also provided knowledge and skills to initiate improvements
Chetty et al (2014) (22)	To develop a model of care for the rehabilitation of PLHIV in a semi-rural African setting	Mixed methods using a Learning in Action Approach and Delphi technique.	Local HIV experts, multidisciplinary health care team, department of health representatives; non-governmental organization representative and service users at the study setting	Design paper (no outcomes)
Chetty et al (2015) (23)	To provide an overview of current models of rehabilitative care and examine how these can inform the inclusion of rehabilitation into a model of care for PLHIV within a public health care South African framework	Review paper	None	The need to develop a model to guide rehabilitation of people living with HIV in South Africa, involving multiple stakeholders, is essential to address the cumulative disabling effects of the virus and its treatment.

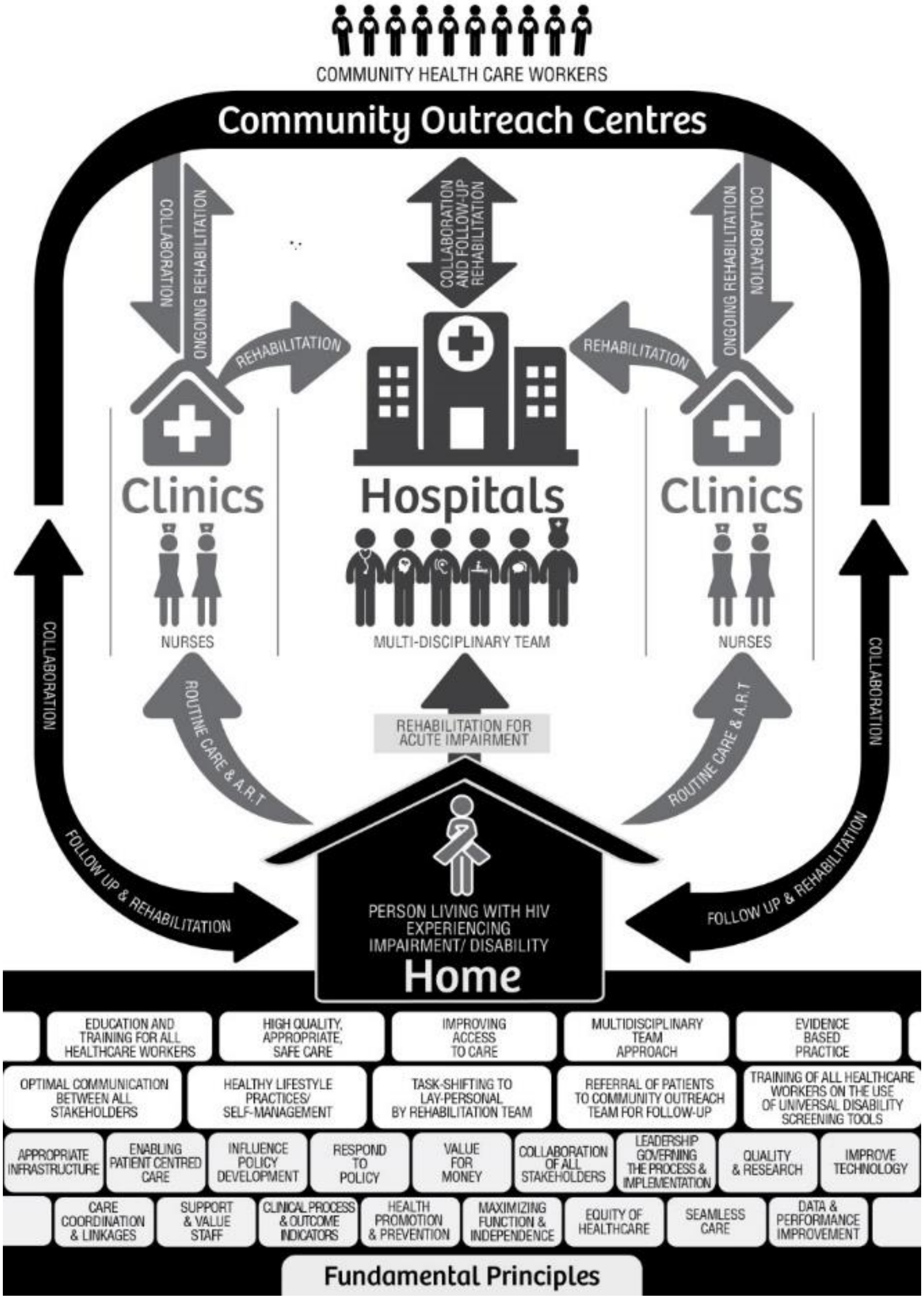

FIGURE 1: Model of care for the rehabilitation of PLHIV in a semi-rural South African setting

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Sources of evidence informing the scope of this paper

This theoretical paper is the fifth and concluding article in a series of papers contributing to a doctoral study focusing on HBR for PLHIV. This study was situated in the same resource-poor community in which the Chetty model was developed. The study aimed to design an HBR intervention for adult PLHIV as a pathway to comprehensive care and to determine the effect of this intervention on PLHIVs' perceived disability, quality of life, functional mobility and capacity. The study process included four distinct steps: a scoping review of available literature (24), a description of the study methodology (25), and the presentation of both quantitative and qualitative study results (26,27). Table 2 summarises the four papers that were undertaken as part of the overarching doctoral study. This final paper, assesses to what extent the study was able to implement the principles of the Chetty model (18).

TABLE 2: Summary of study papers

Author (year)	**Objective**	**Method**	**Participants**	**Key outcomes**
Cobbing et al (2016) (24)	To summarise the evidence related to the effectiveness of HBR interventions designed specifically for adult PLHIV	Scoping review method	None (scoping review)	A small number of paper (six) suggest that six articles are that HBR is a safe management option that may confer a number of physical and psychological benefits for adult PLHIV
Cobbing et al (2015) (25)	To describe the design of a novel HBR intervention for adult PLHIV in a resource-poor South African setting	Design paper	None (design paper)	Design paper (no outcomes)
Cobbing et al (2016) (26)	To investigate the effects of a 16-week HBR intervention on the quality of life, functional mobility, and functional capacity of adult PLHIV in KwaZulu-Natal, South Africa	Single-blinded randomized controlled trial design	Adult PLHIV with mobility limitations	HBR for PLHIV is a safe means of addressing the functional deficits experienced by PLHIV and appears likely to improve quality of life
Cobbing et al (2017) (27)	To explore CCWs' experiences of being involved in carrying out a HBR intervention for PLHIV	Qualitative (semi-structured interviews)	Community care workers	Participants described the factors that enabled them to successfully implement the intervention as well as a number of inhibitors

The systematic scoping of the existing literature revealed a paucity of evidence related to HBR interventions for PLHIV (24) with only six articles meeting the review's inclusion criteria. Synthesis of the evidence from this review and the practical experience of the lead author as a rehabilitation practitioner working with PLHIV, informed the design of the study intervention, outlined in detail in the methodological article (25). This design ensured that the study intervention would be of a high methodological quality (as required by the Chetty model), scoring 8 out of a possible 10 points on the PEDro scale, a tool employed to assess the quality of RCTs (Maher, 2003). The intervention study itself used an RCT design assigning people to either a HBR group or a group which received information material. The results indicate that HBR is a safe strategy for treating the functional limitations experienced by PLHIV and may further improve their quality of life (26). Collected data also showed through within-group changes, that the group receiving HBR (intervention group) improved more than the group receiving health information (control group) across all outcome measures. These results demonstrate the clinical significance of this HBR intervention for adult PLHIV, which can be defined as evidence that an intervention has a beneficial impact on individuals exposed to it, thus representing the ability to make a difference in their lives (28). Statistically, however, between-group differences were non-significant. Non-significance of results may have been due to the trial time (16-week intervention) not being long enough or the fact that participants in the intervention and control groups came from the same community, which may have enabled contamination. Furthermore, for ethical reasons, participants in the control group received health information on exercise and lifestyle, which may have explained the improvements in this group.

A task shifting approach was employed, in which four community care workers (CCWs) who lived in the study community received training from a qualified physiotherapist to enable them to implement this HBR programme (training is also a requirement of the Chetty model). This training, conducted over a four-week period, included theoretical instruction on research ethics, basic anatomy and HIV-related pathology, as well as practical skills including strength and aerobic exercise prescription. The experiences of the CCWs involvement in this programme are further described in a qualitative article (27). Participants reported feeling empowered by the knowledge and skills they attained through this study and gave valuable advice for improving future interventions in this field.

Methods

For the purposes of this paper, the authors use the Chetty model to assess if the intervention was able to apply the fundamental principles of the model. A comparison of the overall study in relation to the Chetty model was undertaken using a desk review to assess how the process and results of the study adhere to the fundamental principles of this model as well as to highlight areas that were not adequately addressed. The first author took the lead on this task, after which the two co-authors (who were research supervisors for this study and who are both widely-published experts in the fields of HIV and disability) analysed and revised this comparison where necessary. Table 3 indicates which of the principles of the Chetty model this study was able to implement and how each principle was addressed.

TABLE 3: Principles of Chetty model addressed by study

Principle	Implemented	Description	Not fully implemented	Description
Education training for all healthcare workers	✓	CCWs trained before and during intervention[20, 23]		
High quality, appropriate, safe care	✓	RCT shown to be safe and beneficial to intervention group[20]		
Improving access to care	✓	Participants received rehabilitation in their own homes[20]		
Multidisciplinary team approach			✓	Training/supervision of CCWs primarily by physiotherapist
Evidence-based practice	✓	Rigorous study design based on strong evidence base[22, 23]		
Optimal communication between stakeholders	✓	All stakeholders at research site informed of study progress before, during and after study[23]		
Healthy lifestyle practices/ self-management	✓	Participants taught self-management of health[20]		
Task shifting to lay personnel	✓	A central tenet of this study was the training of CCWs to implement intervention[20, 23, 24]		
Referral of patients to community outreach	✓	Participants referred to outreach (provided by the local NGO) when necessary[23]		
Training of HCWs on use of disability screening tools			✓	Participants screened for disability in previous cohort
Appropriate infrastructure	✓	Safe appropriate venue for pre- and post-intervention testing. Equipment provided when necessary to participants[20, 23]		
Enabling patient-centred care	✓	Close communication with participants and the provision of needs-based rehabilitation[20, 23]		

Influencing policy development			✓	This is yet to be fully achieved. The PHD student could not do this on his own, however his supervisor has used these study results to inform the new SA NSP.
Respond to policy	✓	CBR is central to both national and global policies[22]		
Value for money			✓	The cost-effectiveness of this intervention is being analysed (results are not available at present).
Collaboration of all stakeholders	✓	All stakeholders at the research site were consulted about the overall study design[23]		
Leadership governing process of implementation			✓	This is yet to be fully achieved. Broader implementation will be sought after further research has been conducted and policymakers have been engaged.
Quality and research	✓	High quality RCT (score of 8/10 on PEDRO scale) conducted and complemented by additional qualitative research methods[20, 24]		
Improve technology			✓	Communication was not optimal between CCWs and HBR participants, resulting in missed appointments and participants not attending testing.
Care coordination and linkages	✓	Participants referred to both local NGO and district hospital for further care when required[20]		
Support and value staff	✓	CCWs reported personal growth from their involvement in the study[24]		
Clinical process and outcome indicators	✓	Valid and reliable outcome measures were employed[20, 23]		
Health promotion and prevention	✓	Participants in both groups received information on healthy living[20, 23]		
Maximising function and independence	✓	This was the main focus of the specific rehabilitation provided to each participant[20]		
Equity of healthcare	✓	Participants received high quality free care in their own homes[20]		
Seamless care	✓	Participants referred for further care when required[20]		
Data and performance improvement	✓	Participant diaries utilized and extensive data collected on outcome measures pre- and post-intervention, as well as interviews of CCWs[20, 23, 24]		

The elements of the Chetty model that were implemented in this study included the training of healthcare workers, task shifting to lay workers, support of staff, improved access to safe patient-centred care, linkages to institutional care and community outreach, as well as a specific focus on maximising the function and independence of study participants. Furthermore, the HBR programme was based on a sound evidence-based information (24) and responded to relevant local and international policies related to community-based rehabilitation 29), primary health care (14,30) task shifting (31) and HIV management (5,12). The study process included a high quality, rigorous RCT research method, with the data obtained from valid and reliable outcome indicators. It is also important to acknowledge that the study could take advantage of the overall project which provided the path for the intervention being conducted in a setting where the researchers had worked for a number of years, where healthcare staff had been trained on the relationship between HIV and disability and were thus more receptive to alternative rehabilitation solutions.

Discussion

The assessment described above suggests that the development and implementation of the HBR programme adhered to the majority of the fundamental principles of the Chetty model. The fact that trained CCWs were able to safely implement the HBR intervention provides empirical support for a task shifting approach to the rehabilitation management of PLHIV. Task shifting has been defined as the reassignment of specific tasks to different cadres of HCWs (32) and has been proposed as a solution to the shortage of health professionals in South Africa (33). Indeed, it has been demonstrated in the same study location, that appropriately trained lay counsellors can effectively deliver group-based counselling for PLHIV with co-morbid depression (34). Similarly the Framework and Strategy on Disability and Rehabilitation Services in South Africa (12) promotes the rehabilitation of patients in their own homes and the training of CCWs to detect disability and refer appropriately. The participants recruited the HBR intervention in this study were selected from an existing cohort who had already been screened for potential mobility limitation (11). The CCWs working on the intervention were not trained to identify disability, however, and thus the study did not include a fundamental principle of the Chetty model of care, namely to train all workers on the use of disability screening tools. Hence, future research needs to identify simplified screening tools and ways to train healthcare staff at all levels to screen and identify functional limitations. The pilot workshops included in the overall project echo this analysis as they revealed that healthcare workers can address certain elements of disability-inclusive healthcare services (for example the creation of disability help desks) but that others elements of care such as screening for disability and referral to rehabilitation services needs more long term planning and innovation (20).

Another key principle of the Chetty model of care that could not be implemented in this study was the full adoption of a multidisciplinary team approach in the design and implementation of the HBR intervention. While the pre and post-intervention testing for the RCT assessed a broad range of outcome measures, assessing physical, spiritual and psychological factors, the intervention focused primarily on providing rehabilitation that addressed participants' physical and functional limitations, reflecting the background of the lead author, a qualified physiotherapist. The lead author also functioned as the supervising rehabilitation specialist, who conducted the training of the CCWs and supervised them throughout the 16-week programme. In order to better reflect a holistic and integrated approach of the Chetty model the research team need to develop innovations that will involve collaboration with the full cross-section of health professionals. Integration could for instance be facilitated through enhanced training which allow CCWs to employ simple screening tests that assess an individual's physical function, psychological state and social needs. A trained CCW could also provide counselling and facilitate referral to an appropriate professional. This screening could take place during routine clinic visits, at patients' homes or even in patient adherence clubs, where both screening and rehabilitation services could be provided.

The Chetty model of care also recommends that alternative rehabilitation interventions for PLHIV should represent good value for money for state and external funders. With a specific focus on HIV care in Africa, two separate reviews (32,35) concluded that task shifting will ensure cost-effectiveness and sustainability of interventions, without compromising patient care. Indeed, studies of HBR interventions for other chronic disease populations (36–38) have shown that these interventions are as cost-effective, if not more so, than traditional institution-based interventions. It is important, therefore, that research funds are allocated to measure the cost of novel rehabilitation interventions for PLHIV in comparison to current practice, in addition to assessing outcome measures of health, quality of life and function. A cost-benefit analysis of the HBR intervention implemented in this PhD study is currently being conducted, but no results were available at the time of writing. Where possible, all rehabilitation interventions that provide an alternative to the standard of care, should be assessed for cost-effectiveness, in order to enable policy-makers and stakeholders to assess the feasibility of taking up these approaches in the public sector. The Chetty model needs to be supported by more practical approaches on how to collect this kind of data efficiently.

Implementing the Chetty model should take advantage of existing initiatives for integrated community care and this is indeed a potential addition that could be made to the Chetty principles. For instance the South African Department of Health's have recently trialed ward-based outreach teams (WBOTs), comprising of six CCWs supervised by one nurse, to improve health promotion and disease prevention in resource-poor communities (39). While this initiative has shown some success, it has been argued that the role of the CCWs involved in this initiative is too narrow and their scope should be broadened to include curative functions (40). By including information on rehabilitation and disability assessment into the training of the CCW involved in these WBOTs, the rehabilitative options available to all people living with disability in under-resourced communities would be increased. The Chetty model could be implemented using such structures and, through doing this, benefit all people who have functional limitations or disabilities (not only those with HIV). This may potentially reduce the cost burden to the public health service in the longer term, by ensuring that these individuals do not develop more severe disabilities that incur high treatment costs.

Those principals which involved a larger component of stakeholders, access to technology or collaboration with policy makers where more difficult to implement within the doctoral study context. Some of those will be implemented however within the larger project and therefore further follow up and assessment of the implementation of the Chetty model over time in this context will be very beneficial to understand if and how this theoretical model can be implemented.

Conclusion

This paper has shown how the HBR intervention, designed and assessed in this study, complements a wider model of chronic care for PLHIV that has been developed in the same resource-poor location. Study participants were provided with safe, evidence-based and accessible patient-centred rehabilitation using a task shifting paradigm that empowered and trained lay care workers from the study community. The assessment of this study within the wider Chetty model has the potential to further inform pragmatic implementation strategies that may enhance the health-related quality of life of PLHIV and provide alternative rehabilitation options, particularly for people experiencing disability in resource-poor communities. Such a trial needs to integrate the approach from this study and other fundamental principles of the model of care that this HBR intervention did not seek to address. These elements include the adoption of a multi-disciplinary approach throughout the research process, the investigation of programme cost-effectiveness and potential training approaches for disability screening. Evidence of this nature could then be used to inform policy development and ultimately the translation of theory into practice. As more and more PLHIV gain access to effective treatment and live longer lives, it is imperative that healthcare workers, advocates, researchers, communities and wider stakeholders form collaborations that focus on providing the appropriate policy and operational structures to ensure that rehabilitation is widely included in the management and care of this population. This will give PLHIV the best possible chance of achieving a better health-related quality of life and the opportunity to participate more fully in all of their life pursuits.

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References

1. Moyle D. Speaking Truth to Power: The Story of the AIDS Law Project. Jacana; 2015.
2. UNAIDS. Global AIDS update [Internet]. 2016. Available from: http://www.unaids.org/en/resources/documents/2016/Global-AIDS-update-2016
3. South African Parliament. Minister Aaron Motsoaledi: Health Department Budget Vote 2016/17 [Internet]. 2016. Available from: http://www.gov.za/speeches/debate-health-budget-vote-national-assembly-10-may-2016-dr-aaron-motsoaledi-minister-health
4. UNAIDS. 90-90-90: an ambitious treatment target to help end the AIDS epidemic [Internet]. UNAIDS Geneva, Switzerland; 2014. Available from: http://www.unaids.org/en/resources/documents/2014/90-90-90
5. World Health Organization. Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection Recommendations for a public health approach: Second edition [Internet]. 2016. Available from: http://www.who.int/hiv/pub/arv/arv-2016/en/
6. Heywood M. The Treatment Action Campaign's Quest for Equality in HIV and Health: Learning from and Lessons for the Trade Union Movement. Glob Labour J. 2015;6(3).
7. Lazarus J V, Safreed-Harmon K, Barton SE, Costagliola D, Dedes N, del Amo Valero J, et al. Beyond viral suppression of HIV–the new quality of life frontier. BMC Med. BioMed Central; 2016;14(1):94.
8. Hanass-Hancock J, Chappell P, Myezwa H, Kwagala B, Boivin J-M, Lloyd J, et al. Committing to Inclusion to End AIDS by 2030. Lancet HIV. 2016;In press.
9. Deeks SG, Lewin SR, Havlir D V. The end of AIDS: HIV infection as a chronic disease. The Lancet. 2013.
10. Nixon S, Forman L, Hanass-Hancock J, Mac-Seing M, Munyanukato N, Myezwa H, et al. Rehabilitation: A crucial component in the future of HIV care and support. South Afr J HIV Med. 2011;12(2):12–4.
11. Hanass-Hancock J, Myezwa H, Carpenter B. Disability and Living with HIV: Baseline from a Cohort of People on Long Term ART in South Africa. PLoS One. Public Library of Science; 2015;10(12):e0143936.
12. Department of Health. Framework and Strategy for Disability and Rehabilitation services in South Africa (2015-2020) [Internet]. 2015. Available from: ilifalabantwana.co.za/wp-content/uploads/2016/07/Framework-25-may_1_3.docx
13. South African National AIDS Council. National Strategic Plan on HIV, STIs and TB, 2012-2016 [Internet]. 2012. Available from: http://www.sahivsoc.org/upload/documents/National_Strategic_Plan_2012.pdf
14. Department of Health. National Health Insurance for South Africa: Towards Universal Health Coverage [Internet]. 2015. Available from: https://www.health-e.org.za/wp-content/uploads/2015/12/National-Health-Insurance-for-South-Africa-White-Paper.pdf
15. Department of Health. White Paper on the Rights of Persons with Disabilities [Internet]. 2016. Available from: http://www.gov.za/sites/www.gov.za/files/39792_gon230.pdf
16. Cobbing S, Hanass-Hancock J, Deane M. Physiotherapy rehabilitation in the context of HIV and disability in KwaZulu-Natal, South Africa. Disabil Rehabil [Internet]. 2014;36(20):1–8. Available from: http://www.ncbi.nlm.nih.gov/pubmed/24383469

17. Myezwa H, Hanass-Hancock J, Pautz N, Smith R, Carpenter B. Investigating the Interaction between Disability and Depressive Symptoms in the Era of Widespread Access to ART. J AIDS Clin Res [Internet]. 2016;7(77). Available from: http://dx.doi.org/10.4172/2155-6113.1000584

18. Chetty V. A model of care for the rehabilitation of people living with HIV in a semi-rural South African setting. South African Heal Rev 2014/15. 2015;183.

19. Chetty V, Hanass-Hancock J, Myezwa H. Expert consensus on the rehabilitation framework guiding a model of care for people living with HIV in a South African setting. J Assoc Nurses AIDS Care. Elsevier; 2016;27(1):77–88.

20. Hanass-Hancock J, Alli F. Closing the gap: training for healthcare workers and people with disabilities on the interrelationship of HIV and disability. Disabil Rehabil [Internet]. Informa UK Ltd; 2014;0(0):1–10. Available from: http://informahealthcare.com/doi/abs/10.3109/09638288.2014.991455

21. Cobbing S, Hanass-Hancock J, Deane M. Physiotherapy rehabilitation in the context of HIV and disability in KwaZulu-Natal, South Africa. Disabil Rehabil [Internet]. 2014;36(20):1687–94. Available from: http://www.tandfonline.com/doi/full/10.3109/09638288.2013.872199

22. Chetty V, Hanass-Hancock J. Development of a model of care for rehabilitation of people living with HIV in a semirural setting in South Africa. JMIR Res Protoc. JMIR Publications Inc.; 2014;3(4).

23. Chetty V, Hanass-Hancock J. The need for a Rehabilitation Model to address the disparities of public healthcare for people living with HIV in South Africa. African J Disabil [Internet]. 2015;4(1):1–6. Available from: http://ajod.org/index.php/ajod/article/view/137

24. Cobbing S, Hanass-Hancock J, Myezwa H. Home-based rehabilitation interventions for adults living with HIV: a scoping review. African J AIDS Res. Taylor & Francis; 2016;15(1):77–88.

25. Cobbing S, Hanass-Hancock J, Myezwa H. A home-based rehabilitation intervention for people living with HIV and disability in a resource-poor community, KwaZulu-Natal: study protocol for a randomised controlled trial. Trials. 2015;16.

26. Cobbing S, Hanass-Hancock J, Myezwa H. A home-based rehabilitation intervention for adults living with HIV: A randomized controlled trial. J Assoc Nurses AIDS Care. Elsevier; 2016;

27. Cobbing S, Chetty V, Hanass-Hancock J, Myezwa H. “Knowing I can be helpful makes me feel good inside, it makes me feel essential”: community health care workers’ experiences of conducting a home-based rehabilitation intervention for people living with HIV in KwaZulu-Natal, South Africa. AIDS Care. Taylor & Francis; 2017;1–5.

28. Jacobson NS, Truax P. Clinical significance: a statistical approach to defining meaningful change in psychotherapy research. J Consult Clin Psychol. American Psychological Association; 1991;59(1):12.

29. World Health Organisation. Community-based rehabilitation: CBR Guidelines [Internet]. Geneva: WHO. 2010. Available from: http://www.who.int/disabilities/cbr/guidelines/en/

30. Department of Health. The primary health care package for South Africa: a set of norms and standards [Internet]. Government Printer Pretoria; 2001. Available from: https://www.westerncape.gov.za/general-publication/primary-health-care-package-sa-set-norms-and-standards

31. World Health Organisation. Task shifting: rational redistribution of tasks among health workforce teams: global recommendations and guidelines. Geneva: World Health Organization; 2007;

32. Callaghan M, Ford N, Schneider H. A systematic review of task- shifting for HIV treatment and care in Africa. Hum Resour Health. 2010;8:8.

33. Schneider H, Hlophe H, van Rensburg D. Community health workers and the response to HIV/AIDS in South Africa: tensions and prospects. Health Policy Plan. Oxford Univ Press; 2008;23(3):179–87.

34. Petersen I, Hanass Hancock J, Bhana a., Govender K. A group-based counselling intervention for depression comorbid with HIV/AIDS using a task shifting approach in South Africa: A randomized controlled pilot study. J Affect Disord [Internet]. Elsevier; 2014;158:78–84. Available from: http://dx.doi.org/10.1016/j.jad.2014.02.013

35. Crowley T, Mayers P. Trends in task shifting in HIV treatment in Africa: Effectiveness, challenges and acceptability to the health professions. African J Prim Heal Care Fam Med. AOSIS Publishing; 2015;7(1):1–9.

36. Collins L, Scuffham P, Gargett S. Cost-analysis of gym-based versus home-based cardiac rehabilitation programs. Aust Heal Rev. CSIRO; 2001;24(1):51–61.

37. Salvetti XM, Oliveira JA, Servantes DM, de Paola AAV. How much do the benefits cost? Effects of a home-based training programme on cardiovascular fitness, quality of life, programme cost and adherence for patients with coronary disease. Clin Rehabil. SAGE Publications; 2008;22(10–11):987–96.

38. Munro J, Corrigall H, Angus NJ, Thompson D, Leslie S. Home versus hospital-based cardiac rehabilitation: a systematic review. Deakin University; 2011;

39. Padayachee T, Chetty N, Matse M, Mampe T, Schneider H. Progress in the establishment of ward based outreach teams: experiences in the North West Province. Health Systems Trust; 2013;

40. Doherty T, Kroon M, Rhoda N, Sanders D. Ending preventable child deaths in South Africa: What role can ward-based outreach teams play? SAMJ South African Med J. Health & Medical Publishing Group; 2016;106(7):672–4.

CHAPTER 7: CONCLUSION

A Nation should not be *judged* by how it treats its highest citizens, but its lowest ones.
Nelson Rolihlahla Mandela (1918-2013)

This final chapter will provide readers with a final summary of the overall doctoral work, with specific reference to the study aim and objectives set out in Chapter 1. The significance of these findings will be proposed and the limitations of the study design and process will be discussed. Finally, recommendations for future research and practice will be summarized.

7.1. Alignment of Phd thesis with study aim and objectives

The overall study aim was to determine the effect of a specifically tailored disability-inclusive HBR intervention on PLHIVs' perceived disability, quality of life, functional mobility and functional capacity. Objective 1, which was to design a specifically tailored disability-inclusive HBR intervention for adult PLHIV, was achieved through information obtained via the rigorous scoping review methodology, the results of which are presented in Chapter 2. The methodology for this intervention is presented in Chapter 3. Study objectives 2, 3, 4 and 5 were to determine the effect of this intervention on adult PLHIVs' perceived disability, quality of life, functional mobility and functional capacity respectively. These objectives were met through an analysis of the within-group and between-group differences in the study outcome measures, recorded before and after the study intervention. These results are presented, in full, in Chapter 4. The qualitative paper included in Chapter 5 relates to study objective 6 and supports the quantitative findings in the previous chapter. This paper interrogates the experiences of the research assistants involved in conducting the study intervention and describes the successes and challenges they encountered, as well as their suggestions for the design of future interventions of this nature. Chapter 6 presents a manuscript that aims to meet study objective 7, namely to describe how the HBR intervention adhered to the fundamental principles of a theoretical model of integrated care developed for this study setting.

7.2. Significance

This Phd study has responded to a clear gap in the literature, namely a significant dearth of literature on HBR interventions for PLHIV, particularly in resource-poor communities where HIV is endemic. In a recently updated systematic review of exercise interventions for PLHIV, O'Brien et al (O’Brien et al., 2016) called on new research that includes intention to treat analyses, blinded assessment of clinically meaningful outcomes and the investigation of community-based programmes. The HBR intervention trialed in this PhD satisfies all of these recommendations. It further provides an empirically-assessed practical example of how HBR interventions can successfully be included in a broader model of care for PLHIV in this study setting.

Dunleavy (2003) proposes that a PhD should involve novel, substantive work that makes a distinct contribution to the discipline in which the research is conducted. This PhD study demonstrates its novelty in presenting the first empirical account of a randomised controlled trial designed to assess the effects of a needs-based HBR intervention on adult PLHIV who experience functional limitations. This is in marked contrast to previous published HBR interventions for PLHIV, which have prescribed the same exercises for each participant. Furthermore, by employing lay HCWs from the study community to supervise participants, this PhD study also describes the first account of the use of a task shifting model in the design and implementation of a HBR intervention for PLHIV. Israel et al. (2010) propose that this collaboration between researchers and community members can assist in eliminating health disparities and improving health in the communities involved.

This thesis provides quantitative and qualitative evidence of the successes and challenges of a HBR programme designed for PLHIV who experience disability. By employing the results of this study to initiate new interventions and improve existing HBR programmes, not only will individual PLHIV benefit but the healthcare workers involved in the care of PLHIV will also further their knowledge and skills related to the rehabilitation required for this vulnerable population. The importance of this unique work has already been recognized, with the candidate being selected (in September 2016) as a post-doctoral fellow on the Developing Research Innovation, Localization and Leadership in South Africa (DRILL) programme. This initiative, which represents a collaboration between academics and the Department of Health, aims to deliver, support and ultimately lead a reformed health worker whose training and development will equip them to work effectively in remote, rural and underserved parts of KwaZulu-Natal Province. This fellowship represents a wonderful opportunity to build on the findings of this PhD study and to ultimately translate the findings into common practice in the public healthcare system. By involving professionals, researchers and stakeholders from a wide range of backgrounds it is hoped that this will ensure that this training will be multi-disciplinary in nature, will involve assessment as well as care and will be focused on all chronic conditions, not just HIV.

7.3. Limitations

Each stage of this PhD study exhibited certain limitations and weaknesses. As outlined in Chapter 1, the very choice of the research question and study location are representative of both the candidate's ontological position and history of work in this specific research setting. Thus, caution should be taken when attempting to generalize the results of this study to communities in other parts of South Africa and the globe. The scoping review that informed the design of the main study intervention was potentially limited by the inclusion of articles published in English only, as well as the exclusion of grey literature in the search strategy for this review. The study outcome measures were translated from English into isiZulu (without full back translation and cognitive debriefing of the translated tools) – this may have negatively affected the validity of these tools for the chosen study sample. The randomised control trial also revealed limitations related to both the design of the trial as well as the interpretation of the study findings. The fact that it involved a "needs-based" rehabilitation programme ensured that it was particularly relevant to the real, functional problems faced by PLHIV, but it makes it very difficult to replicate this study in another setting. The non-significance of the study results may have occurred as a result of a number of factors, including the length of the intervention, the relatively small sample size (four participants short of the sought sample), the dropout rate, potential sharing of knowledge between study groups and the fact that, for ethical reasons, participants in the control group were given advice on exercise and healthy living (see Appendix 10). In effect, thus, this intervention was not being compared to conventional practice, but rather to a group of control participants who received health information that may have influenced their outcomes. While the qualitative paper describing the research assistants' experiences included all four staff employed to supervise participants, some may consider this a relatively small sample from which to extract meaningful thematic data. Large sample sizes, however, are not necessarily an important feature of a qualitative methodology, which can derive valuable data from just one participant (Silverman, 2013). Finally, the inclusion of the study participants' experiences of receiving the intervention would have provided a more complete description of the successes and failures of this HBR programme.

7.4. Recommendations

By communicating this information to a wider audience, through the publication of the five papers included in this PhD thesis, it is hoped that researchers will design and investigate other novel rehabilitation interventions that aim to address the multiple disabling effects of HIV, particularly in hyper-epidemic resource-poor areas where these are needed most. Researchers should consider assessing interventions of a longer duration and employ alternative research designs (such as cross-over design) in order to increase the validity of study findings. Publishing rigorous qualitative evidence with relevant qualitative enquiry (including interviewing study participants) will increase the likelihood that health care personnel working in the field of rehabilitation will be informed and thus, better equipped to implement evidence-based interventions in their daily practice. These interventions also have the potential to be of benefit to non-HIV infected individuals living with disability and other chronic conditions, thus further reducing the burden of disease in resource-poor countries. Further research is required to assess the cost-effectiveness of alternative rehabilitation interventions for PLHIV and other chronic conditions, particularly programmes that employ novel task-shifting strategies. Having gathered sufficient evidence on both the health benefits and cost of these interventions, researchers and healthcare workers need to combine this with a knowledge of local and global policies in order to advocate that public and non-governmental organisations fund and support interventions focused on improving the lives of PLHIV. Multidisciplinary collaborations should focus on efforts to train a new cadre of community healthcare workers that can conduct a wide range of disability screening and basic rehabilitation services. Where possible, these new evidence-based initiatives should be integrated into existing community rehabilitation projects and other multidisciplinary interventions, such as the ward-based outreach teams currently being trialed in South Africa.

7.5. Conclusion

This PhD thesis has presented the findings of a novel HBR intervention designed specifically for PLHIV and disability. The overall study aim and specific research objectives were achieved in that a rigourous, systematic approach was taken in the design of the main study intervention and the effects of the intervention on PLHIVs' perceived disability, quality of life, functional mobility and functional capacity were presented and discussed in relation to local and global evidence. As PLHIV are living longer lives due to wider access to ART, it has become increasingly evident that they are prone to a wide range of disabilities. This has a serious impact on their health-related quality of life and their ability to function optimally in their activities of daily living. The work presented in this PhD thesis provides multi-faceted evidence that shows that appropriately trained lay community healthcare workers can safely and successfully implement a novel HBR intervention for PLHIV and disability. Researchers should take cognizance of both the successes and the limitations described in this thesis, in order to build on this research. By collaborating closely with communities and healthcare workers, researchers can further broaden the design and scope of this work to investigate multidisciplinary interventions that focus on the screening and treatment of PLHIV and people living with other chronic conditions. Together with all interested stakeholders and civil society organisations, it is crucial that concerted efforts are made to ensure that the theoretical findings of studies such as this are translated into concrete policies and practices that contribute to improving the health of people living in resource-poor communities.

REFERENCES (for operational definitions and chapters 1 and 7)[1]

Bury, T. (2005). Developmental articles primary health care and community based rehabilitation: implications for physical therapy. *Asia Pac Disabil Rehabil J*, *16*(2), 29–61. Retrieved from http://www.aifo.it/english/disability/apdrj/apdrj205/phc-cbr.pdf

Cella, D. F. (1994). Quality of life: concepts and definition. *Journal of Pain and Symptom Management*, *9*(3), 186–192.

Chaiyawat, P., & Kulkantrakorn, K. (2012). Effectiveness of home rehabilitation program for ischemic stroke upon disability and quality of life: a randomized controlled trial. *Clinical Neurology and Neurosurgery*, *114*(7), 866–870.

Chappell, P., & Johannsmeier, C. (2009). The impact of community based rehabilitation as implemented by community rehabilitation facilitators on people with disabilities, their families and communities within South Africa. *Disability and Rehabilitation*, *31*(1), 7–13. http://doi.org/10.1080/09638280802280429

Chetty, V., & Hanass-Hancock, J. (2015). The need for a Rehabilitation Model to address the disparities of public healthcare for people living with HIV in South Africa. *African Journal of Disability*, *4*(1), 1–6. http://doi.org/10.4102/ajod.v4i1.137

Chu, C., & Selwyn, P. A. (2011). An epidemic in evolution: the need for new models of HIV care in the chronic disease era. *Journal of Urban Health*, *88*(3), 556–566.

Cobbing, S., Hanass-Hancock, J., & Deane, M. (2014). Physiotherapy rehabilitation in the context of HIV and disability in KwaZulu-Natal, South Africa. *Disability and Rehabilitation*, *36*(20), 1–8. http://doi.org/10.3109/09638288.2013.872199

Creswell, J. W. (2013). *Research design: Qualitative, quantitative, and mixed methods approaches*. Sage publications.

de Morton, N. A. (2009). The PEDro scale is a valid measure of the methodological quality of clinical trials: a demographic study. *Australian Journal of Physiotherapy*, *55*(2), 129–133.

Department of Health. (2001). *National Guidelines on home-base care/community-based care*. Department of health, Pretoria: Government Printer.

Dunleavy, P. (2003). *Authoring a PhD: How to plan, draft, write and finish a doctoral thesis or dissertation*. Palgrave Macmillan.

Gomes-Neto, M., Conceicao, C. S., Carvalho, V. O., & Brites, C. (2013). A systematic review of the effects of different types of therapeutic exercise on physiologic and functional measurements in patients with HIV/AIDS. *Clinics*, *68*(8), 1157–1167.

Gomes-Neto, M., Conceição, C. S., Carvalho, V. O., & Brites, C. (2015). Effects of Combined Aerobic and Resistance Exercise on Exercise Capacity, Muscle Strength and Quality of Life in HIV-Infected Patients: A Systematic Review and Meta-Analysis. *PloS One*, *10*(9), e0138066.

Hanass-Hancock, J., & Casale, M. (2014). An exploratory model to illustrate the interrelationship between HIV, disability, and caregiving in Southern Africa. *Journal of the Association of Nurses in AIDS Care*, *25*(4), 351–363. http://doi.org/10.1016/j.jana.2013.10.001

Hanass-Hancock, J., Myezwa, H., & Carpenter, B. (2015). Disability and Living with HIV: Baseline from a Cohort of People on Long Term ART in South Africa. *PloS One*, *10*(12),

---

[1] American Psychological Assocation (6th edition) referencing style used

e0143936.

Hanass-Hancock, J., Regondi, I., & Nixon, S. (2013). HIV-related disability in HIV hyper-endemic countries: a scoping review. *World Journal of AIDS*, *3*(September), 257–279.

Hoffmann, C., & Rockstroh, J. K. (2012). The Structure of HIV-1 Infection In. *HIV*, *2013*, 20–21.

Hussein, A. (2009). The use of triangulation in social sciences research: Can qualitative and quantitative methods be combined? *Journal of Comparative Social Work*, *4*(1).

Israel, B. A., Coombe, C. M., Cheezum, R. R., Schulz, A. J., McGranaghan, R. J., Lichtenstein, R., … Burris, A. (2010). Community-based participatory research: a capacity-building approach for policy advocacy aimed at eliminating health disparities. *American Journal of Public Health*, *100*(11), 2094–2102.

Maher, C. G., Sherrington, C., Herbert, R. D., Moseley, A. M., & Elkins, M. (2003). Reliability of the PEDro scale for rating quality of randomized controlled trials. *Physical Therapy*, *83*(8), 713–721.

Munro, J., Corrigall, H., Angus, N. J., Thompson, D., & Leslie, S. (2011). Home versus hospital-based cardiac rehabilitation: a systematic review.

Myezwa, H., Hanass-Hancock, J., Pautz, N., Smith, R., & Carpenter, B. (2016). Investigating the Interaction between Disability and Depressive Symptoms in the Era of Widespread Access to ART. *J AIDS Clin Res*, *7*(77). http://doi.org/10.4172/2155-6113.1000584

Myezwa, H., Stewart, A., Musenge, E., & Nesara, P. (2009). Assessment of HIV-positive in-patients using the International Classification of Functioning, Disability and Health (ICF) at Chris Hani Baragwanath Hospital, Johannesburg. *African Journal of AIDS Research*, *8*(1), 93–105. http://doi.org/10.2989/AJAR.2009.8.1.10.723

Nixon, S., Forman, L., Hanass-Hancock, J., Mac-Seing, M., Munyanukato, N., Myezwa, H., & Retis, C. (2011). Rehabilitation: A crucial component in the future of HIV care and support. *Southern African Journal of HIV Medicine*, *12*(2), 12–14.

O'Brien, K. K., Tynan, A.-M., Nixon, S. A., & Glazier, R. H. (2016). Effectiveness of aerobic exercise for adults living with HIV: systematic review and meta-analysis using the Cochrane Collaboration protocol. *BMC Infectious Diseases*, *16*(1), 1.

O'Brien, K., Tynan, a-M., Nixon, S., & Glazier, R. H. (2008). Effects of progressive resistive exercise in adults living with HIV/AIDS: systematic review and meta-analysis of randomized trials. *AIDS Care*, *20*(788857691), 631–653. http://doi.org/10.1080/09540120701661708

Oxford English Dictionary. (2016). Advocacy. Retrieved from https://en.oxforddictionaries.com/definition/advocacy

PEDro. (2016). PEDro Statistics. Retrieved from http://www.pedro.org.au/english/downloads/pedro-statistics/

Pradella, C. O., Belmonte, G. M., Maia, M. N., Delgado, C. S., Luise, A. P. T., Nascimento, O. A., … Jardim, J. R. (2015). Home-based pulmonary rehabilitation for subjects with COPD: a randomized study. *Respiratory Care*, *60*(4), 526–532.

Remington, P. L., Brownson, R. C., Wegner, M. V, & Davies, J. (2010). *Chronic disease epidemiology and control*. American public health association Washington, DC, USA.

Republic of South Africa. (1996). Constitution of the Republic of South Africa, Act 108 of 1996. *Government Gazette*. Government Printer Pretoria. Retrieved from http://www.gov.za/sites/www.gov.za/files/images/a108-96.pdf

Shisana, O., Rehle, T., Simbayi, L. C., Onoya, D., Jooste, S., Zungu, N., & Zuma, K. (2014).

South African national HIV prevalence, incidence and behaviour survey, 2012. *Pretoria: Human Sciences Research Council*. Retrieved from http://www.hsrc.ac.za/en/research-outputs/view/6871

Silverman, D. (2013). *Doing qualitative research: A practical handbook* (4th ed.). London: SAGE Publications Limited.

UNAIDS. (2014). *The Gap Report 2014*. Retrieved from http://files.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2014/UNAIDS_Gap_report_en.pdf

UNAIDS. (2016). Global AIDS update. Retrieved from http://www.unaids.org/en/resources/documents/2016/Global-AIDS-update-2016

United Nations. (1948). Universal Declaration of Human Rights. Retrieved from http://www.un.org/en/universal-declaration-human-rights/

United Nations. (2007). The Convention on the Rights of Persons with Disabilities. Retrieved from http://www.un.org/disabilities/convention/conventionfull.shtml

Van As, M., Myezwa, H., Stewart, A., Maleka, D., & Musenge, E. (2009). The International Classification of Function Disability and Health (ICF) in adults visiting the HIV outpatient clinic at a regional hospital in Johannesburg, South Africa. *AIDS Care*, *21*(1), 50–58. http://doi.org/10.1080/09540120802068829

World Health Organisation. (2007). Task shifting: rational redistribution of tasks among health workforce teams: global recommendations and guidelines.

World Health Organisation. (2010). Community-based rehabilitation: CBR Guidelines. Retrieved from http://www.who.int/disabilities/cbr/guidelines/en/

World Health Organisation. (2011). *World report on disability*. World Health Organization,. Retrieved from http://www.who.int/disabilities/world_report/2011/report.pdf

World Health Organization. (2001). International classification of functioning, disability and health (ICF). World Health Organization Geneva, switzerland.

Worthington, C., Myers, T., O'Brien, K., Nixon, S., & Cockerill, R. (2005). Rehabilitation in HIV/AIDS: development of an expanded conceptual framework. *AIDS Patient Care and STDs*, *19*(4), 258–271. http://doi.org/10.1089/apc.2005.19.258

APPENDICES

Appendix 1: University of KwaZulu-Natal College of Health Sciences: Guidelines for presentation of PhD theses by research

Appendix 2: PEDro Scale

Appendix 3: Ethical clearance letter

Appendix 4: Summary of studies informing the design of the HBR intervention

Appendix 5: WHOQOL-HIV BREF

Appendix 6: WHODAS 2.0 (12 item version)

Appendix 7: Rivermead Mobility Index

Appendix 8: Six Minute Walk Test

Appendix 9: Information sheet provided to study participants

Appendix 10: Exercise and information sheet provided to participants in study control group

Appendix 11: Pre-intervention results (intervention group)

Appendix 12: Post-intervention results (intervention group)

Appendix 13: Schedule of training programme provided for CCWs

Appendix 14: Information sheet and consent form for CCWs (English language version)

Appendix 15: Interview schedule for CCWs (English language version)

Appendix 16: Preliminary publication 1

Appendix 17: Preliminary publication 2

GUIDELINES FOR PRESENTATION OF MASTERS AND PHD DISSERTATIONS/THESES BY RESEARCH

1. Purpose

The purpose of this document is to provide guidance to students and supervisors on how to prepare a dissertation/thesis for Masters by Research and PhD degrees using the manuscript or publication format..

2. Introduction

These guidelines must be read together with the College of Health Sciences (CHS) Handbook as well as the Jacobs documents on examination policies and procedures for PhD degrees. The rules on thesis format are based on modification of point 1 of the definition of terms section in the Jacobs document. In this section a thesis is defined as *"the supervised research component of all PhD degrees, whether by supervised research only, or coursework and research, or by papers that are either published or in manuscript form (the supervised research component of the PhD degree by paper(s) comprises the introduction, literature review, account of the methodology, selection of manuscripts, and conclusion)."* A dissertation is defined as "*the supervised research component of all Masters degrees, whether by supervised research only, or coursework and research, or by papers that are either published or in manuscript form (the supervised research component of the Masters degree by paper(s) comprises the introduction, literature review, account of the methodology, selection of manuscripts, and conclusion*)."

2.1 PhD thesis

In the CHS Handbook the rules for a PhD thesis are not in one place; they are stated in DR8 a i & ii, DR9 c and CHS 16. DR8 a i & ii and direct that a thesis be presented in the standard format together with one published paper or an unpublished manuscript that has been submitted to an accredited journal, arising from the doctoral research. CHS16 (thesis by publications states that the thesis may comprise of at least three published papers or in press in accredited journals; such papers must have the student as the prime author. The same CHS16 provides for a thesis by manuscripts that may have at least 3 papers with the student as the prime author that have not yet been published but are in the form of manuscripts; at least two of such papers must constitute original research. In both cases (thesis by publications and manuscripts), there must be introductory and concluding integrative material sections.

The standard type thesis is being phased out in many African countries in favour of the other options that originate from the Scandinavian countries. While this format ensures that all details of the work done for the doctoral degree are captured and thoroughly interrogated, they often remain as grey literature which is mainly useful to other students, usually within the same university, although with digitization of theses, such work may become more accessible beyond the source university. Apart from the risk of losing good work because of it not being on the public domain, as students rarely publish such work after graduating, this approach denies the college additional productivity units (PUs) emanating from publications.

The thesis by publication encourages students to publish key aspects of their doctoral research as they will not graduate if the papers are not published or in press. This approach ensures that the work of the student enters the public domain before the thesis is examined, providing the examiner with some assurance of prior peer review. The thesis must constitute a full study of the magnitude expected of a PhD with the papers providing a sound thread or storyline. Furthermore, the college maximizes the students' work as PUs are awarded for the papers as well as for graduating. However, this approach may negatively affect throughput and frustrate students as they cannot graduate unless all the papers are published or in press, in addition to the synthesis chapter demonstrating the story line of the thesis.

The option of a thesis by manuscripts ensures that students make efforts to start publishing. The risk of not passing because of failure to publish all papers (as in the thesis by publication) does not exist under this option. However, the PUs emanating from publications from the doctoral work are not guaranteed as the submitted papers may eventually be rejected. Thus there is a possibility of the doctoral work remaining on the university library shelves as is the case for the standard thesis format. The standard thesis does have the advantage that more details of the doctoral work are usually included.

In view of the above, the best option for the college is that of a thesis by publication. However, in the interim, the attractive option is that of thesis by manuscripts, as it provides the possibility of publication without putting the student at risk of delayed graduation when some of the manuscripts are not published/accepted, which also disadvantages the college in terms of PU earnings. The standard thesis option should ultimately be phased out for the stated reasons and students are not encouraged to present their theses in that format. Consequently this document does not describe the standard thesis.

2.2 MSc dissertation

The rules on presentation of MSc dissertations are presented in CR13 (course work), CHS 14 (course work) and MR9 (research) in the CHS Handbook. CR13 c and MR9 c direct that a dissertation "may comprise one or more papers of which the student is the prime author, published or in press in peer-reviewed journals approved by the relevant college academic affairs board or in manuscripts written in a paper format, accompanied by introductory and concluding integrative material." Such a dissertation should include a detailed description of the student's own distinct contribution to the papers. Both CHS14 and CR13 specify that reviews and other types of papers in addition to original research paper/s may be included, provided they are on the same topic.

3 *Length of thesis and dissertation by word count*

Table 1 provides a guide of the length of a thesis or dissertation by word count excluding preliminary pages and annexes.

Table 1: Thesis length by word count

Sections				
	Minimum	Maximum	Minimum	Maximum
Introduction	2700	2700	2000	2000
Chapters	10000	25000	6000	11000
synthesis	2000	2000	1700	1700
bridging	300	300	300	300
Total	15000	30000	10000	15000

4. *Intention to submit*

A written intention to submit a thesis or dissertation should be submitted to the appropriate postgraduate office with endorsement of the supervisor at least three months before the actual date of submission which should be before November if the student intends to graduate in the following year. The actual submission will under normal circumstances require approval of the supervisor.

5. Format for theses/dissertation

There is little variation in the actual format of the PhD thesis and Masters dissertation for the various types described above. The box below summarise the outline of a thesis/dissertation for the thesis by manuscripts and thesis by publications.

Box 1: Outline of thesis

Preliminary pages

i. Title page
ii. Preface and Declaration
iii. Dedication
iv. Acknowledgements
v. Table of contents
vi. List of figures, tables and acronyms (separately presented)
vii. Abstract

Main Text

1. Chapter 1: Introduction
    Introduction including literature review
    Research questions and/or objectives
    Brief overview of general methodology including study design
2. Chapter 2
    First manuscript/publication
3. Chapter 3
    Second manuscript/publication
4. Chapter n
    Final manuscript/publication
5. Chapter n+1: Synthesis
    Synthesis
    Conclusions
    Recommendations
6. References Appendices

NB. Between the manuscripts or publications there must be a 1 page (maximum) bridging text to demonstrate the link between them

6. Details for thesis/dissertation subheadings

This section summarizes what is expected under each subheading shown in Boxes 1 and indicates where there might be variations between a Masters Dissertation and PhD Thesis.

6.*1 Title Page*

The officially approved title that is concise (Fewest words that adequately describe the contents of the thesis/dissertation – usually 15 or fewer words) is presented at the top. This should be followed by the candidate's name in a new line. At the bottom the thesis statement should be presented. The thesis statement may be stated as "*Submitted in fulfillment of the requirements for the degree of ____ in the School of _______, University of KwaZulu-Natal"* for a PhD/Masters by Research thesis. In the case of a Masters Dissertation it should be stated as "Submitted as the dissertation component in partial fulfilment (% stated) for the degree of ______ in the School of ______, University of KwaZulu-Natal". For both Masters and PhD the date of submission must be stated.

6.2 Preface (Optional)

The preface merely states the reason (motivating factors) why the study was conducted without getting into details of what was investigated.

6.3 Declaration

This must be structured as follows:

I, Dr/Mr _________, declare as follows:

1. That the work described in this thesis has not been submitted to UKZN or other tertiary institution for purposes of obtaining an academic qualification, whether by myself or any other party.

   Where a colleague has indeed prepared a thesis based on related work essentially derived from the same project, this must be stated here, accompanied by the name, the degree for which submitted, the University, the year submitted (or in preparation) and a concise description of the work covered by that thesis such that the examiner can be assured that a single body of work is not being used to justify more than one degree.
2. That my contribution to the project was as follows:

   This is followed by a concise description of the candidate's personal involvement in and contribution to the project, in sufficient detail that the examiner is in no doubt as to the extent of their contribution.
3. That the contributions of others to the project were as follows:

   This is followed by a list of all others who contributed intellectually to the project, each accompanied by a concise description of their contribution. This does not include people who ordinarily would be "acknowledged" as opposed to considered for authorship.

4. Signed ______________________ Date________________

6.4 Dedication

This is an optional section. Should it be included it must be very brief merely indicating to whom the work is dedicated. Avoid anything too flowery

6.5 Acknowledgements

This section acknowledges all individuals, groups of people or institutions that the candidate feels indebted to for the support they rendered. The funding source for the work should also be acknowledged.

6.6 Table of contents

Table of contents must be inserted after the preliminary sections and must capture all major sections of the thesis at the various levels (primary, secondary, tertiary subheadings). It should be electronically generated and should be able to take the reader to specific headings in the thesis.

6.7 Lists of figures, tables and acronyms

These lists must be presented separately. All titles of figures presented in the thesis/dissertation must be listed indicating on what page they appear. Similarly for tables the titles must be presented indicating on what page they appear. In the case of acronyms, the acronym is stated and all the words describing the acronym are presented. Only key acronyms should be stated. In some cases they may not be listed as long as full text is presented whenever the acronym is used for the first time.

6.8 Abstract

The abstract should summarize the thesis mainly stating the purpose of the study, highlights of chapters and the new knowledge contributed by the thesis. The abstract must be approved by the supervisor of the thesis and should not be more than 350 words in length.

6.9 Introduction

The introductory chapter for both types of thesis is similar. The section should include literature review and have the following information. Headings are used as appropriate and need not correspond exactly to the following.

i. Background and the context of the study
ii. Description of the core research problem and its significance
iii. A comprehensive, critical, coherent overview of the relevant literature leading to clearly defined knowledge gaps
iv. A coherent problem statement highlighting the nature and magnitude of the problem, the discrepancy, knowledge gaps therein and possible factors influencing the problem.
v. Clear and SMART research questions, objectives and hypothesis and/or theoretical framework
vi. A conceptual framework (optional)
vii. Description of the study area and general methodology *(in a standard thesis this should be a stand-alone section)*
viii. Layout of the thesis (thesis structure) indicating what chapters are presented in the thesis and how they address the objectives.

6.10 Literature review

This section is subsumed in the introduction within the stipulated word count for a thesis or dissertation.

6.11 Methodology

A standalone section is not needed as the methods are adequately described in each manuscript/publication.

6.12 Data chapters/manuscripts/publications

The full published paper or manuscript submitted for publication should be presented as published or submitted to the journal. The actual published paper should be scanned and inserted in the chapter. There should be a separator page between chapters that has text linking the previous chapter to the next and providing details of the next manuscript/publication indicating publication status.

6.13 General discussion/Synthesis chapter

This is a general discussion that demonstrates the logical thread that runs across the various manuscripts/publications (synthesis). There should be no doubt that the manuscripts/publications complement each other and address the original objectives stated in the general introduction of the thesis. The general discussion/synthesis chapter should end with a conclusion and recommendations where necessary.

6.14 References

Only references cited in the introduction and synthesis chapters should be listed as all other references should be within the manuscripts presented under data chapters.

6.15 Annexes

All information (questionnaires, diagrams, ethics certificates, etc) considered important but not essential for inclusion in the actual thesis is put in this section as reference material. In addition papers that emanated from the work but not directly contributing to the thesis may be included.

7. Thesis formatting

For standardisation of thesis the following formatting specifications should be followed.

7.1 Font

Times New Roman 11pt should be used throughout the thesis. However, major headings may be made bigger (12pt) but using the same font type

7.2 Paper size and margins

A4 (297 x 210 mm) should be used and in the final thesis both sides of the paper should be used. However, the loose bound copy submitted for examination should be printed on only one side. The recommended margins are 30mm for all the left, right, top and bottom margins.

7.3 Line spacing

The copy submitted for examination should have 1.5 line spacing but the final copy should have single line spacing. Paragraphs should be separated by a blank line. Published or submitted manuscripts should remain in their original format in all aspects as they are inserted in their published format in appropriate places.

7.4 Headings

A consistent numbering system and captions should be maintained with first level being in CAPS and centred, second level being **normal bold** font and third level being ***italics bold***. If there is need for 4th level it should be *normal italics*.

7.7 Pagination

Page numbers should be centred at the bottom of the page. All preliminary pages should be numbered in lower case Roman numerals and subsequent pages should be numbered as indicated in the Box The title page should not be numbered.

The body of the thesis (chapter 1 onwards) should be numbered consecutively with Arabic numerals. The numbers should continue consecutively from the introduction through the through the publications or submitted manuscripts and subsequent sections. The published papers will therefore bear two numbers: a set specific to the manuscript (it is recommended to place these in the upper right hand corner) or published paper, as well as the consecutive numbers belonging to the thesis as a whole. Care must be taken to distinguish these in terms of position and font.

7.8 Referencing

Supervisors have the freedom to decide the type of citation of references but there must be consistency. This is mainly applicable to the standard type of thesis. In the case of thesis by manuscripts or publications, individual papers will maintain the reference system of the journal but the supervisor can decide on the type of referencing for the introductory and synthesis chapters.

8. Final thesis submission

The thesis should be submitted for examination in a loose bound form accompanied by a PDF copy. After the examination process the final version PDF copy of the thesis must be submitted to PG office for onward submission to the library. It is not a requirement to submit a copy fully bound in leather cloth or similar material.

PEDro scale

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1. eligibility criteria were specified no ☐ yes ☐ where:
2. subjects were randomly allocated to groups (in a crossover study, subjects were randomly allocated an order in which treatments were received) no ☐ yes ☐ where:
3. allocation was concealed no ☐ yes ☐ where:
4. the groups were similar at baseline regarding the most important prognostic indicators no ☐ yes ☐ where:
5. there was blinding of all subjects no ☐ yes ☐ where:
6. there was blinding of all therapists who administered the therapy no ☐ yes ☐ where:
7. there was blinding of all assessors who measured at least one key outcome no ☐ yes ☐ where:
8. measures of at least one key outcome were obtained from more than 85% of the subjects initially allocated to groups no ☐ yes ☐ where:
9. all subjects for whom outcome measures were available received the treatment or control condition as allocated or, where this was not the case, data for at least one key outcome was analysed by "intention to treat" no ☐ yes ☐ where:
10. the results of between-group statistical comparisons are reported for at least one key outcome no ☐ yes ☐ where:
11. the study provides both point measures and measures of variability for at least one key outcome no ☐ yes ☐ where:

The PEDro scale is based on the Delphi list developed by Verhagen and colleagues at the Department of Epidemiology, University of Maastricht (*Verhagen AP et al (1998). The Delphi list: a criteria list for quality assessment of randomised clinical trials for conducting systematic reviews developed by Delphi consensus. Journal of Clinical Epidemiology, 51(12):1235-41*). The list is based on "expert consensus" not, for the most part, on empirical data. Two additional items not on the Delphi list (PEDro scale items 8 and 10) have been included in the PEDro scale. As more empirical data comes to hand it may become possible to "weight" scale items so that the PEDro score reflects the importance of individual scale items.

The purpose of the PEDro scale is to help the users of the PEDro database rapidly identify which of the known or suspected randomised clinical trials (ie RCTs or CCTs) archived on the PEDro database are likely to be internally valid (criteria 2-9), and could have sufficient statistical information to make their results interpretable (criteria 10-11). An additional criterion (criterion 1) that relates to the external validity (or "generalisability" or "applicability" of the trial) has been retained so that the Delphi list is complete, but this criterion will not be used to calculate the PEDro score reported on the PEDro web site.

The PEDro scale should not be used as a measure of the "validity" of a study's conclusions. In particular, we caution users of the PEDro scale that studies which show significant treatment effects and which score highly on the PEDro scale do not necessarily provide evidence that the treatment is clinically useful. Additional considerations include whether the treatment effect was big enough to be clinically worthwhile, whether the positive effects of the treatment outweigh its negative effects, and the cost-effectiveness of the treatment. The scale should not be used to compare the "quality" of trials performed in different areas of therapy, primarily because it is not possible to satisfy all scale items in some areas of physiotherapy practice.

Last amended June 21st, 1999

Notes on administration of the PEDro scale:

All criteria	**Points are only awarded when a criterion is clearly satisfied**. If on a literal reading of the trial report it is possible that a criterion was not satisfied, a point should not be awarded for that criterion.
Criterion 1	This criterion is satisfied if the report describes the source of subjects and a list of criteria used to determine who was eligible to participate in the study.
Criterion 2	A study is considered to have used random allocation if the report states that allocation was random. The precise method of randomisation need not be specified. Procedures such as coin-tossing and dice-rolling should be considered random. Quasi-randomisation allocation procedures such as allocation by hospital record number or birth date, or alternation, do not satisfy this criterion.
Criterion 3	*Concealed allocation* means that the person who determined if a subject was eligible for inclusion in the trial was unaware, when this decision was made, of which group the subject would be allocated to. A point is awarded for this criteria, even if it is not stated that allocation was concealed, when the report states that allocation was by sealed opaque envelopes or that allocation involved contacting the holder of the allocation schedule who was "off-site".
Criterion 4	At a minimum, in studies of therapeutic interventions, the report must describe at least one measure of the severity of the condition being treated and at least one (different) key outcome measure at baseline. The rater must be satisfied that the groups' outcomes would not be expected to differ, on the basis of baseline differences in prognostic variables alone, by a clinically significant amount. This criterion is satisfied even if only baseline data of study completers are presented.
Criteria 4, 7-11	*Key outcomes* are those outcomes which provide the primary measure of the effectiveness (or lack of effectiveness) of the therapy. In most studies, more than one variable is used as an outcome measure.
Criterion 5-7	*Blinding* means the person in question (subject, therapist or assessor) did not know which group the subject had been allocated to. In addition, subjects and therapists are only considered to be "blind" if it could be expected that they would have been unable to distinguish between the treatments applied to different groups. In trials in which key outcomes are self-reported (eg, visual analogue scale, pain diary), the assessor is considered to be blind if the subject was blind.
Criterion 8	This criterion is only satisfied if the report explicitly states *both* the number of subjects initially allocated to groups *and* the number of subjects from whom key outcome measures were obtained. In trials in which outcomes are measured at several points in time, a key outcome must have been measured in more than 85% of subjects at one of those points in time.
Criterion 9	An *intention to treat* analysis means that, where subjects did not receive treatment (or the control condition) as allocated, and where measures of outcomes were available, the analysis was performed as if subjects received the treatment (or control condition) they were allocated to. This criterion is satisfied, even if there is no mention of analysis by intention to treat, if the report explicitly states that all subjects received treatment or control conditions as allocated.
Criterion 10	A *between-group* statistical comparison involves statistical comparison of one group with another. Depending on the design of the study, this may involve comparison of two or more treatments, or comparison of treatment with a control condition. The analysis may be a simple comparison of outcomes measured after the treatment was administered, or a comparison of the change in one group with the change in another (when a factorial analysis of variance has been used to analyse the data, the latter is often reported as a group × time interaction). The comparison may be in the form hypothesis testing (which provides a "p" value, describing the probability that the groups differed only by chance) or in the form of an estimate (for example, the mean or median difference, or a difference in proportions, or number needed to treat, or a relative risk or hazard ratio) and its confidence interval.
Criterion 11	A *point measure* is a measure of the size of the treatment effect. The treatment effect may be described as a difference in group outcomes, or as the outcome in (each of) all groups. *Measures of variability* include standard deviations, standard errors, confidence intervals, interquartile ranges (or other quantile ranges), and ranges. Point measures and/or measures of variability may be provided graphically (for example, SDs may be given as error bars in a Figure) as long as it is clear what is being graphed (for example, as long as it is clear whether error bars represent SDs or SEs). Where outcomes are categorical, this criterion is considered to have been met if the number of subjects in each category is given for each group.

UNIVERSITY OF KWAZULU-NATAL™
INYUVESI YAKWAZULU-NATALI

11 September 2014

Mr Saul Cobbing
Department of Physiotherapy
E Block
Westville Campus
UKZN
cobbing@ukzn.ac.za

Dear Mr Cobbing

PROTOCOL: A home-based rehabilitation intervention for people living with HIV and disability in a resource -poor community, KwaZulu-Natal. REF: BFC052/14

The Biomedical Research Ethics Committee (BREC) has considered the abovementioned application.

The study was provisionally approved by a quorate meeting of BREC on 11 February 2014 pending appropriate responses to queries raised. Your responses dated 28 March 2014 to queries raised on 27 February 2014 have been noted and approved by a quorate Biomedical Research Ethics Committee meeting held on 09 September 2014. The conditions have now been met and the study is given full ethics approval and may begin as from 11 September 2014.

This approval is valid for one year from **11 September 2014.** To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on the appropriate BREC form 2-3 months before the expiry date.

Any amendments to this study, unless urgently required to ensure safety of participants, must be approved by BREC prior to implementation.

Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2004), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx. BREC is registered with the South African National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 678).

Biomedical Research Ethics Committee
Professor D R Wassenaar (Chair)
Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban 4000
Telephone: +27 (0) 31 260 2486 **Facsimile:** +27 (0) 31 260 4609 **Email:** brec@ukzn.ac.za
Website: http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx

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The following Committee members were present at the meeting that took place on 11 February 2014:

Prof D Wassenaar	Chair
Dr T Crankshaw	External - Public Health
Dr U Govind	Private Pract - Gen. Practitioner
Dr T Hardcastle	Surgery - Trauma
Dr Z Khumalo	KZN Health (External) General Medicine
Dr RN Naidoo	Family Medicine
Dr S Paruk	Psychiatry
Prof V Rambiritch	Pharmacology
Prof C Rout	Anaesthetics
Dr A Sathar	External
Dr D Singh	Critical Care
Dr S Singh	Dentistry
Prof J Tsoka-Gwegweni	Public Health

We wish you well with this study. We would appreciate receiving copies of all publications arising out of this study.

[redacted]

Chair: Biomedical Research Ethics Committee

Characteristics of studies that informed study HBR intervention

Authors	Participants (number)	Duration (weeks)	Frequency (weekly)	Location	Improvements			
					Strength	Aerobic	QoL	Other improvements
	PLHIV							
Lang (1993)[1]	10	Varying	Varying	Home	NA	NA	NA	
Lox (1996)[2]	33	12	3x	Not reported	Y	Y	NA	Body composition
Baigis (2002)[3]	123	15	3x	Home	N	N	NA	
Driscoll (2004)[4]	37	12	3x	Fitness centre	Y	Y	NA	Body composition
Fillipas (2006)[5]	40	24	2x	Clinic or gym	NA	Y	N	Self-efficacy, cognitive function
Dolan (2006)[6]	40	16	3x	Home	Y	Y	NA	Body composition
Lindegaard (2008)[7]	20	16	3x	Fitness centre	Y	Y	NA	Body composition
Mutimura (2008)[8]	100	24	3x	Fitness centre	NA	Y	Y	Body composition
Maharaj (2011)[9]	52	12	4x	Home and clinic	NA	NA	Y	
Yarasheski (2011)[10]	44	16	3x	Fitness centre	NA	NA	NA	Body composition
Roos (2014)[11]	84	52	3-5x	Home	NA	Y	N	Cardiac risk factors
Pullen (2014)[12]	1 (case study)	12	3x	Home and clinic	Y	Y	Y	CD4, body composition
	Other conditions							
Weaver (2003) [13]	*136 (Hip/knee replacement)*	24	Varying	Home	NA	NA	Y	Function
Siggeirsdottir (2005)[14]	*50 (Hip replacement)*	24	Varying	Home	NA	NA	Y	Function
Chaiyawat (2012)[15]	*60 (Stroke)*	24	Once monthly	Home	NA	NA	NA	Function
Salpakoski (2014) [16]	*81 (Hip fracture)*	52	Varying	Home	NA	NA	NA	Function

Y = improvement, N = no improvement; NA = not assessed; QoL = quality of life

References:

1. Lang C. Community physiotherapy for people with HIV/AIDS. *Physiotherapy*. 1993;79(3):163-167.
2. Lox CL, McAuley E, Tucker RS. Aerobic and resistance exercise training effects on body composition, muscular strength, and cardiovascular fitness in an hiv—1 population. *Int J Behav Med*. 1996;3(1):55-69.
3. Baigis J, Korniewicz DM, Chase G, Butz A, Jacobson D, Wu AW. Effectiveness of a home-based exercise intervention for HIV-infected adults: a randomized trial. *J Assoc Nurses AIDS Care*. 2002;13(2):33-45.
4. Driscoll SD, Meininger GE, Lareau MT, et al. Effects of exercise training and metformin on body composition and cardiovascular indices in HIV-infected patients. *Aids*. 2004;18(3):465-473.
5. Fillipas S, Oldmeadow LB, Bailey MJ, Cherry CL. A six-month, supervised, aerobic and resistance exercise program improves self-efficacy in people with human immunodeficiency virus: a randomised controlled trial. *Aust J Physiother*. 2006;52(Anthony 1991):185-190.

6. Dolan SE, Frontera W, Librizzi J, et al. Effects of a supervised home-based aerobic and progressive resistance training regimen in women infected with human immunodeficiency virus: a randomized trial. *Arch Intern Med*. 2006;166:1225-1231. doi:10.1001/archinte.166.11.1225.
7. Lindegaard B, Hansen T, Hvid T, et al. The effect of strength and endurance training on insulin sensitivity and fat distribution in human immunodeficiency virus-infected patients with lipodystrophy. *J Clin Endocrinol Metab*. 2008;93(10):3860-3869.
8. Mutimura E, Stewart A, Crowther NJ, Yarasheski KE, Cade WT. The effects of exercise training on quality of life in HAART-treated HIV-positive Rwandan subjects with body fat redistribution. *Qual Life Res*. 2008;17:377-385. doi:10.1007/s11136-008-9319-4.
9. Maharaj SS, Chetty V. Rehabilitation program for the quality of life for individuals on highly active antiretroviral therapy in KwaZulu-Natal, South Africa. *Int J Rehabil Res*. 2011;34:360-365. doi:10.1097/MRR.0b013e32834d2bab.
10. Yarasheski KE, Cade WT, Overton ET, et al. Exercise training augments the peripheral insulin-sensitizing effects of pioglitazone in HIV-infected adults with insulin resistance and central adiposity. *Am J Physiol Metab*. 2011;300(1):E243-E251.
11. Roos R, Myezwa H, Aswegen H Van, Musenge E. Effects of an Education and Home-Based Pedometer Walking Program on Ischemic Heart Disease Risk Factors in People Infected with HIV : A Randomized Trial. 2014;67(3):268-276.
12. Pullen SD, Chigbo NN, Nwigwe EC, Chukwuka CJ, Amah CC, Idu SC. Physiotherapy intervention as a complementary treatment for people living with HIV/AIDS. *HIV/AIDS - Res Palliat Care*. 2014;6:99-107. doi:10.2147/HIV.S62121.
13. Weaver F, Hynes D, Hopkinson W, et al. Preoperative risks and outcomes of hip and knee arthroplasty in the Veterans Health Administration. *J Arthroplasty*. 2003;18(6):693-708.
14. Siggeirsdottir K, Olafsson Ö, Jonsson Jr H, Iwarsson S, Gudnason V, Jonsson BY. Short hospital stay augmented with education and home-based rehabilitation improves function and quality of life after hip replacement: randomized study of 50 patients with 6 months of follow-up. *Acta Orthop*. 2005;76(4):555-562.
15. Chaiyawat P, Kulkantrakorn K. Effectiveness of home rehabilitation program for ischemic stroke upon disability and quality of life: a randomized controlled trial. *Clin Neurol Neurosurg*. 2012;114(7):866-870.
16. Salpakoski A, Törmäkangas T, Edgren J, et al. Effects of a multicomponent home-based physical rehabilitation program on mobility recovery after hip fracture: a randomized controlled trial. *J Am Med Dir Assoc*. 2014;15(5):361-368.

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English only
Distr.: General

WHOQOL-HIV BREF

MENTAL HEALTH: EVIDENCE AND RESEARCH
DEPARTMENT OF MENTAL HEALTH
AND SUBSTANCE DEPENDENCE
WORLD HEALTH ORGANIZATION
GENEVA

		Raw Score	Transformed Score	
Domain 1	(6-Q3) + (6-Q4) + Q14 + Q21 ☐ + ☐ + ☐ + ☐			
Domain 2	Q6 + Q11 + Q15 + Q24 + (6-Q31) ☐ + ☐ + ☐ + ☐ + ☐			
Domain 3	(6-Q5) + Q20 + Q22 + Q23 ☐ + ☐ + ☐ + ☐			
Domain 4	Q17 + Q25 + Q26 + Q27 ☐ + ☐ + ☐ + ☐			
Domain 5	Q12 + Q13 + Q16 + Q18 + Q19 + Q28 + Q29 + Q30 ☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐			
Domain 6	Q7 + (6–Q8) + (6-Q9) + (6-Q10) ☐ + ☐ + ☐ + ☐			

Further copies of this document may be obtained from

Department of Mental Health and Substance Dependence
World Health Organization
CH-1211 Geneva 27
Switzerland

ABOUT YOU

Before you begin we would like to ask you to answer a few general questions about yourself: by circling the correct answer or by filling in the space provided.

What is your **gender**?	Male / Female
How old are you?	_____________ (age in years)
What is the highest **education** you received?	None at all / Primary / Secondary / Tertiary
What is your **marital status**?	Single / Married/ Living as married / Separated / Divorced / Widowed
How is your **health**?	Very Poor / Poor / Neither Poor nor Good / Good / Very Good
Do you consider yourself currently ill?	Yes / No

If there is something wrong with you, what do you think it is? _________________________

Please respond to the following questions if they are applicable to you:

What is your **HIV serostatus**? Asymptomatic / Symptomatic / AIDS converted

In what year did you first **test positive** for HIV? ____________________________________

In what year do you think you were infected? ____

How do you believe you were **infected with HIV**? (circle one only):
Sex with a man / Sex with a woman / Injecting drugs / Blood products / Other (specify)_________________

Instructions

This assessment asks how you feel about your quality of life, health, or other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the one** that appears most appropriate. This can often be your first response. Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last two weeks.** For example, thinking about the last two weeks, a question might ask:

		Not at all	A little	A moderate amount	Very much	Extremely
11 (F5.3)	How well are you able to concentrate?	1	2	3	4	5

You should circle the number that best fits how well are you able to concentrate over the last two weeks. So you would circle the number 4 if you were able to concentrate very much. You would circle number 1 if you were not able to concentrate at all in the last two weeks.

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither poor nor good	Good	Very good
1(G1)	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2 (G4)	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3 (F1.4)	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4 (F50.1)	How much are you bothered by any physical problems related to your HIV infection?	1	2	3	4	5
5 (F11.3)	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
6 (F4.1)	How much do you enjoy life?	1	2	3	4	5
7 (F24.2)	To what extent do you feel your life to be meaningful?	1	2	3	4	5
8 (F52.2)	To what extent are you bothered by people blaming you for your HIV status	1	2	3	4	5
9 (F53.4)	How much do you fear the future?	1	2	3	4	5
10 (F54.1)	How much do you worry about death?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
11 (F5.3)	How well are you able to concentrate?	1	2	3	4	5
12 (F16.1)	How safe do you feel in your daily life?	1	2	3	4	5
13 (F22.1)	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely
14 (F2.1)	Do you have enough energy for everyday life?	1	2	3	4	5
15 (F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5
16 (F18.1)	Have you enough money to meet your needs?	1	2	3	4	5
17 (F51.1)	To what extent do you feel accepted by the people you know?	1	2	3	4	5
18 (F20.1)	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5

19 (F21.1)	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
20 (F9.1)	How well are you able to get around?	1	2	3	4	5

The following questions ask you how **good or satisfied** you have felt about various aspects of your life over the last two weeks.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
21 (F3.3)	How satisfied are you with your sleep?	1	2	3	4	5
22 (F10.3)	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
23 (F12.4)	How satisfied are you with your capacity for work?	1	2	3	4	5
24 (F6.3)	How satisfied are you with yourself?	1	2	3	4	5
25 (F13.3)	How satisfied are you with your personal relationships?	1	2	3	4	5
26 (F15.3)	How satisfied are you with your sex life?	1	2	3	4	5
27 (F14.4)	How satisfied are you with the support you get from your friends?	1	2	3	4	5
28 (F17.3)	How satisfied are you with the conditions of your living place?	1	2	3	4	5
29 (F19.3)	How satisfied are you with your access to health services?	1	2	3	4	5
30 (F23.3)	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
31 (F8.1)	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Did someone help you to fill out this form? ____

How long did it take to fill this form out? ____

Do you have any comments about the assessment? ______________________________________

____

____

____

THANK YOU FOR YOUR HELP

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WORLD HEALTH ORGANIZATION
DISABILITY ASSESSMENT SCHEDULE 2.0

12-item version, interviewer-administered

Introduction

This instrument was developed by the WHO *Classification, Terminology and Standards* team, within the framework of the WHO/National Institutes of Health (NIH) Joint Project on Assessment and Classification of Disability.

Before using this instrument, interviewers must be trained using the manual *Measuring Health and Disability: Manual for WHO Disability Assessment Schedule – WHODAS 2.0* (WHO, 2010), which includes an interview guide and other training material.

The versions of the interview available are as follows:

- 36-item – Interviewer-administered[a]
- 36-item – Self-administered
- 36-item – Proxy-administered[b]
- 12-item – Interviewer-administered[c]
- 12-item – Self-administered
- 12-item – Proxy-administered
- 12+24-item – Interviewer-administered

[a] A computerized version of the interview (*iShell*) is available for computer-assisted interviews or for data entry

[b] Relatives, friends or caretakers

[c] The 12-item version explains 81% of the variance of the more detailed 36-item version

For more details of the versions please refer to the WHODAS 2.0 manual *Measuring Health and Disability: Manual for WHO Disability Assessment Schedule – WHODAS 2.0* (WHO, 2010).

Permission to translate this instrument into any language should be obtained from WHO, and all translations should be prepared according to the WHO translation guidelines, as detailed in the accompanying manual.

For additional information, please visit www.who.int/whodas or contact:

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WHODAS 2.0

WORLD HEALTH ORGANIZATION
DISABILITY ASSESSMENT SCHEDULE 2.0

12
Interview

This questionnaire contains the interviewer-administered, 12-item version of WHODAS 2.0.

Instructions to the interviewer are written in bold and italics – do not read these aloud

Text for the respondent to hear is written in

standard print in blue.

Read this text aloud

Section 1 Face sheet

Complete items F1–F5 before starting each interview				
F1	Respondent identity number			
F2	Interviewer identity number			
F3	Assessment time point (1, 2, etc)			
F4	Interview date	______ day	______ month	______ year
F5	Living situation at time of interview (circle only one)	Independent in community		1
		Assisted living		2
		Hospitalized		3

Please continue to next page ...

WHODAS 2.0

WORLD HEALTH ORGANIZATION
DISABILITY ASSESSMENT SCHEDULE 2.0

12
Interview

Section 2 Demographic and background information

This interview has been developed by the World Health Organization (WHO) to better understand the difficulties people may have due to their health conditions. The information that you provide in this interview is confidential and will be used only for research. The interview will take 5–10 minutes to complete.

For respondents from the general population (not the clinical population) say:

Even if you are healthy and have no difficulties, I need to ask all of the questions so that the survey is complete.

I will start with some background questions.

A1	***Record sex as observed***	Female	1
		Male	2
A2	How old are you now?	______ years	
A3	How many years in all did you spend studying in school, college or university?	______ years	
A4	What is your current marital status? ***(Select the single best option)***	Never married	1
		Currently married	2
		Separated	3
		Divorced	4
		Widowed	5
		Cohabiting	6
A5	Which describes your main work status best? ***(Select the single best option)***	Paid work	1
		Self-employed, such as own your business or farming	2
		Non-paid work, such as volunteer or charity	3
		Student	4
		Keeping house/ homemaker	5
		Retired	6
		Unemployed (health reasons)	7
		Unemployed (other reasons)	8
		Other (specify)______________ ____________________	9

Please continue to next page...

Section 3 Preamble

Say to respondent:

The interview is about difficulties people have because of health conditions.

Hand flashcard #1 to respondent

By health condition I mean diseases or illnesses, or other health problems that may be short or long lasting; injuries; mental or emotional problems; and problems with alcohol or drugs.

Remember to keep all of your health problems in mind as you answer the questions. When I ask you about difficulties in doing an activity think about...

Point to flashcard #1

- Increased effort
- Discomfort or pain
- Slowness
- Changes in the way you do the activity.

When answering, I'd like you to think back over the past 30 days. I would also like you to answer these questions thinking about how much difficulty you have had, on average, over the past 30 days, while doing the activity as you usually do it.

Hand flashcard #2 to respondent

Use this scale when responding.

Read scale aloud:

None, mild, moderate, severe, extreme or cannot do.

Ensure that the respondent can easily see flashcards #1 and #2 throughout the interview

Please continue to next page...

WHODAS 2.0

WORLD HEALTH ORGANIZATION
DISABILITY ASSESSMENT SCHEDULE 2.0

12
Interview

Section 4 Core questions

Show flashcard #2

In the past 30 days, how much difficulty did you have in:		None	Mild	Moderate	Severe	Extreme or cannot do
S1	Standing for long periods such as 30 minutes?	1	2	3	4	5
S2	Taking care of your household responsibilities?	1	2	3	4	5
S3	Learning a new task, for example, learning how to get to a new place?	1	2	3	4	5
S4	How much of a problem did you have joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?	1	2	3	4	5
S5	How much have you been emotionally affected by your health problems?	1	2	3	4	5

In the past 30 days, how much difficulty did you have in:		None	Mild	Moderate	Severe	Extreme or cannot do
S6	Concentrating on doing something for ten minutes?	1	2	3	4	5
S7	Walking a long distance such as a kilometre [or equivalent]?	1	2	3	4	5
S8	Washing your whole body?	1	2	3	4	5
S9	Getting dressed?	1	2	3	4	5
S10	Dealing with people you do not know?	1	2	3	4	5
S11	Maintaining a friendship?	1	2	3	4	5
S12	Your day-to-day work/school?	1	2	3	4	5

H1	Overall, in the past 30 days, how many days were these difficulties present?	***Record number of days*** ____
H2	In the past 30 days, for how many days were you totally unable to carry out your usual activities or work because of any health condition?	***Record number of days*** ____
H3	In the past 30 days, not counting the days that you were totally unable, for how many days did you cut back or reduce your usual activities or work because of any health condition?	***Record number of days*** ____

This concludes our interview. Thank you for participating.

Health conditions:

- Diseases, illnesses or other health problems
- Injuries
- Mental or emotional problems
- Problems with alcohol
- Problems with drugs

Having difficulty with an activity means:

- Increased effort
- Discomfort or pain
- Slowness
- Changes in the way you do the activity

Think about the past 30 days only.

WHODAS 2.0

WORLD HEALTH ORGANIZATION
DISABILITY ASSESSMENT SCHEDULE 2.0

Flashcard 2

1	2	3	4	5
None	**Mild**	**Moderate**	**Severe**	**Extreme or cannot do**

The Rivermead Mobility Index

Name: ___________________________

Day							
Month							
Year							
Topic and Question:							
Turning over in bed: Do you turn over from your back to your side without help?							
Lying to sitting: From lying in bed, do you get up to sit on the edge of the bed on your own?							
Sitting balance: Do you sit on the edge of the bed without holding on for 10 seconds?							
Sitting to standing: Do you stand up from any chair in less than 15 seconds and stand there for 15 seconds, using hands and/or an aid if necessary?							
Standing unsupported: (Ask to stand) Observe standing for 10 seconds without any aid							
Transfer: Do you manage to move from bed to chair and back without any help?							
Walking inside: (with an aid if necessary): Do you walk 10 meters, with an aid if necessary, but with no standby help?							
Stairs: Do you manage a flight of stairs without help?							
Walking outside: (even ground): Do you walk around outside, on pavements, without help?							
Walking inside: (with no aid): Do you walk 10 meters inside, with no caliper, splint, or other aid (including furniture or walls) without help?							
Picking up off floor: Do you manage to walk five meters, pick something up from the floor, and then walk back without help?							
Walking outside: (uneven ground): Do you walk over uneven ground (grass, gravel, snow, ice etc) without help?							
Bathing: Do you get into/out of a bath or shower and to wash yourself unsupervised and without help?							
Up and down four steps: Do you manage to go up and down four steps with no rail, but using an aid if necessary?							
Running: Do you run 10 meters without limping in four seconds (fast walk, not limping, is acceptable)?							
Total							

The Rivermead Mobility Index is provided courtesy of Dr. Derick Wade and the Oxford Centre for Enablement.

American Thoracic Society

ATS Statement: Guidelines for the Six-Minute Walk Test

THIS OFFICIAL STATEMENT OF THE AMERICAN THORACIC SOCIETY WAS APPROVED BY THE ATS BOARD OF DIRECTORS MARCH 2002

CONTENTS

PURPOSE AND SCOPE

This statement provides practical guidelines for the 6-minute walk test (6MWT). Specifically, it reviews indications, details factors that influence results, presents a brief step-by-step protocol, outlines safety measures, describes proper patient preparation and procedures, and offers guidelines for clinical interpretation of results. These recommendations are not intended to limit the use of alternative protocols for research studies. We do not discuss the general topic of clinical exercise testing.

As with other American Thoracic Society statements on pulmonary function testing, these guidelines come out of a consensus conference. Drafts were prepared by two members (P.L.E. and R.J.Z.) and were based on a comprehensive Medline literature search from 1970 through 2001, augmented by suggestions from other committee members. Each draft responded to comments from the working committee. The guidelines follow previously published methods as closely as possible and provide a rationale for each specific recommendation. The final recommendations represent a consensus of the committee. The committee recommends that these guidelines be reviewed in five years and in the meantime encourages further research in areas of controversy.

BACKGROUND

There are several modalities available for the objective evaluation of functional exercise capacity. Some provide a very complete assessment of all systems involved in exercise performance (high tech), whereas others provide basic information but are low tech and are simpler to perform. The modality used should be chosen based on the clinical question to be addressed and on available resources. The most popular clinical exercise tests in order of increasing complexity are stair climbing, a 6MWT, a shuttle-walk test, detection of exercise-induced asthma, a cardiac stress test (e.g., Bruce protocol), and a cardiopulmonary exercise test (1, 2). Other professional organizations have published standards for cardiac stress testing (3, 4).

Assessment of functional capacity has traditionally been done by merely asking patients the following: “How many flights of stairs can you climb or how many blocks can you walk?” However, patients vary in their recollection and may report overestimations or underestimations of their true functional capacity. Objective measurements are usually better than self-reports. In the early 1960s, Balke developed a simple test to evaluate the functional capacity by measuring the distance walked during a defined period of time (5). A 12-minute field performance test was then developed to evaluate the level of physical fitness of healthy individuals (6). The walking test was also adapted to assess disability in patients with chronic bronchitis (7). In an attempt to accommodate patients with respiratory disease for whom walking 12 minutes was too exhausting, a 6-minute walk was found to perform as well as the 12-minute walk (8). A recent review of functional walking tests concluded that “the 6MWT is easy to administer, better tolerated, and more reflective of activities of daily living than the other walk tests” (9).

The 6MWT is a practical simple test that requires a 100-ft hallway but no exercise equipment or advanced training for technicians. Walking is an activity performed daily by all but the most severely impaired patients. This test measures the distance that a patient can quickly walk on a flat, hard surface in a period of 6 minutes (the 6MWD). It evaluates the global and integrated responses of all the systems involved during exercise, including the pulmonary and cardiovascular systems, systemic circulation, peripheral circulation, blood, neuromuscular units, and muscle metabolism. It does not provide specific information on the function of each of the different organs and systems involved in exercise or the mechanism of exercise limitation, as is possible with maximal cardiopulmonary exercise testing. The self-paced 6MWT assesses the submaximal level of functional capacity. Most patients do not achieve maximal exercise capacity during the 6MWT; instead, they choose their own intensity of exercise and are allowed to stop and rest during the test. However, because most activities of daily living are performed at submaximal levels of exertion, the 6MWD may better reflect the functional exercise level for daily physical activities.

INDICATIONS AND LIMITATIONS

The strongest indication for the 6MWT is for measuring the response to medical interventions in patients with moderate to severe heart or lung disease. The 6MWT has also been used as a one-time measure of functional status of patients, as well as a predictor of morbidity and mortality (*see* Table 1 for a list of these indications). The fact that investigators have used the 6MWT in these settings does not prove that the test is clinically useful (or the best test) for determining functional capacity or changes in functional capacity due to an intervention in patients with these diseases. Further studies are necessary to determine the utility of the 6MWT in various clinical situations.

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Formal cardiopulmonary exercise testing provides a global assessment of the exercise response, an objective determination of functional capacity and impairment, determination of the appropriate intensity needed to perform prolonged exercise, quantification of factors limiting exercise, and a definition of the underlying pathophysiologic mechanisms such as the contribution of different organ systems involved in exercise. The 6MWT does not determine peak oxygen uptake, diagnose the cause of dyspnea on exertion, or evaluate the causes or mechanisms of exercise limitation (1, 2). The information provided by a 6MWT should be considered complementary to cardiopulmonary exercise testing, not a replacement for it. Despite the difference between these two functional tests, some good correlations between them have been reported. For example, a significant correlation (r = 0.73) between 6MWD and peak oxygen uptake has been reported for patients with end-stage lung diseases (36, 37).

In some clinical situations, the 6MWT provides information that may be a better index of the patient's ability to perform daily activities than is peak oxygen uptake; for example, 6MWD correlates better with formal measures of quality of life (38). Changes in 6MWD after therapeutic interventions correlate with subjective improvement in dyspnea (39, 40). The reproducibility of the 6MWD (with a coefficient of variation of approximately 8%) appears to be better than the reproducibility of 1-second forced expiratory volume in patients with chronic obstructive pulmonary disease (COPD) (8, 41–43). Questionnaire indices of functional status have a larger short-term variability (22–33%) than does the 6MWD (37).

The shuttle-walking test is similar to the 6MWT, but it uses an audio signal from a tape cassette to direct the walking pace of the patient back and forth on a 10-m course (44–47). The walking speed is increased every minute, and the test ends when the patient cannot reach the turnaround point within the required time. The exercise performed is similar to a symptom-limited, maximal, incremental treadmill test. An advantage of the shuttle walking test is that it has a better correlation with peak oxygen uptake than the 6MWD. Disadvantages include less validation, less widespread use, and more potential for cardiovascular problems.

CONTRAINDICATIONS

Absolute contraindications for the 6MWT include the following: unstable angina during the previous month and myocardial infarction during the previous month. Relative contraindications include a resting heart rate of more than 120, a systolic blood pressure of more than 180 mm Hg, and a diastolic blood pressure of more than 100 mm Hg.

Patients with any of these findings should be referred to the physician ordering or supervising the test for individual clinical assessment and a decision about the conduct of the test. The results from a resting electrocardiogram done during the previous 6 months should also be reviewed before testing. Stable exertional angina is not an absolute contraindication for a 6MWT, but patients with these symptoms should perform the test after using their antiangina medication, and rescue nitrate medication should be readily available.

Rationale

Patients with the previously mentioned risk factors may be at increased risk for arrhythmias or cardiovascular collapse during testing. However, each patient determines the intensity of their exercise, and the test (without electrocardiogram monitoring) has been performed in thousands of older persons (31, 48–50) and thousands of patients with heart failure or cardiomyopathy (32, 51, 52) without serious adverse events. The contraindications listed previously here were used by study investigators based on their impressions of the general safety of the 6MWT and their desire to be prudent, but it is unknown whether adverse events would occur if such patients performed a 6MWT; they are, therefore, listed as relative contraindications.

TABLE 1. INDICATIONS FOR THE SIX-MINUTE WALK TEST

- Pretreatment and posttreatment comparisons
  - Lung transplantation (9, 10)
  - Lung resection (11)
  - Lung volume reduction surgery (12, 13)
  - Pulmonary rehabilitation (14, 15)
  - COPD (16–18)
  - Pulmonary hypertension
  - Heart failure (19, 20)
- Functional status (single measurement)
  - COPD (21, 22)
  - Cystic fibrosis (23, 24)
  - Heart failure (25–27)
  - Peripheral vascular disease (28, 29)
  - Fibromyalgia (30)
  - Older patients (31)
- Predictor of morbidity and mortality
  - Heart failure (32, 33)
  - COPD (34, 35)
  - Primary pulmonary hypertension (10, 36)

Definition of abbreviation: COPD = chronic obstructive pulmonary disease.

SAFETY ISSUES

1. Testing should be performed in a location where a rapid, appropriate response to an emergency is possible. The appropriate location of a crash cart should be determined by the physician supervising the facility.
2. Supplies that must be available include oxygen, sublingual nitroglycerine, aspirin, and albuterol (metered dose inhaler or nebulizer). A telephone or other means should be in place to enable a call for help.
3. The technician should be certified in cardiopulmonary resuscitation with a minimum of Basic Life Support by an American Health Association–approved cardiopulmonary resuscitation course. Advanced cardiac life support certification is desirable. Training, experience, and certification in related health care fields (registered nurse, registered respiratory therapist, certified pulmonary function technician, etc.) are also desirable. A certified individual should be readily available to respond if needed.
4. Physicians are not required to be present during all tests. The physician ordering the test or a supervising laboratory physician may decide whether physician attendance at a specific test is required.
5. If a patient is on chronic oxygen therapy, oxygen should be given at their standard rate or as directed by a physician or a protocol.

Reasons for immediately stopping a 6MWT include the following: (*1*) chest pain, (*2*) intolerable dyspnea, (*3*) leg cramps, (*4*) staggering, (*5*) diaphoresis, and (*6*) pale or ashen appearance.

Technicians must be trained to recognize these problems and the appropriate responses. If a test is stopped for any of these reasons, the patient should sit or lie supine as appropriate depending on the severity or the event and the technician's assessment of the severity of the event and the risk of syncope. The following should be obtained based on the judgment of the technician: blood pressure, pulse rate, oxygen saturation, and a physician evaluation. Oxygen should be administered as appropriate.

TECHNICAL ASPECTS OF THE 6MWT

Location

The 6MWT should be performed indoors, along a long, flat, straight, enclosed corridor with a hard surface that is seldom traveled. If the weather is comfortable, the test may be performed outdoors. The walking course must be 30 m in length. A 100-ft hallway is, therefore, required. The length of the corridor should be marked every 3 m. The turnaround points should be marked with a cone (such as an orange traffic cone). A starting line, which marks the beginning and end of each 60-m lap, should be marked on the floor using brightly colored tape.

Rationale. A shorter corridor requires patients to take more time to reverse directions more often, reducing the 6MWD. Most studies have used a 30-m corridor, but some have used 20- or 50-m corridors (52–55). A recent multicenter study found no significant effect of the length of straight courses ranging from 50 to 164 ft, but patients walked farther on continuous (oval) tracks (mean 92 ft farther) (54).

The use of a treadmill to determine the 6MWD might save space and allow constant monitoring during the exercise, but the use of a treadmill for 6-minute walk testing is not recommended. Patients are unable to pace themselves on a treadmill. In one study of patients with severe lung disease, the mean distance walked on the treadmill during 6 minutes (with the speed adjusted by the patients) was shorter by a mean of 14% when compared with the standard 6MWD using a 100-ft hallway (57). The range of differences was wide, with patients walking between 400–1,300 ft on the treadmill who walked 1,200 ft in the hallway. Treadmill test results, therefore, are not interchangeable with corridor tests.

REQUIRED EQUIPMENT

1. Countdown timer (or stopwatch)
2. Mechanical lap counter
3. Two small cones to mark the turnaround points
4. A chair that can be easily moved along the walking course
5. Worksheets on a clipboard
6. A source of oxygen
7. Sphygmomanometer
8. Telephone
9. Automated electronic defibrillator

PATIENT PREPARATION

1. Comfortable clothing should be worn.
2. Appropriate shoes for walking should be worn.
3. Patients should use their usual walking aids during the test (cane, walker, etc.).
4. The patient’s usual medical regimen should be continued.
5. A light meal is acceptable before early morning or early afternoon tests.
6. Patients should not have exercised vigorously within 2 hours of beginning the test.

MEASUREMENTS

1. Repeat testing should be performed about the same time of day to minimize intraday variability.
2. A “warm-up” period before the test should not be performed.
3. The patient should sit at rest in a chair, located near the starting position, for at least 10 minutes before the test starts. During this time, check for contraindications, measure pulse and blood pressure, and make sure that clothing and shoes are appropriate. Compete the first portion of the worksheet (*see* the Appendix).
4. Pulse oximetry is optional. If it is performed, measure and record baseline heart rate and oxygen saturation (SpO_2) and follow manufacturer’s instructions to maximize the signal and to minimize motion artifact (56, 57). Make sure the readings are stable before recording. Note pulse regularity and whether the oximeter signal quality is acceptable.

   The rationale for measuring oxygen saturation is that although the distance is the primary outcome measure, improvement during serial evaluations may be manifest either by an increased distance or by reduced symptoms with the same distance walked (39). The SpO_2 should not be used for constant monitoring during the exercise. The technician must not walk with the patient to observe the SpO_2. If worn during the walk, the pulse oximeter must be lightweight (less than 2 pounds), battery powered, and held in place (perhaps by a “fanny pack”) so that the patient does not have to hold or stabilize it and so that stride is not affected. Many pulse oximeters have considerable motion artifact that prevents accurate readings during the walk. (57)

5. Have the patient stand and rate their baseline dyspnea and overall fatigue using the Borg scale (*see* Table 2 for the Borg scale and instructions [58]).
6. Set the lap counter to zero and the timer to 6 minutes. Assemble all necessary equipment (lap counter, timer, clipboard, Borg Scale, worksheet) and move to the starting point.
7. Instruct the patient as follows:

   “The object of this test is to walk as far as possible for 6 minutes. You will walk back and forth in this hallway. Six minutes is a long time to walk, so you will be exerting yourself. You will probably get out of breath or become exhausted. You are permitted to slow down, to stop, and to rest as necessary. You may lean against the wall while resting, but resume walking as soon as you are able.

   You will be walking back and forth around the cones. You should pivot briskly around the cones and continue back the other way without hesitation. Now I’m going to show you. Please watch the way I turn without hesitation.”

   Demonstrate by walking one lap yourself. Walk and pivot around a cone briskly.

   “Are you ready to do that? I am going to use this counter to keep track of the number of laps you complete. I will click it each time you turn around at this starting line. Remember that the object is to walk AS FAR AS POSSIBLE for 6 minutes, but don’t run or jog.

   Start now, or whenever you are ready.”

TABLE 2. THE BORG SCALE

0	Nothing at all
0.5	Very, very slight (just noticeable)
1	Very slight
2	Slight (light)
3	Moderate
4	Somewhat severe
5	Severe (heavy)
6	
7	Very severe
8	
9	
10	Very, very severe (maximal)

This Borg scale should be printed on heavy paper (11 inches high and perhaps laminated) in 20-point type size. At the beginning of the 6-minute exercise, show the scale to the patient and ask the patient this: “Please grade your level of shortness of breath using this scale.” Then ask this: “Please grade your level of fatigue using this scale.”

At the end of the exercise, remind the patient of the breathing number that they chose before the exercise and ask the patient to grade their breathing level again. Then ask the patient to grade their level of fatigue, after reminding them of their grade before the exercise.

8. Position the patient at the starting line. You should also stand near the starting line during the test. Do not walk with the patient. As soon as the patient starts to walk, start the timer.
9. Do not talk to anyone during the walk. Use an even tone of voice when using the standard phrases of encouragement. Watch the patient. Do not get distracted and lose count of the laps. Each time the participant returns to the starting line, click the lap counter once (or mark the lap on the worksheet). Let the participant see you do it. Exaggerate the click using body language, like using a stopwatch at a race.

   After the first minute, tell the patient the following (in even tones): "You are doing well. You have 5 minutes to go."

   When the timer shows 4 minutes remaining, tell the patient the following: "Keep up the good work. You have 4 minutes to go."

   When the timer shows 3 minutes remaining, tell the patient the following: "You are doing well. You are halfway done."

   When the timer shows 2 minutes remaining, tell the patient the following: "Keep up the good work. You have only 2 minutes left."

   When the timer shows only 1 minute remaining, tell the patient: "You are doing well. You have only 1 minute to go."

   Do not use other words of encouragement (or body language to speed up).

   If the patient stops walking during the test and needs a rest, say this: "You can lean against the wall if you would like; then continue walking whenever you feel able." Do not stop the timer. If the patient stops before the 6 minutes are up and refuses to continue (or you decide that they should not continue), wheel the chair over for the patient to sit on, discontinue the walk, and note on the worksheet the distance, the time stopped, and the reason for stopping prematurely.

   When the timer is 15 seconds from completion, say this: "In a moment I'm going to tell you to stop. When I do, just stop right where you are and I will come to you."

   When the timer rings (or buzzes), say this: "Stop!" Walk over to the patient. Consider taking the chair if they look exhausted. Mark the spot where they stopped by placing a bean bag or a piece of tape on the floor.
10. Post-test: Record the postwalk Borg dyspnea and fatigue levels and ask this: "What, if anything, kept you from walking farther?"
11. If using a pulse oximeter, measure SpO_2 and pulse rate from the oximeter and then remove the sensor.
12. Record the number of laps from the counter (or tick marks on the worksheet).
13. Record the additional distance covered (the number of meters in the final partial lap) using the markers on the wall as distance guides. Calculate the total distance walked, rounding to the nearest meter, and record it on the worksheet.
14. Congratulate the patient on good effort and offer a drink of water.

QUALITY ASSURANCE

Sources of Variability

There are many sources of 6MWD variability (*see* Table 3). The sources of variability caused by the test procedure itself should be controlled as much as possible. This is done by following the standards found in this document and by using a quality-assurance program.

Practice Tests

A practice test is not needed in most clinical settings but should be considered. If a practice test is done, wait for at least 1 hour before the second test and report the highest 6MWD as the patient's 6MWD baseline.

Rationale. The 6MWD is only slightly higher for a second 6MWT performed a day later. The mean reported increase ranges from 0 to 17% (23, 27, 40, 41, 54, 59). A multicenter study of 470 highly motivated patients with severe COPD performed two 6MWTs 1 day apart, and on average, the 6MWD was only 66 ft (5.8%) higher on the second day (54).

Performance (without an intervention) usually reaches a plateau after two tests done within a week (8, 60). The training effect may be due to improved coordination, finding optimal stride length, and overcoming anxiety. The possibility of a practice or training effect from tests repeated after more than a month has not been studied or reported; however, it is likely that the effect of training wears off (does not persist) after a few weeks.

Technician Training and Experience

Technicians who perform 6MWTs should be trained using the standard protocol and then supervised for several tests before performing them alone. They should also have completed cardiopulmonary resuscitation training.

Rationale. One multicenter study of older people found that after correction for many other factors, two of the technicians had mean 6MWDs that were approximately 7% lower than the other two sites (31).

Encouragement

Only the standardized phrases for encouragement (as specified previously here) must be used during the test.

Rationale. Encouragement significantly increases the distance walked (42). Reproducibility for tests with and without encouragement is similar. Some studies have used encouragement every 30 seconds, every minute, or every 2 minutes. We have chosen every minute and standard phrases. Some studies (53) have instructed patients to walk as fast as possible. Although larger mean 6MWDs may be obtained thereby, we recommend that such phrases not be used, as they emphasize initial speed at the expense of earlier fatigue and possible excessive cardiac stress in some patients with heart disease.

TABLE 3. 6MWD SOURCES OF VARIABILITY

Factors reducing the 6MWD
Shorter height
Older age
Higher body weight
Female sex
Impaired cognition
A shorter corridor (more turns)
Pulmonary disease (COPD, asthma, cystic fibrosis, interstitial lung disease)
Cardiovascular disease (angina, MI, CHF, stroke, TIA, PVD, AAI)
Musculoskeletal disorders (arthritis, ankle, knee, or hip injuries, muscle wasting, etc.)
Factors increasing the 6MWD
Taller height (longer legs)
Male sex
High motivation
A patient who has previously performed the test
Medication for a disabling disease taken just before the test
Oxygen supplementation in patients with exercise-induced hypoxemia

Definition of abbreviations: COPD = chronic obstructive pulmonary disease; 6MWD = 6-minute walking distance.

Supplemental Oxygen

If oxygen supplementation is needed during the walks and serial tests are planned (after an intervention other than oxygen therapy), then during all walks by that patient oxygen should be delivered in the same way with the same flow. If the flow must be increased during subsequent visits due to worsening gas exchange, this should be noted on the worksheet and considered during interpretation of the change noted in 6MWD. The type of oxygen delivery device should also be noted on the report: for instance, the patient carried liquid oxygen or pushed or pulled an oxygen tank, the delivery was pulsed or continuous, or a technician walked behind the patient with the oxygen source (not recommended). Measurements of pulse and SpO_2 should be made after waiting at least 10 minutes after any change in oxygen delivery.

Rationale. For patients with COPD or interstitial lung disease, oxygen supplementation increases the 6MWD (17, 59, 61, 63). Carrying a portable gas container (but not using it for supplemental oxygen) reduced the mean 6MWD by 14% in one study of patients with severe respiratory disability, but using the container to deliver supplemental oxygen during the exercise increased the mean 6MWD by 20–35% (59).

Medications

The type of medication, dose, and number of hours taken before the test should be noted.

Rationale. Significant improvement in the distance walked, or the dyspnea scale, after administration of bronchodilators has been demonstrated in patients with COPD (62, 63), as well as cardiovascular medications in patients with heart failure (19).

INTERPRETATION

Most 6MWTs will be done before and after intervention, and the primary question to be answered after both tests have been completed is whether the patient has experienced a clinically significant improvement. With a good quality-assurance program, with patients tested by the same technician, and after one or two practice tests, short-term reproducibility of the 6MWD is excellent (37). It is not known whether it is best for clinical purposes to express change in 6MWD as (*1*) an absolute value, (*2*) a percentage change, or (*3*) a change in the percentage of predicted value. Until further research is available, we recommend that change in 6MWD be expressed as an absolute value (e.g., the patient walked 50 m farther).

A statistically significant mean increase in 6MWD in a group of study participants is often much less than a clinically significant increase in an individual patient. In one study of 112 patients (half of them women) with stable, severe COPD, the smallest difference in 6MWD that was associated with a noticeable clinical difference in the patients' perception of exercise performance was a mean of 54 m (95% confidence interval, 37–71 m) (64). This study suggests that for individual patients with COPD, an improvement of more than 70 m in the 6MWD after an intervention is necessary to be 95% confident that the improvement was significant. In an observational study of 45 older patients with heart failure, the smallest difference in 6MWD that was associated with a noticeable difference in their global rating of worsening was a mean of 43 m (20). The 6MWD was more responsive to deterioration than to improvement in heart failure symptoms.

Reported Mean Changes in 6MWD After Interventions

Supplemental oxygen (4 L/min) during exercise in patients with COPD or interstitial lung disease increased mean 6MWD by approximately 95 m (36%) in one study (59). Patients taking an inhaled corticosteroid experienced a mean 33 m (8%) increase in 6MWD in an international COPD study (16). Patients with COPD in a study of the effects of exercise and diaphragmatic strength training experienced a mean increase in 6MWD of 50 m (20%) (65). Lung volume reduction surgery in patients with very severe COPD has been reported to increase 6MWD by a mean of 55 m (20%) (13).

Cardiac rehabilitation in patients referred with various heart diseases increased 6MWD by a mean of 170 m (15%) in a recent study (66). In 25 older patients with heart failure, an angiotensin-converting enzyme inhibitor medication (50 mg captopril per day) improved 6MWD a mean of 64 m (39%) compared with a mean increase of only 8% in those receiving a placebo (19).

Interpreting Single Measurements of Functional Status

Optimal reference equations from healthy population-based samples using standardized 6MWT methods are not yet available. In one study, the median 6MWD was approximately 580 m for 117 healthy men and 500 m for 173 healthy women (50). A mean 6MWD of 630 m was reported by another study of 51 healthy older adults (55). Differences in the population sampled, type and frequency of encouragement, corridor length, and number of practice tests may account for reported differences in mean 6MWD in healthy persons. Age, height, weight, and sex independently affect the 6MWD in healthy adults; therefore, these factors should be taken into consideration when interpreting the results of single measurements made to determine functional status. We encourage investigators to publish reference equations for healthy persons using the previously mentioned standardized procedures.

A low 6MWD is nonspecific and nondiagnostic. When the 6MWD is reduced, a thorough search for the cause of the impairment is warranted. The following tests may then be helpful: pulmonary function, cardiac function, ankle–arm index, muscle strength, nutritional status, orthopedic function, and cognitive function.

Conclusions

The 6MWT is a useful measure of functional capacity targeted at people with at least moderately severe impairment. The test has been widely used for preoperative and postoperative evaluation and for measuring the response to therapeutic interventions for pulmonary and cardiac disease. These guidelines provide a standardized approach to performing the 6MWT. The committee hopes that these guidelines will encourage further research into the 6MWT and allow direct comparisons among different studies.

This statement was developed by the ATS Committee on Proficiency Standards for Clinical Pulmonary Function Laboratories.

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References

1. Wasserman K, Hansen JE, Sue DY, Casaburi R, Whipp BJ. Principles of exercise testing and interpretation, 3rd edition. Philadelphia: Lippincott, Williams & Wilkins; 1999.

2. Weisman IM, Zeballos RJ. An integrated approach to the interpretation of cardiopulmonary exercise testing. *Clin Chest Med* 1994;15:421–445.
3. Fletcher GF, Balady G, Froelicher VF, Hartley LH, Haskell WL, Pollock ML. Exercise standards: a statement for healthcare professionals from the American Heart Association: writing group. *Circulation* 1995; 91:580–615.
4. Pina IL, Balady GJ, Hanson P, Labovitz AJ, Madonna DW, Myers J. Guidelines for clinical exercise testing laboratories: a statement for healthcare professionals from the Committee on Exercise and Cardiac Rehabilitation, American Heart Association. *Circulation* 1995;91:912–921.
5. Balke B. A simple field test for the assessment of physical fitness. *CARI Report* 1963;63:18.
6. Cooper KH. A means of assessing maximal oxygen intake: correlation between field and treadmill testing. *JAMA* 1968;203:201–204.
7. McGavin CR, Gupta SP, McHardy GJR. Twelve-minute walking test for assessing disability in chronic bronchitis. *BMJ* 1976;1:822–823.
8. Butland RJA, Pang J, Gross ER, Woodcock AA, Geddes DM. Two-, six-, and 12-minute walking tests in respiratory disease. *BMJ* 1982; 284:1607–1608.
9. Solway S, Brooks D, Lacasse Y, Thomas S. A qualitative systematic overview of the measurement properties of functional walk tests used in the cardiorespiratory domain. *Chest* 2001;119:256–270.
10. Kadikar A, Maurer J, Kesten S. The six-minute walk test: a guide to assessment for lung transplantation. *J Heart Lung Transplant* 1997;16: 313–319.
11. Holden DA, Rice TW, Stelmach K, Meeker DP. Exercise testing, 6 min walk, and stair climb in the evaluation of patients at high risk for pulmonary resection. *Chest* 1992;102:1774–1779.
12. Sciurba FC, Rogers RM, Keenan RJ, Slivka WA, Gorcsan J 3rd, Ferson PF, Holbert JM, Brown ML, Landreneau RJ. Improvement in pulmonary function and elastic recoil after lung-reduction surgery for diffuse emphysema. *N Engl J Med* 1996;334:1095–1099.
13. Criner GJ, Cordova FC, Furukawa S, Kuzma AM, Travaline JM, Leyenson V, O'Brien GM. Prospective randomized trial comparing bilateral lung volume reduction surgery to pulmonary rehabilitation in severe COPD. *Am J Respir Crit Care Med* 1999;160:2018–2027.
14. Sinclair DJM, Ingram CG. Controlled trial of supervised exercise training in chronic bronchitis. *BMJ* 1980;280:519–521.
15. Roomi J, Johnson MM, Waters K, Yohannes A, Helm A, Connolly MJ. Respiratory rehabilitation, exercise capacity and quality of life in chronic airways disease in old age. *Age Ageing* 1996;25:12–16.
16. Paggiaro PL, Dahle R, Bakran I, Frith L, Hollingworth K, Efthimiou J. Multicentre randomised placebo-controlled trial of inhaled fluticasone propionate in patients with COPD. *Lancet* 1998;351:773–780.
17. Leggett RJ, Flenley DC. Portable oxygen and exercise tolerance in patients with chronic hypoxic cor pulmonale. *BMJ* 1977;2:84–86.
18. Spence DPS, Hay JG, Carter J, Pearson MG, Calverley PMA. Oxygen desaturation and breathlessness during corridor walking in COPD: effect of oxitropium bromide. *Thorax* 1993;48:1145–1150.
19. DeBock V, Mets T, Romagnoli M, Derde MP. Captopril treatment of chronic heart failure in the very old. *J Gerontol* 1994;49:M148–M152.
20. O'Keeffe ST, Lye M, Donnnellan C, Carmichael DN. Reproducibility and responsiveness of quality of life assessment and six minute walk test in elderly heart failure patients. *Heart* 1998;80:377–382.
21. Bernstein ML, Despars JA, Singh NP, Avalos K, Stansbury DW, Light RW. Re-analysis of the 12 minute walk in patients with COPD. *Chest* 1994;105:163–167.
22. Hajiro T, Nishimura K, Tsukino M, Ikeda A, Koyama H, Izumi T. Analysis of clinical methods used to evaluate dyspnea in patients with COPD. *Am J Respir Crit Care Med* 1998;158:1185–1189.
23. Gulmans VAM, vanVeldhoven NHMJ, deMeer K, Helders PJM. The six-minute walking test in children with cystic fibrosis: reliability and validity. *Pediatr Pulmonol* 1996;22:85–89.
24. Nixon PA, Joswiak ML, Fricker FJ. A six-minute walk test for assessing exercise tolerance in severely ill children. *J Pediatr* 1996;129:362–366.
25. Bittner V. Six-minute walk test in patients with cardiac dysfunction. *Cardiologia* 1997;42:897–902.
26. Peeters P, Mets T. The 6 minute walk as an appropriate exercise test in elderly patients with chronic heart failure. *J Gerontol* 1996;51A: M147–M151.
27. Zugck C, Kruger C, Durr S, Gerber SH, Haunstetter A, Hornig K, Kubler W, Haass M. Is the 6-minute walk test a reliable substitute for peak oxygen uptake in patients with dilated cardiomyopathy? *Eur Heart J* 2000;21:540–549.
28. Montogomery PS, Gardner AW. The clinical utility of a six-minute walk test in peripheral arterial occlusive disease patients. *J Am Geriatr Soc* 1998;46:706–711.
29. Cahan MA, Montgomery P, Otis RB, Clancy R, Flinn W, Gardner A. The effect of cigarette smoking status on six-minute walk distance in patients with intermittent claudication. *Angiology* 1999;50:537–546.
30. King S, Wessel J, Bhambhani Y, Maikala R, Sholter D, Maksymowych W. Validity and reliability of the 6 minute walk in persons with fibromyalgia. *J Rheumatol* 1999;26:2233–2237.
31. Enright PL, McBurnie MA, Bittner V, Tracy RP, McNamara R, Newman AB, the Cardiovascular Health Study. The six minute walk test: a quick measure of functional status in elderly adults. *Chest* (In press)
32. Bittner V, Weiner DH, Yusuf S, Rogers WJ, McIntyre KM, Bangdiwala SI, Kronenberg MW, Kostis JB, Kohn RM, Guillotte M, *et al*. Prediction of mortality and morbidity with a 6-minute walk test in patients with left ventricular dysfunction. *JAMA* 1993;270:1702–1707.
33. Cahalin LP, Mathier MA, Semigran MJ, Dec GW, DiSalvo TG. The six-minute walk test predicts peak oxygen uptake and survival in patients with advanced heart failure. *Chest* 1996;110:325–332.
34. Cote CG, Celli BR. In patients with COPD, the 6 minute walking distance is a better predictor of health care utilization than FEV1, blood gases, and dyspnea [abstract]. *Eur Respir J* 1998;383.
35. Kessler R, Faller M, Fourgaut G, Mennecier B, Weitzenblum E. Predictive factors of hospitalization for acute exacerbation in a series of 64 patients with chronic obstructive pulmonary disease. *Am J Respir Crit Care Med* 1999;159:158–164.
36. Cahalin L, Pappagianopoulos P, Prevost S, Wain J, Ginns L. The relationship of the 6-min walk test to maximal oxygen consumption in transplant candidates with end-stage lung disease. *Chest* 1995;108:452–459.
37. Guyatt GH, Thompson PJ, Berman LB, Sullivan MJ, Townsend M, Jones NL, Pugsley SO. How should we measure function in patients with chronic heart and lung disease? *J Chronic Dis* 1985;38:517–524.
38. Guyatt GH, Townsend M, Keller J, Singer J, Nogradi S. Measuring functional status in chronic lung disease: conclusions from a random control trial. *Respir Med* 1991;85(Suppl B):17–21.
39. Niederman MS, Clemente PH, Fein AM, Feinsilver SH, Robinson DA, Ilowite JS, Bernstein MG. Benefits of a multidisciplinary pulmonary rehabilitation program: improvements are independent of lung function. *Chest* 1991;99:798–804.
40. Noseda A, Carpiaux J, Prigogine T, Schmerber J. Lung function, maximum and submaximum exercise testing in COPD patients: reproducibility over a long interval. *Lung* 1989;167:247–257.
41. Knox AJ, Morrison JF, Muers MF. Reproducibility of walking test results in chronic obstructive airways disease. *Thorax* 1988;43:388–392.
42. Guyatt GH, Pugsley SO, Sullivan MJ, Thompson PJ, Berman LB, Jones NL, Fallen EL, Taylor DW. Effect of encouragement on walking test performance. *Thorax* 1984;39:818–822.
43. Leger LA. A maximal multistage 20-m shuttle run test to predict VO2 max. *Eur J Appl Physiol* 1982;49:1–12.
44. Singh SJ, Morgan MDL, Scott S, Walters D, Hardman AE. Development of a shuttle walking test of disability in patients with chronic airways obstruction. *Thorax* 1992;47:1019–1024.
45. Revill SM, Morgan MDL, Singh SJ, Williams J, Hardman AE. The endurance shuttle walk: a new field test for the assessment of endurance capacity in chronic obstructive pulmonary disease. *Thorax* 1999;54:213–222.
46. Singh SJ, Morgan MDL, Hardman AE, Rowe C, Bardsley PA. Comparison of oxygen uptake during a conventional treadmill test and the shuttle walking test in chronic airflow limitation. *Eur Respir J* 1994;7: 2016–2020.
47. Morales FJ, Martinez A, Mendez M, Agarrado A, Ortega F, Fernandez-Guerra J, Montemayor T, Burgos J. A shuttle walk test for assessment of functional capacity in chronic heart failure. *Am Heart J* 1999;138:292–298.
48. Enright PL, Sherrill DL. Reference equations for the six-minute walk in healthy adults. *Am J Respir Crit Care Med* 1998;158:1384–1387.
49. Barst RJ, Rubin LJ, McGoon MD, Caldwell EJ. Long WA, Levy PS. Survival in primary pulmonary hypertension with long-term continuous intravenous prostacyclin. *Ann Intern Med* 1994;121:409–415.
50. Miyamoto S, Nagaya N, Satoh T, Kyotani S, Sakamaki F, Fujita M, Nakanishi N, Miyatake K. Clinical correlates and prognostic significance of six-minute walk test in patients with primary pulmonary hypertension. *Am J Respir Crit Care Med* 2000;161:487–492.
51. Guyatt GH, Sullivan MJ, Thompson PJ, Fallen EL, Pugsley SO, Taylor DW, Berman LB. The 6-minute walk: a new measure of exercise capacity in patients with chronic heart failure. *Can Med Assoc J* 1985; 132:919–923.
52. Lipkin DP, Scrivin AJ, Crake T, Poole-Wilson PA. Six minute walking test for assessing exercise capacity in chronic heart failure. *BMJ* 1986; 292:653–655.
53. Troosters T, Gosselink R, Decramer M. Six minute walking distance in healthy elderly subjects. *Eur Respir J* 1999;14:270–274.

54. Weiss RA, *et al.* Six minute walk test in severe COPD: reliability and effect of walking course layout and length. Paper presented at ACCP Conference; September 2000; San Francisco.
55. Stevens D, Elpern E, Sharma K, Szidon P, Ankin M, Kesten S. Comparison of hallway and treadmill six-minute walk tests. *Am J Respir Crit Care Med* 1999;160:1540–1543.
56. Jensen LA, Onyskiw JE, Prasad NGN. Meta-analysis of arterial oxygen saturation monitoring by pulse oximetry in adults. *Heart Lung* 1998; 27:387–408.
57. Barthelemy JC, Geyssant A, Riffat J, Antoniadis A, Berruyer J, LaCour JR. Accuracy of pulse oximetry during moderate exercise: a comparative study. *Scand J Clin Lab Invest* 1990;50:533–539.
58. Borg GAV. Psycho-physical bases of perceived exertion. *Med Sci Sports Exerc* 1982;14:377–381.
59. Leach RM, Davidson AC, Chinn S, Twort CHC, Cameron IR, Batemen NT. Portable liquid oxygen and exercise ability in severe respiratory disability. *Thorax* 1992;47:781–789.
60. Mungall IPF, Hainsworth R. Assessment of respiratory function in patients with chronic obstructive airways disease. *Thorax* 1979;34:254–258.
61. Roberts CM, Bell J, Wedzicha JA. Comparison of the efficacy of a demand oxygen delivery system with continuous low flow oxygen in subjects with stable COPD and severe oxygen desaturation on walking. *Thorax* 1996;51:831–834.
62. Hay JG, Stone P, Carter J, Church S, Eyre-Brook A, Pearson MG, Woodcock AA, Calverley PM. Bronchodilator reversibility, exercise performance and breathlessness in stable chronic obstructive pulmonary disease. *Eur Respir J* 1992;5:659–664.
63. Grove A, Lipworth BJ, Reid P, Smith RP, Lamage L, Ingram CG, Jenkins RJ, Winter JH, Dhillon DP. Effects of regular salmeterol on lung function and exercise capacity in patients with COPD. *Thorax* 1996;51:689–693.
64. Redelmeier DA, Bayoumi AM, Goldstein RS, Guyatt GH. Interpreting small differences in functional status: The six minute walk test in chronic lung disease patients. *Am J Respir Crit Care Med* 1997;155:1278–1282.
65. Weiner P, Magadle R, Berar-Yanay N, Davidovich A, Weiner M. The cumulative effect of long-acting bronchodilators, exercise, and inspiratory muscle training on the perception of dyspnea in patients with advanced COPD. *Chest* 2000;118:672–678.
66. Bittner V, Sanderson B, Breland J, Adams C, Schuman C. Assessing functional capacity as an outcome in cardiac rehabilitation: role of the 6 minute walk test. *Clinical Exercise Physiology* 2000.

APPENDIX

The following elements should be present on the 6MWT worksheet and report:

Lap counter: __ __ __ __ __   __ __ __ __ __   __ __ __ __ __

Patient name: ____________________   Patient ID# ___________

Walk # ______   Tech ID: _________   Date: __________

Gender: M F   Age: ____   Race: ____   Height: ___ft ____in, ____ meters

Weight: ______ lbs, _____kg   Blood pressure: _____ / _____

Medications taken before the test (dose and time): _________________

Supplemental oxygen during the test: No   Yes, flow ______ L/min, type _____

	Baseline	End of Test
Time	___:___	___:___
Heart Rate	_____	_____
Dyspnea	____	____ (Borg scale)
Fatigue	____	____ (Borg scale)
SpO_2	____ %	____%

Stopped or paused before 6 minutes? No   Yes, reason: _______________

Other symptoms at end of exercise: angina   dizziness   hip, leg, or calf pain

Number of laps: ____ (×60 meters) + final partial lap: _____ meters =

Total distance walked in 6 minutes: ______ meters

Predicted distance: _____ meters   Percent predicted: _____%

Tech comments:

Interpretation (including comparison with a preintervention 6MWD):

PARTICIPANT INFORMATION SHEET

I request your participation in my study on “A home-based rehabilitation intervention for people living with HIV and disability in a resource-poor community, KwaZulu-Natal”. Before you decide whether to participate in this study, it is important that you understand why the research is being done and what your participation involves. Please take the time to read this information sheet carefully before agreeing to participate in the study. If you are unable to read this information, the researcher or a research assistant will be happy to read it to you.

WHAT IS THE PURPOSE OF THIS STUDY?

I am currently undertaking a doctoral degree, through the University of KwaZulu-Natal (UKZN), Department of Physiotherapy. The study aims to investigate the effects of a home-based rehabilitation programme on people living with HIV and physical disability. It is hoped that the results of this study are able to contribute to the improved design of rehabilitation interventions for people living with HIV and disability.

WHAT DOES THIS STUDY INVOLVE FOR YOU?

If you agree to participate in this study you will be randomly allocated into one of two study groups. The groups will be randomly selected by a computer so you cannot choose which group you are in. You will also not know which group you are in before consenting to take part in the study.

Group 1 will be called the *control group*. If you are allocated to this group you will be provided with written information on exercises to do at home that will help with your physical difficulties. You will also be eligible to receive physiotherapy treatment at the the study hospital physiotherapy department, if you are referred to this department by one of the hospital doctors.

Group 2 will be called the *experimental group*. If you are allocated to this group you will be visited once a week by a trained community healthcare worker who will help you with exercises in your own home, designed to help you with your physical difficulties. These weekly visits will continue for a period of four months. You will also receive the written information given to the participants in Group 1.

Whether you are in Group 1 or Group 2, you will be required to come to the study hospital on two separate dates, four months apart. At both of these visits you will be asked to answer two questionnaires and perform two tests designed to assess your functional ability and level of endurance. These visits will take approximately two hours each of your time. You will be remunerated for your transport costs to and from the hospital, for each visit.

WHAT HAPPENS NEXT?

If you decide to take part in the study you will be asked to sign a consent form. A follow-up visit to the study hospital will then be scheduled in order to conduct the first set of questionnaires and tests. You will be given a copy of this patient information sheet for your own records.

DOES MY PARTICIPATION IN THIS STUDY INVOLVE ANY PHYSICAL RISK?

There will be no physical risk if you are allocated to the control group. There may, however, be a minimal chance of physical harm if you are allocated to the experimental group. While it is anticipated that you will *benefit* physically from receiving weekly physical rehabilitation and exercise supervision by a trained research assistant, some of the known side effects of exercise include muscle stiffness, fatigue and minor joint pain. Every effort will be made by the research assistants to ensure that the benefits outweigh these negative effects of exercise. However, should these side-effects persist for more than three days, you will be referred back to the study hospital for assessment and treatment, should this be required.

WHO WILL RECEIVE THE RESULTS OF THIS STUDY?

Your name and any other personal information will be kept confidential at all times. Information from the study that may be presented or published will never identify you personally.

CAN I WITHDRAW FROM THE SUDY

The study is voluntary and you are free to withdraw from it, however your participation will be greatly appreciated. If you decide to withdraw from the study, this will in no way influence your continued treatment and care at the study hospital.

Should you have any questions please feel free to contact either of the individuals listed below. You can also contact the UKZN Biomedical Research Ethics Committee with any concerns or complaints you may have regarding this study.

Researcher: Mr Saul Cobbing	Supervisor: Dr Jill Hanass-Hancock
Telephone (work): 031 2608147	031 2603125
Cell Number: 0846356006	07720196216
Email: cobbing@ukzn.ac.za	hanasshj@ukzn.ac.za

UKZN Biomedical Research Ethics Committee

Telephone: 031 2604769

e-mail: BREC@ukzn.ac.za

PARTICIPANT CONSENT FORM

I, ____, consent to participate in the study “A home-based rehabilitation intervention for people living with HIV and disability in a resource-poor community, KwaZulu-Natal” and have read and understood the study information sheet outlining the purpose and requirements of my participation in the proposed study.

Participants’ Signature	Date
_________________________________	_______________

Mr Saul Cobbing	Supervisor: Dr Jill Hanass-Hancock
Telephone (work): 031 2608147	031 2603125
Cell Number: 0846356006	07720196216
Email: cobbing@ukzn.ac.za	hanasshj@ukzn.ac.za

Biomedical Research Ethics Committee

Telephone: 031 2604769

e-mail: BREC@ukzn.ac.za

Regular exercise is important for staying healthy, because it:

- Improves your cardiovascular fitness
- Improves your body composition
- Increases your strength
- Improves your quality of life

DO ✓

- Keep active around the house – do not sit in a chair or lie in bed throughout the day
- Warm up before exercise (march on the spot for 2 minutes lifting your arms and legs)
- Stretch your muscles after your warm up
- Walk regularly – try and walk 5 times per week
- Walk for 5 minutes and add one minute more each day until you are walking for 30 minutes
- Choose other activities/types of exercise that you enjoy, including housework or gardening
- Cool down and stretch after exercise
- Drink enough water throughout the day but especially before and after exercise
- Eat regular meals with a good balance of different types of food

DO NOT ✗

- Smoke
- Use drugs
- Drink an excessive amount of alcohol
- Eat uncooked meat or drink unpurified water
- Stop taking the medication you have been given by the clinic

If you are experiencing any physical problems such as weakness, numbness or pain remember to ask the doctor at your next clinic appointment to refer you to the physiotherapist at [redacted]. If you have any other queries please phone [redacted], a research assistant at UKZN, on [redacted].

Thank you again for agreeing to participate in this research.

Saul Cobbing (University of KwaZulu-Natal)

Cell number: [redacted]

UNIVERSITY OF
KWAZULU-NATAL
INYUVESI
YAKWAZULU-NATALI

WHOQOL (PRE)

Code	Group	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**17**	**18**	**19**	**20**	**21**	**22**	**23**	**24**	**25**	**26**	**27**	**28**	**29**	**30**	**31**
001	1	2	2	2	4	4	4	3	1	4	4	2	2	3	1	2	1	3	1	2	1	2	2	2	3	1	1	4	4	1	2	3
002	1	3	4	2	3	3	4	2	3	2	2	3	4	4	4	3	3	3	3	3	2	4	4	3	4	4	4	4	3	2	2	3
003	1	4	5	3	5	2	5	5	1	2	5	4	4	4	4	4	3	4	4	4	5	4	4	4	4	4	4	2	5	4	4	1
004	1	3	1	3	3	2	4	3	1	3	4	4	4	3	3	3	1	4	3	4	3	3	4	4	4	2	2	4	4	4	4	3
005	1	3	2	3	2	2	3	3	1	2	4	4	3	4	4	3	1	3	2	4	4	4	4	3	4	3	3	3	3	3	2	3
006	2	3	4	3	3	1	4	3	1	3	1	4	4	4	4	4	4	4	5	3	3	2	3	2	4	2	2	3	3	4	2	2
007	2	3	4	2	3	4	4	3	2	3	2	2	4	2	3	3	2	3	3	2	4	4	4	4	4	4	4	3	4	4	4	3
008	2	4	4	3	3	3	4	3	2	2	2	4	4	2	4	4	2	3	3	3	4	4	4	4	4	4	1	4	3	4	3	3
009	1	3	3	2	4	4	3	3	4	4	3	3	4	2	4	4	2	4	3	3	4	2	4	4	4	4	1	4	4	4	4	3
010	1	4	4	2	2	3	4	3	5	3	4	2	4	4	4	4	2	2	3	4	5	2	4	4	4	4	4	2	4	4	2	3
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012	1	3	2	3	4	4	4	3	2	4	4	2	3	3	2	4	1	4	3	4	2	4	3	4	4	2	2	4	2	4	2	2
013	1	3	2	3	3	4	4	3	1	1	1	4	4	3	2	3	2	2	4	4	3	3	4	4	4	4	4	2	2	4	4	3
014	1	3	2	2	4	4	3	4	4	4	4	4	3	3	2	2	2	2	2	2	2	4	4	2	2	3	2	1	2	2	2	4
015	1	3	4	3	2	4	4	3	1	3	4	2	4	3	3	3	1	4	4	4	3	3	3	4	4	1	1	3	2	3	3	2
016	1	4	2	1	1	4	4	2	1	1	1	4	4	3	4	4	2	4	3	4	5	4	4	4	4	3	2	2	2	2	4	3
017	2	4	4	2	2	3	3	3	1	1	1	4	4	4	4	4	3	3	4	4	4	4	4	4	4	4	1	4	4	4	4	3
018	1	2	4	3	3	4	4	3	4	2	2	2	4	3	2	3	2	2	3	3	5	5	3	2	4	1	1	4	3	4	2	3
019	2	3	4	3	3	4	4	3	1	1	4	2	2	2	1	1	2	1	3	2	2	4	5	3	4	2	1	4	2	4	4	3
020	2	4	2	4	4	4	2	4	1	2	4	3	3	3	3	3	2	4	2	4	4	3	3	3	4	5	2	4	3	2	4	3
021	2	2	4	4	4	4	4	3	1	4	4	2	3	3	3	4	2	3	3	3	4	4	3	3	4	3	1	3	3	4	5	2
022	2	3	4	2	4	2	4	3	1	2	4	4	4	3	4	4	3	2	3	2	4	4	4	4	4	2	2	4	2	2	4	4
023	2	3	3	2	3	4	4	3	1	4	4	2	4	3	4	4	1	3	3	2	4	5	4	4	4	3	3	1	2	4	2	2
024	1	2	2	3	2	4	2	3	1	1	3	2	3	3	2	4	3	4	4	3	3	3	2	2	2	4	4	4	4	3	2	2
025	2	3	4	3	2	1	3	3	1	2	2	4	4	3	3	4	1	4	3	3	3	3	3	3	3	3	1	3	4	3	2	2
026	2	3	4	2	1	4	4	3	3	3	4	3	4	3	4	4	2	3	3	3	5	3	4	4	4	3	3	4	4	3	2	2
027	1	1	1	2	1	4	5	2	1	4	4	5	5	5	4	4	3	4	4	4	4	3	4	3	5	4	4	4	3	4	2	3
028	1	4	4	4	1	2	4	3	4	1	1	5	4	4	4	5	2	4	4	3	4	4	4	4	5	5	3	4	4	4	3	3
029	1	4	4	1	1	1	4	3	2	3	4	2	4	4	4	4	2	4	4	2	4	2	4	4	4	4	3	4	4	4	2	3
030	2	2	2	3	4	2	4	2	2	2	4	3	4	3	3	4	3	1	2	4	4	2	3	4	4	4	1	3	1	4	3	3
031	2	2	2	4	3	4	3	2	4	2	2	4	4	2	2	4	2	4	3	4	4	3	4	3	4	1	1	4	4	4	4	4

032	1	3	4	3	4	4	4	3	1	2	4	4	4	4	3	4	2	4	4	4	4	3	3	3	2	4	4	4	4	4	5	3
033	1	2	2	4	3	4	2	4	2	4	2	4	4	3	3	4	2	3	1	4	4	2	3	4	2	1	1	4	1	3	5	4
034	2	3	4	4	4	5	4	5	4	2	3	3	4	4	3	3	1	4	4	4	4	2	2	3	3	2	4	4	4	4	4	4
035	1	3	4	4	3	1	4	2	4	1	1	5	4	4	5	4	1	4	4	4	4	4	4	4	4	4	5	4	4	4	5	2
036	2	3	3	4	1	4	4	1	4	2	1	4	4	4	4	5	2	3	4	4	4	4	5	4	4	4	4	4	4	4	4	2
037	1	3	2	2	2	2	1	1	1	3	5	2	2	3	1	2	2	2	3	4	4	4	3	3	3	2	2	4	2	2	1	3
038	1	4	4	3	4	4	2	2	1	4	5	4	4	4	4	4	2	2	2	4	4	2	2	2	4	1	1	1	4	4	2	4
039	2	2	2	2	2	4	3	3	1	3	4	2	4	4	2	2	2	4	3	3	3	3	4	3	4	2	1	4	4	2	2	4
040	1	3	3	2	4	2	4	1	5	2	4	3	4	3	4	4	1	2	2	3	2	2	2	2	2	2	2	4	2	4	2	2
041	2	3	2	4	3	4	4	3	1	1	1	4	2	3	1	3	1	4	2	4	2	2	2	2	3	3	2	3	2	3	2	4
042	1	4	4	3	4	4	4	2	1	3	2	4	4	4	4	4	2	3	4	3	4	4	4	4	3	4	3	4	4	4	4	2
043	2	4	4	3	3	4	4	3	1	4	4	4	4	3	2	4	1	4	4	4	2	4	4	4	4	4	2	4	4	3	2	3
044	1	2	2	2	4	3	3	2	1	4	4	2	2	3	3	3	1	4	4	4	2	5	4	4	4	4	2	2	4	4	2	3
045	1	2	2	5	5	5	1	1	1	2	2	4	2	1	1	1	1	2	1	1	1	1	1	1	1	1	1	3	2	2	2	5
046	2	3	4	3	4	4	4	3	1	3	2	4	3	4	4	4	1	4	4	4	4	4	4	4	4	4	4	2	4	3	2	2
047	2	3	4	3	4	4	4	3	4	2	4	2	3	2	3	3	1	4	2	2	3	2	2	3	4	4	2	4	2	2	2	3
048	2	4	3	3	4	4	4	3	1	3	5	3	4	2	3	3	2	2	2	4	3	2	3	3	4	1	1	3	2	2	2	4
049	1	3	4	4	4	4	4	3	2	4	4	4	3	3	2	2	1	1	3	2	4	4	4	2	4	4	4	2	2	3	4	3
050	1	4	4	4	3	5	5	4	1	1	4	4	4	3	4	4	1	4	3	4	4	4	4	2	4	2	4	4	2	4	2	3
051	2	4	4	4	3	4	4	2	1	1	2	4	4	3	4	4	1	4	4	4	4	2	2	2	4	4	4	2	3	4	4	4
052	2	3	2	2	2	4	4	1	1	3	2	3	1	2	2	4	1	4	4	4	4	4	4	3	4	4	4	1	4	2	4	1
053	2	4	4	2	1	4	4	3	1	1	1	4	4	3	3	4	2	4	3	3	4	4	4	3	4	4	3	2	4	4	2	3
054	1	3	2	3	4	4	2	3	1	4	2	2	3	4	4	4	1	4	4	3	4	2	3	2	4	4	4	4	4	4	4	3
055	2	3	4	2	2	4	4	4	1	1	1	3	4	4	2	4	2	4	4	4	2	4	4	4	4	1	1	4	4	4	4	1
056	1	2	3	3	2	4	4	3	1	2	2	4	4	3	2	3	2	1	2	3	4	4	4	3	4	1	1	1	4	1	2	3
057	2	4	4	2	2	1	4	3	1	1	2	4	4	4	4	4	3	3	4	4	3	4	4	4	4	1	1	5	4	4	2	2
058	2	2	2	2	4	4	4	2	1	4	4	2	2	3	2	4	1	4	2	1	3	2	2	2	4	4	3	3	2	2	2	3
059	1	3	4	2	3	4	4	3	1	4	1	3	4	4	3	4	2	3	2	1	4	3	4	2	4	2	2	2	4	3	2	4
060	2	3	3	2	4	4	4	2	1	2	4	4	2	4	4	4	2	4	3	3	4	4	4	4	3	4	4	4	4	3	5	2
061	2	3	2	4	3	4	4	3	1	4	4	4	4	3	3	3	1	2	2	3	3	3	4	2	4	1	1	2	2	2	2	3
062	2	5	2	3	2	1	4	3	4	2	4	4	4	2	4	4	1	4	2	2	4	2	4	3	3	2	2	3	2	2	2	4
063	2	4	4	4	2	1	3	4	3	3	1	4	3	4	4	4	1	4	4	4	4	4	4	2	4	4	4	2	3	3	2	2
064	1	3	4	3	4	2	4	3	1	2	4	3	3	3	3	4	2	4	4	3	4	3	3	3	3	4	4	2	4	3	2	3
065	2	3	2	4	4	4	1	2	1	3	4	3	1	2	2	3	1	4	3	4	4	2	2	4	2	1	1	4	4	3	2	4

066	2	2	2	3	4	3	4	2	3	1	1	3	3	1	4	4	1	3	4	2	3	4	2	2	4	2	2	2	2	4	1	3
067	2	3	4	1	1	4	4	2	1	1	1	4	4	3	4	4	1	4	3	2	4	4	4	2	4	4	4	4	4	4	4	3
068	2	3	2	3	2	4	4	2	1	1	1	3	4	2	2	4	1	4	2	2	4	2	4	4	4	4	4	5	1	4	2	2
069	1	5	4	1	1	1	4	3	1	1	1	3	4	4	4	5	2	4	4	4	4	4	4	4	4	1	1	4	4	4	4	2
070	1	4	4	2	1	1	4	3	3	4	5	4	4	5	4	4	2	3	4	2	4	4	4	4	4	5	4	5	4	4	2	3
071	2	4	4	2	1	4	4	3	1	1	1	4	4	4	4	4	2	4	4	3	4	2	4	4	4	1	1	4	2	3	4	2
072	2	3	4	1	2	4	4	2	1	5	5	4	4	4	4	4	1	1	3	2	4	4	4	4	4	4	4	2	4	3	4	2
073	1	4	4	4	4	3	4	1	1	1	4	4	4	3	2	4	1	4	4	4	4	4	4	3	4	5	5	4	2	3	2	2
074	1	4	4	4	1	1	4	2	1	1	4	4	4	3	4	4	2	4	4	4	4	2	4	4	4	4	4	4	4	4	4	2
075	2	2	4	3	2	1	2	1	1	3	3	4	3	3	3	3	1	4	3	4	4	4	4	4	4	1	1	4	2	3	2	3
076	1	3	2	3	3	4	4	2	5	3	4	3	2	3	2	3	1	4	4	4	4	2	2	2	4	4	4	2	2	2	2	3

1 = intervention group; 2 = control group

WHODAS (PRE)

Code	Group	S1	S2	S3	S4	S5	S6	S7	S8	S9	S10	S11	S12	WHOTot
001	1	4	4	4	4	1	4	4	3	3	1	1	3	36
002	1	3	3	3	1	5	3	3	1	1	1	1	1	26
003	1	1	1	1	1	2	1	1	1	1	1	1	1	13
004	1	4	1	3	1	5	3	1	1	1	1	1	2	24
005	1	3	3	2	2	3	1	3	1	1	2	4	1	26
006	2	1	1	1	1	1	1	3	1	1	3	4	1	19
007	2	1	1	1	1	4	1	1	1	1	1	2	1	16
008	2	1	1	1	1	2	3	1	1	1	3	2	1	18
009	1	1	1	1	1	2	1	1	1	1	1	1	3	15
010	1	1	1	1	1	3	1	3	1	1	1	1	1	16
011	1	1	1	1	1	3	1	1	1	1	1	3	1	16
012	1	1	1	3	1	2	3	3	1	1	1	3	1	21
013	1	3	1	1	1	3	3	3	1	1	1	1	1	20
014	1	1	1	1	1	1	3	1	1	1	1	1	1	14
015	1	1	1	1	1	2	3	3	1	1	1	1	1	17
016	1	1	1	1	1	3	1	1	1	1	1	3	1	16
017	2	1	1	1	1	3	1	1	1	1	1	1	1	14
018	1	1	1	3	3	3	2	3	1	1	1	1	1	21
019	2	1	1	3	1	2	3	3	1	1	1	1	1	19
020	2	2	3	1	1	3	1	2	1	1	1	1	1	18
021	2	1	1	3	1	1	1	2	1	1	3	4	1	20
022	2	1	1	1	1	1	1	1	1	1	1	1	1	12
023	2	2	3	1	1	2	1	1	1	1	1	2	3	19
024	1	3	3	1	1	3	1	3	1	1	1	1	3	22
025	2	2	2	2	3	2	1	5	1	1	2	3	2	26
026	2	1	1	1	1	1	1	1	1	1	1	1	1	12
027	1	5	5	5	5	4	2	5	4	4	3	3	5	50
028	1	1	1	2	1	1	1	1	1	1	1	1	1	13
029	1	1	1	1	1	1	2	2	1	1	1	1	1	14
030	2	3	2	3	1	1	1	3	1	1	1	1	2	20
031	2	2	1	1	1	4	1	3	1	1	1	3	1	20

032	1	1	1	3	3	3	1	3	1	1	1	3	1	22
033	1	3	3	3	1	3	1	2	1	1	1	3	3	25
034	2	1	1	1	4	1	2	1	1	1	1	1	1	16
035	1	1	1	1	1	2	1	1	1	1	1	1	1	13
036	2	1	1	1	1	1	1	1	1	1	1	1	1	12
037	1	1	1	1	1	2	2	1	1	1	1	1	1	14
038	1	1	1	1	1	1	1	1	1	1	1	1	1	12
039	2	2	3	3	1	4	2	1	1	1	1	1	3	23
040	1	1	1	2	1	1	1	1	1	1	1	1	1	13
041	2	2	2	2	1	1	1	3	1	1	1	3	2	20
042	1	1	1	1	1	2	1	1	1	1	1	1	1	13
043	2	1	1	2	1	1	1	2	1	1	1	1	1	14
044	1	1	2	2	1	2	2	2	1	1	1	1	2	18
045	1	4	4	4	4	5	3	4	4	3	3	3	4	45
046	2	3	1	3	1	1	1	3	1	1	1	3	1	20
047	2	1	2	3	2	3	3	1	1	1	1	1	2	21
048	2	3	2	1	1	3	1	3	1	1	1	1	2	20
049	1	1	1	1	1	3	1	2	1	1	1	4	1	18
050	1	1	1	1	1	1	1	1	1	1	1	1	1	12
051	2	1	1	1	1	2	1	1	1	1	1	1	1	13
052	2	1	1	1	1	1	1	1	1	1	1	1	1	12
053	2	1	1	1	1	1	1	1	1	1	1	1	1	12
054	1	3	2	2	1	1	1	3	1	1	1	1	2	19
055	2	1	1	1	1	1	1	1	1	1	1	1	1	12
056	1	1	1	1	1	1	1	1	1	1	1	1	1	12
057	2	3	1	1	1	1	1	1	1	1	1	1	1	14
058	2	1	1	1	1	1	1	1	1	1	1	1	1	12
059	1	1	1	1	1	1	1	1	1	1	1	1	1	12
060	2	1	1	1	1	1	1	1	1	1	1	1	1	12
061	2	1	1	3	2	1	1	1	1	1	1	1	1	15
062	2	1	1	1	1	1	1	1	1	1	1	1	1	12
063	2	1	1	1	1	1	1	1	1	1	1	1	1	12
064	1	1	1	1	1	1	1	1	1	1	1	1	1	12
065	2	1	1	2	1	3	1	1	1	1	1	1	1	15

066	2	1	1	1	1	1	2	1	1	1	1	1	1	13
067	2	1	1	1	1	1	1	1	1	1	1	1	1	12
068	2	1	1	1	1	1	1	1	1	1	1	1	2	13
069	1	1	1	1	1	1	1	1	1	1	1	1	1	12
070	1	1	1	1	1	1	1	1	1	1	1	1	1	12
071	2	1	1	2	1	2	1	1	1	1	1	2	1	15
072	2	1	1	1	1	1	1	1	1	1	1	2	1	13
073	1	1	1	1	1	1	1	1	1	1	1	1	1	12
074	1	1	1	1	1	1	1	1	1	1	1	1	1	12
075	2	2	1	1	1	2	1	1	1	1	1	1	1	14
076	1	1	1	1	1	1	1	1	1	1	1	2	1	13

1 = intervention group; 2 = control group

RMI (PRE)

Code	Group	R1	R2	R3	R4	R5	R6	R7	R8	R9	R10	R11	R12	R13	R14	R15	Rtot
001	1	1	1	1	1	1	1	1	0	0	1	1	1	1	1	0	12
002	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	14
003	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
004	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
005	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
006	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
007	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
008	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
009	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
010	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
011	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
012	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
013	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
014	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
015	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
016	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
017	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
018	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
019	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
020	2	1	1	1	0	0	1	1	1	1	1	1	1	1	1	0	12
021	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
022	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
023	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	14
024	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
025	2	1	1	1	1	1	1	1	1	0	1	1	0	1	0	0	11
026	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
027	1	1	1	1	0	0	0	0	0	0	0	0	0	0	0	0	3
028	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	14
029	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
030	2	1	1	1	1	1	1	1	1	0	1	1	1	1	0	0	12

031	2	1	1	1	1	1	1	1	0	0	1	1	0	1	0	0	10
032	1	1	0	0	1	1	1	1	1	0	1	1	1	1	1	0	11
033	1	1	1	1	1	1	1	1	1	0	1	1	1	1	1	0	13
034	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
035	1	1	0	0	1	1	1	1	1	1	1	1	1	1	1	0	12
036	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
037	1	1	1	1	1	1	1	1	1	1	1	0	1	1	1	1	14
038	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
039	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	14
040	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
041	2	1	1	1	0	0	1	1	1	0	1	1	0	1	1	0	10
042	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
043	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	14
044	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
045	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
046	2	1	1	1	1	1	1	1	1	1	0	1	1	1	1	0	13
047	2	1	1	1	1	1	0	0	1	1	0	0	0	1	1	0	9
048	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	14
049	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
050	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
051	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
052	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
053	2	1	1	1	1	1	1	1	1	1	1	1	0	1	1	0	13
054	1	1	1	1	1	1	1	1	1	0	1	1	1	1	1	1	14
055	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	14
056	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
057	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
058	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
059	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
060	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
061	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	14
062	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
063	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15

064	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
065	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	14
066	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
067	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
068	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
069	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
070	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
071	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	14
072	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	14
073	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
074	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
075	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	14
076	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15

1 = intervention group; 2 = control group

6MWT (PRE)

Code	Group	PulsePre	RRPre	SBPPre	DBPPre	B1Pre	B2Pre	PulsePost	RRPost	SBPPost	DBPPost	B1Post	B2Post	Distance
001	1	98	18	168	98	2	3	105	26	182	104	4	5	114
002	1	88	16	132	94	1	2	76	20	139	95	4	3	183
003	1	98	18	139	91	0	0	100	22	144	108	0	0	368
004	1	80	16	131	96	0	0	80	22	126	94	1	2	331
005	1	62	14	158	92	1	2	62	22	160	99	2	1	308
006	2	48	18	125	62	0	0	101	20	143	62	1	2	210
007	2	75	16	140	98	3	2	72	20	176	81	4	3	280
008	2	58	16	131	67	0	0	55	20	128	81	1	1	245
009	1	66	16	144	91	0	0	66	20	142	99	1	2	275
010	1	75	16	115	77	0	0	71	22	122	80	1	2	357
011	1	72	14	138	91	0	0	73	20	129	80	0	0	325
012	1	71	16	108	64	0	0	68	24	117	85	3	2	193
013	1	76	16	112	82	0	0	74	22	138	95	1	1	310
014	1	56	16	121	71	0	0	73	22	147	83	2	1	182
015	1	63	16	96	68	0	0	73	20	130	71	1	2	291
016	1	67	16	117	68	0	0	68	22	111	51	0	0	287
017	2	72	20	113	72	0	0	79	20	152	73	0	0	236
018	1	58	16	149	93	0	0	59	20	161	94	0	0	458
019	2	74	16	99	49	0	0	106	24	115	44	3	2	370
020	2	71	16	125	87	0	0	64	20	140	78	4	3	260
021	2	59	16	129	75	0	0	57	22	140	81	2	1	297
022	2	74	18	130	73	0	0	73	22	158	102	1	1	269
023	2	54	16	109	64	0	0	55	20	110	63	4	3	285
024	1	74	16	110	78	0	0	63	22	112	47	2	3	180
025	2	68	16	108	70	0	0	72	22	121	89	0	0	40
026	2	69	16	124	75	0	0	65	20	129	77	1	0	328
027	1	79	16	159	96	0	1	95	20	163	99	1	2	60
028	1	69	16	129	90	0	0	69	20	126	94	1	1	295
029	1	73	18	110	74	2	3	82	22	117	75	2	1	245
030	2	69	18	121	73	0	2	73	22	115	85	1	4	160
031	2	62	16	127	89	0	0	74	20	133	93	0	3	140

032	1	98	20	171	98	0	1	102	24	176	94	2	3	248
033	1	72	16	119	69	2	2	78	20	118	91	3	3	250
034	2	86	16	101	71	0	2	91	20	116	79	1	2	377
035	1	74	16	145	95	0	2	79	20	132	98	1	2	271
036	2	102	20	146	97	0	0	107	20	148	100	1	1	215
037	1	74	16	114	64	0	0	87	22	121	89	2	1	335
038	1	80	16	118	61	0	0	91	20	125	64	1	1	291
039	2	81	14	117	74	0	0	83	24	128	76	4	2	174
040	1	83	16	108	69	0	0	93	22	113	77	2	2	192
041	2	79	16	122	70	0	0	75	22	128	107	2	1	160
042	1	57	11	111	71	0	0	54	22	120	83	0	0	208
043	2	77	16	121	89	2	3	78	20	116	79	3	4	215
044	1	86	16	83	53	0	0	80	22	87	40	1	2	283
045	1	107	18	87	49	2	3	112	26	93	51	3	4	187
046	2	71	20	109	71	1	3	83	22	114	58	2	1	149
047	2	97	16	108	67	0	0	82	24	112	51	1	2	226
048	2	86	16	152	97	0	0	99	22	159	112	2	1	232
049	1	74	16	101	68	0	0	75	22	115	74	1	1	253
050	1	83	16	151	55	0	0	95	22	152	67	1	2	265
051	2	60	16	127	81	0	0	61	22	149	105	1	0	300
052	2	73	16	115	71	0	0	66	22	120	87	2	1	268
053	2	72	16	169	97	0	0	83	22	121	84	1	1	250
054	1	62	16	108	79	0	0	57	22	105	68	1	0	242
055	2	80	16	111	60	0	0	90	22	132	80	2	3	221
056	1	75	16	130	88	0	0	75	22	125	87	2	3	246
057	2	84	16	115	86	0	0	87	20	123	87	1	0	219
058	2	74	16	147	87	0	0	68	22	135	71	1	2	261
059	1	77	16	123	67	0	0	84	22	107	79	2	1	345
060	2	69	16	115	64	0	0	63	22	102	63	0	1	235
061	2	84	16	155	77	0	0	90	22	147	84	1	2	197
062	2	79	16	137	101	0	0	75	22	126	94	1	1	246
063	2	71	16	119	72	0	0	79	22	105	68	1	1	280
064	1	63	16	152	85	0	0	60	22	167	87	2	1	269
065	2	61	18	117	79	0	0	99	22	131	68	1	0	242

066	2	54	16	133	59	0	0	58	22	146	89	0	0	492
067	2	66	16	90	60	0	0	74	22	104	74	1	2	360
068	2	71	16	132	89	0	0	87	22	122	77	1	0	365
069	1	75	16	124	75	0	0	66	22	134	85	1	2	331
070	1	85	16	130	90	0	0	93	20	132	87	2	2	322
071	2	60	16	120	84	0	0	72	22	173	80	1	0	225
072	2	69	16	123	78	0	0	81	20	129	84	1	2	337
073	1	71	16	97	69	0	0	76	22	121	77	0	1	295
074	1	60	16	164	92	0	0	65	18	105	79	1	1	340
075	2	69	16	114	75	1	0	71	22	94	65	1	2	264
076	1	84	16	121	81	0	0	89	22	140	89	1	2	312

1 = intervention group; 2 = control group

WHOQOL (POST)

Code	Group	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
001	1	2	2	4	4	4	4	2	1	4	4	2	1	3	3	2	1	4	2	4	3	4	23	2	2	2	2	4	1	2	2	4
002	1	4	4	2	3	1	4	3	1	3	1	4	4	4	4	4	1	4	4	2	4	4	4	4	4	4	4	4	4	4	2	3
003	1	3	3	1	4	2	4	2	1	1	1	5	4	4	4	5	1	4	4	4	4	4	5	5	5	4	4	1	4	4	4	3
004	1	Very ill, moved to Empangeni																														
005	1	3	3	4	4	3	4	3	4	4	3	3	4	4	3	3	4	5	4	3	4	5	4	4	4	4	5	4	4	4	4	3
006	2	4	4	3	1	4	4	2	1	1	1	4	4	4	4	4	3	4	4	4	4	4	4	4	4	1	1	4	4	4	2	3
007	2	4	4	1	2	4	4	1	1	2	3	2	4	2	4	4	1	4	2	4	4	4	4	4	4	4	4	2	2	3	4	2
008	2	3	4	3	3	4	4	2	4	1	1	4	4	3	4	4	1	4	4	4	4	4	4	4	4	4	2	4	3	3	3	3
009	1	4	4	1	3	4	4	1	1	4	4	4	4	4	4	4	1	4	4	4	4	4	4	4	4	4	1	4	2	4	2	3
010	1	4	5	1	1	1	4	2	2	3	2	4	4	4	4	4	2	3	4	4	4	2	4	4	4	4	4	2	3	3	4	2
011	1	4	4	2	1	4	4	2	1	1	1	4	4	4	4	4	2	4	4	4	4	4	4	4	4	4	4	4	4	4	4	3
012	1	2	3	2	1	3	3	3	1	2	3	3	3	3	3	3	1	4	3	3	4	5	4	4	2	1	1	4	2	2	2	2
013	1	3	2	3	1	4	4	2	1	4	1	3	3	1	3	3	1	4	3	4	4	2	2	3	2	4	4	2	2	2	4	4
014	1	3	4	2	3	4	4	2	1	4	4	4	4	3	4	4	1	4	4	1	4	4	4	4	4	4	2	2	2	2	4	4
015	1	3	4	3	1	4	4	3	1	3	3	3	4	4	3	4	1	4	4	4	4	2	4	4	4	1	1	4	4	3	3	2
016	1	4	4	4	1	3	4	1	4	1	1	4	4	4	4	4	1	4	4	4	4	4	4	4	4	4	4	4	4	4	2	2
017	2	3	4	3	3	4	3	3	4	1	1	4	4	4	3	3	5	4	5	5	5	4	4	4	4	3	5	5	5	5	5	1
018	1	4	4	1	1	3	3	2	1	1	1	2	4	4	4	4	1	4	2	4	4	4	4	4	4	4	4	4	4	3	2	1
019	2	3	2	4	4	4	4	2	2	3	4	2	2	2	2	4	1	4	4	3	4	4	4	4	3	4	4	2	2	3	2	4
020	2	4	4	3	4	4	4	1	1	1	1	3	4	4	3	4	1	4	3	4	4	3	2	4	4	3	2	4	4	4	3	3
021	2	4	3	3	3	4	4	2	1	1	4	4	4	3	4	4	1	4	2	4	4	4	4	4	4	3	2	4	3	4	3	3
022	2	4	4	3	1	3	4	2	1	1	1	4	4	4	4	4	4	2	4	4	4	2	4	4	4	4	4	4	2	4	4	3
023	2	2	4	3	4	2	4	3	4	1	3	3	4	5	2	4	1	1	2	1	2	5	2	3	4	5	5	1	4	3	4	3
024	1	3	3	3	1	4	4	3	4	3	3	2	2	2	1	4	1	4	2	4	4	3	3	3	4	4	3	4	4	4	3	4
025	2	3	3	4	4	4	4	2	1	2	2	2	3	4	4	4	1	2	3	4	4	4	2	4	4	1	1	4	4	4	4	2
026	2	4	3	1	3	4	4	2	1	1	1	4	4	2	4	4	1	4	4	4	4	2	4	4	4	3	3	4	4	4	2	2
027	1	4	4	1	3	3	4	2	1	1	1	4	4	4	4	4	2	4	3	4	3	4	3	3	4	4	4	4	4	3	4	2
028	1	4	4	3	4	4	4	3	4	3	2	4	4	2	4	4	1	4	2	1	4	2	4	3	4	4	4	2	2	3	4	3
029	1	4	4	3	3	4	4	2	2	4	2	3	4	4	4	4	1	3	4	3	4	3	3	3	4	2	2	4	4	4	2	2
030	2	2	2	4	4	4	2	2	1	1	4	4	3	4	2	2	1	2	2	3	3	2	2	3	4	1	1	4	3	2	2	3

031	2		2	2	3	4	4	3	3	4	4	4	3	2	3	4	4	1	1	2	4	2	2	3	3	3	1	1	4	4	4	4	3
032	1		3	4	2	2	4	4	3	4	2	4	3	4	3	3	3	2	4	3	4	1	3	2	4	3	2	2	4	4	4	3	3
033	1		4	4	1	1	2	4	2	1	2	2	4	3	4	4	4	1	4	1	4	4	2	4	4	4	2	3	2	4	3	4	2
034	2		2	2	4	3	4	4	2	2	4	1	2	2	3	2	2	1	4	3	4	4	3	2	4	4	2	2	4	4	2	1	3
035	1		3	4	3	4	4	4	2	1	2	2	3	4	4	3	4	1	3	3	3	4	2	2	2	4	4	4	4	4	4	2	3
036	2		4	4	3	2	2	3	2	2	1	1	4	4	4	4	4	2	4	3	4	4	4	4	4	4	4	4		4	3	4	2
037	1		4	2	3	2	4	4	3	1	2	4	2	4	4	2	4	1	2	3	4	4	4	4	4	2	2	2	4	4	3	2	4
038	1		5	5	3	4	4	4	2	1	1	1	3	4	5	4	4	1	2	4	4	4	4	4	3	2	2	2	2	3	2	2	4
039	2		3	2	3	4	4	4	2	3	4	1	2	2	4	3	4	1	3	3	4	4	1	2	4	2	2	2	4	2	2	2	4
040	1		3	3	3	2	4	2	3	4	1	1	2	4	2	4	4	1	2	2	4	4	4	2	2	2	2	2	2	2	2	2	2
041	2		4	4	1	2	4	4	2	1	1	2	4	4	4	4	4	2	4	4	4	4	1	4	4	4	4	4	4	4	4	4	2
042	1		4	4	3	3	4	4	2	1	1	1	4	4	4	4	4	1	4	3	4	4	3	4	4	4	4	3	4	4	3	4	2
043	2		1	2	2	4	4	4	2	1	1	4	4	3	4	2	3	1	4	3	4	4	4	4	4	4	1	1	5	4	3	4	3
044	1		3	4	4	4	4	4	2	1	1	4	4	4	1	1	4	1	4	4	4	4	4	2	2	4	2	2	2	4	3	4	4
045	1	RIP																															
046	2		4	4	1	1	4	4	2	1	2	2	4	4	4	4	4	1	4	4	4	4	4	4	4	4	4	4	4	4	4	3	2
047	2		4	3	2	4	4	4	3	3	2	4	4	4	3	3	4	3	4	4	4	1	4	4	3	4	4	4	3	4	4	4	3
048	2		4	4	3	4	4	4	2	1	3	4	4	4	2	1	4	1	4	2	2	2	3	3	4	4	4	4	1	2	3	2	4
049	1		4	4	2	3	4	4	3	3	2	2	3	4	3	4	4	1	2	3	4	4	3	4	4	4	4	4	2	4	4	2	3
050	1		4	4	1	1	4	4	3	1	1	4	4	4	4	4	4	1	4	4	2	4	4	4	2	4	4	4	4	2	2	2	2
051	2		4	4	4	4	4	4	2	1	4	2	4	4	4	3	4	1	4	4	4	4	4	4	4	4	4	4	4	4	4	4	1
052	2		5	5	3	4	4	2	4	1	1	1	4	4	3	4	4	1	4	4	4	4	2	2	4	2	2	2	4	4	2	2	3
053	2	UTC																															
054	1		4	4	1	1	3	3	2	1	1	1	4	4	4	4	4	2	4	4	4	4	4	4	4	4	2	4	4	4	4	4	2
055	2		2	2	4	4	4	2	2	1	1	1	4	4	3	4	4	1	4	4	4	4	4	4	3	4	4	3	4	3	4	4	3
056	1		4	4	2	4	3	4	2	1	3	2	4	4	4	3	4	1	4	4	4	4	4	4	4	4	2	2	4	4	4	2	3
057	2		5	5	1	2	1	4	1	1	1	1	4	4	4	4	4	2	4	4	4	4	4	4	4	4	4	1	4	4	3	3	2
058	2		4	3	3	3	4	2	3	4	3	2	4	3	4	3	3	4	4	4	4	4	3	4	3	4	5	5	3	4	4	4	2
059	1		5	5	2	1	3	3	2	3	1	1	4	4	4	4	4	1	4	2	1	4	4	4	4	4	3	3	4	4	2	2	3
060	2	Moved to E.Cape (work)																															
061	2		4	4	1	1	2	4	2	1	1	1	4	4	4	4	4	2	4	3	4	4	4	4	4	4	1	1	4	4	4	4	2
062	2		3	3	3	4	4	4	2	2	2	4	4	4	2	2	4	1	2	2	2	4	1	4	2	4	2	2	2	3	3	2	4
063	2		4	4	1	2	4	4	2	1	3	4	4	4	4	4	4	1	4	4	4	4	4	2	2	4	4	4	4	4	4	2	2

064	1		4	4	3	2	4	4	3	2	4	4	2	3	4	3	4	5	4	4	3	4	4	4	4	4	5	5	4	4	4	4	3
065	2		3	2	3	4	4	4	2	1	1	2	4	4	4	3	4	1	4	2	4	4	3	4	4	2	2	2	4	4	2	4	2
066	2		4	4	2	1	4	4	2	1	1	1	4	3	2	1	4	1	4	4	4	4	4	4	3	4	2	2	2	2	3	4	4
067	2		4	4	1	1	4	4	2	1	1	1	2	4	4	4	4	1	4	4	2	4	4	4	4	4	4	4	4	4	1	4	4
068	2		3	3	2	4	3	4	3	1	4	1	3	4	4	4	4	1	4	4	1	4	2	4	3	4	4	1	4	4	4	4	2
069	1		4	4	1	1	1	4	2	1	2	1	4	4	4	4	4	1	4	4	4	4	4	4	4	4	4	1	4	4	4	4	2
070	1	Refused																															
071	2		3	2	2	3	4	3	3	4	4	4	3	3	2	2	3	2	3	3	2	3	4	3	2	4	3	3	4	3	2	2	3
072	2	UTC																															
073	1	DNA																															
074	1		4	4	4	4	3	4	3	4	2	1	4	4	4	2	2	4	3	1	4	4	4	4	4	3	4	4	2	3	4	4	2
075	2	UTC																															
076	1		3	2	3	5	4	4	2	4	4	4	2	2	2	1	1	1	1	2	4	3	4	4	4	4	2	2	1	2	2	4	3

1 = intervention group; 2 = control group

Red = participants who did not attend post-intervention testing

WHODAS (POST)

Code	Group	S1	S2	S3	S4	S5	S6	S7	S8	S9	S10	S11	S12	WHOTot
001	1	2	2	2	2	2	2	2	1	1	1	1	2	20
002	1	1	1	1	1	1	1	1	1	1	1	1	1	12
003	1	1	1	1	1	1	1	1	1	1	1	1	1	12
004	1													0
005	1	1	1	1	1	2	1	1	1	1	1	1	1	13
006	2	1	1	1	1	1	1	1	1	1	1	1	1	12
007	2	1	1	1	1	1	1	1	1	1	1	1	1	12
008	2	1	1	1	1	1	1	1	1	1	1	1	1	12
009	1	1	1	1	1	1	1	1	1	1	1	1	1	12
010	1	1	1	1	1	1	1	1	1	1	1	1	1	12
011	1	1	1	1	1	1	1	1	1	1	1	1	1	12
012	1	1	1	1	1	1	1	1	1	1	1	1	1	12
013	1	1	1	1	1	2	1	1	1	1	1	1	1	13
014	1	1	1	1	1	1	1	1	1	1	1	2	1	13
015	1	1	1	1	1	1	1	1	1	1	1	1	1	12
016	1	1	1	1	1	1	1	1	1	1	1	1	1	12
017	2	1	1	1	1	1	1	1	1	1	1	1	1	12
018	1	1	1	1	1	1	1	1	1	1	1	1	1	12
019	2	1	1	2	1	2	2	1	1	1	1	2	1	16
020	2	1	1	1	1	1	1	1	1	1	1	1	1	12
021	2	1	1	1	1	1	1	1	1	1	1	1	1	12
022	2	1	1	1	1	1	1	1	1	1	1	1	1	12
023	2	1	1	1	1	2	1	1	1	1	1	1	1	13
024	1	1	2	1	1	1	1	1	1	1	1	1	2	14
025	2	1	1	2	2	2	1	2	1	2	1	2	1	18
026	2	1	1	1	1	1	1	1	1	1	1	1	1	12
027	1	2	2	2	1	2	1	2	1	1	1	1	1	17
028	1	1	2	1	1	1	1	1	1	1	1	1	2	14
029	1	1	1	1	1	1	1	1	1	1	1	1	1	12
030	2	2	2	2	2	1	1	2	1	1	1	2	2	19

031	2	1	1	1	1	1	1	1	1	1	1	1	1	12
032	1	1	1	1	1	1	1	1	1	1	1	1	1	12
033	1	1	1	1	1	1	1	1	1	1	1	1	1	12
034	2	2	2	1	1	2	1	2	1	1	1	1	2	17
035	1	1	2	1	1	1	1	1	1	1	1	1	2	14
036	2	1	1	1	1	1	1	1	1	1	1	1	1	12
037	1	1	1	1	2	2	2	1	1	1	1	2	1	16
038	1	1	1	1	1	1	1	1	1	1	1	1	1	12
039	2	1	1	1	1	2	1	1	1	1	1	1	1	13
040	1	1	1	1	1	1	2	1	1	1	1	1	1	13
041	2	1	1	1	1	1	1	1	1	1	1	1	1	12
042	1	1	1	1	1	1	1	1	1	1	1	1	1	12
043	2	1	1	1	2	1	1	1	1	1	1	1	1	13
044	1	2	2	2	2	1	2	2	1	1	1	1	2	19
045	1													0
046	2	1	1	1	1	1	1	1	1	1	1	1	1	12
047	2	2	1	1	1	1	1	2	1	1	1	1	1	14
048	2	1	1	1	1	1	1	1	1	1	1	1	1	12
049	1	1	1	1	1	1	1	1	1	1	1	1	1	12
050	1	1	1	1	1	1	1	1	1	1	1	1	1	12
051	2	1	1	1	1	1	1	1	1	1	1	1	1	12
052	2	1	1	1	1	1	1	1	1	1	1	1	1	12
053	2													0
054	1	2	1	1	1	1	1	1	1	1	1	1	1	13
055	2	1	1	1	1	1	1	1	1	1	1	1	1	12
056	1	1	1	1	1	1	1	1	1	1	1	1	1	12
057	2	1	1	1	1	1	1	1	1	1	1	1	1	12
058	2	1	1	1	1	2	1	1	1	1	1	1	1	13
059	1	1	1	1	1	1	1	1	1	1	1	1	1	12
060	2													0
061	2	1	1	1	1	1	1	1	1	1	1	1	1	12
062	2	1	1	1	1	1	1	1	1	1	1	1	1	12
063	2	1	1	1	1	1	1	1	1	1	1	1	1	12

064	1	1	1	1	2	1	2	1	1	1	1	1	1	14
065	2	1	1	1	1	1	1	1	1	1	1	1	1	12
066	2	1	1	1	1	1	2	1	1	1	1	1	1	13
067	2	1	1	1	1	1	1	1	1	1	1	1	1	12
068	2	1	1	1	1	1	2	1	1	1	1	1	1	13
069	1	1	1	1	1	1	1	1	1	1	1	1	1	12
070	1													0
071	2	1	1	1	1	1	1	1	1	1	1	1	1	12
072	2													0
073	1													0
074	1	1	1	1	1	1	1	1	1	1	1	1	1	12
075	2													0
076	1	1	1	1	1	2	1	1	1	1	1	1	1	13

1 = intervention group; 2 = control group

Red = participants who did not attend post-intervention testing

RMI (POST)

Code	Group	R1	R2	R3	R4	R5	R6	R7	R8	R9	R10	R11	R12	R13	R14	R15	Rtot
001	1	1	1	1	1	1	1	1	0	1	1	1	1	1	1	0	13
002	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
003	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
004	1																0
005	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
006	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
007	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
008	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
009	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	14
010	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
011	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
012	1	1	1	1	1	1	1	1	1	0	1	1	0	1	1	1	13
013	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
014	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	14
015	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	14
016	1	1	1	1	1	1	1	1	1	0	1	1	0	1	1	1	13
017	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
018	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
019	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	14
020	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
021	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
022	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
023	2	1	1	1	1	1	1	1	1	1	1	1	0	1	1	0	13
024	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	14
025	2	1	0	0	1	1	1	1	1	0	1	0	0	1	1	0	9
026	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
027	1	1	1	1	1	0	1	0	0	1	0	0	1	1	0	0	8
028	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	14
029	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1		14
030	2	1	1	1	1	1	1	1	0	0	1	0	0	1	0	0	9

031	2	1	1	1	1	1	1	1	1	0	1	1	0	1	1	0	12
032	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
033	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
034	2	1	1	1	1	1	1	1	1	1	1	0	1	1	1	0	13
035	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	14
036	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	14
037	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
038	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
039	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
040	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
041	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
042	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
043	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
044	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
045	1																0
046	2	1	1	1	1	1	1	1	1	1	0	1	1	1	1	0	13
047	2	0	1	0	0	0	0	1	0	0	0	0	0	1	1	0	4
048	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	14
049	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
050	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
051	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
052	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
053	2																0
054	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
055	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	14
056	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
057	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
058	2	1	1	1	1	1	1	1	0	1	1	1	1	1	0	1	13
059	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
060	2																0
061	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
062	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
063	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15

064	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	14
065	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
066	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
067	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
068	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
069	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
070	1																0
071	2	1	1	1	1	1	1	1	1	1	1	1	0	1	1	0	13
072	2																0
073	1																0
074	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
075	2																0
076	1	1	1	1	1	1	1	1	0	0	1	0	1	1	0	0	10

1 = intervention group; 2 = control group

Red = participants who did not attend post-intervention testing

6MWT (POST)

Code	Group	PulsePre	RRPre	SBPPre	DBPPre	B1Pre	B2Pre	PulsePost	RRPost	SBPPost	DBPPost	B1Post	B2Post	Distance
001	1	91	16	139	90	0	0	96	24	156	114	2	1	160
002	1	81	16	118	90	0	0	84	22	125	91	1	1	312
003	1	99	16	127	52	0	0	117	22	107	46	0	0	364
004	1													
005	1	63	16	118	54	0	0	71	22	138	77	1	0	385
006	2	73	16	124	83	0	0	59	24	144	99	1	2	228
007	2	63	16	174	91	0	0	69	22	166	98	1	1	237
008	2	51	16	99	45	0	0	58	22	111	62	1	1	241
009	1	83	16	139	66	0	0	91	22	157	83	1	1	318
010	1	73	16	118	84	0	0	83	22	124	81	1	0	323
011	1	93	16	114	71	0	0	93	22	126	89	1	0	394
012	1	79	16	119	76	0	0	93	22	111	75	1	1	315
013	1	81	16	131	97	0	0	83	22	135	81	1	1	320
014	1	79	16	120	71	0	0	82	22	107	73	1	1	221
015	1	48	16	96	53	0	0	64	22	100	54	1	0	297
016	1	83	16	108	71	0	0	90	22	121	75	1	0	364
017	2	88	16	130	66	0	0	94	22	104	71	1	2	332
018	1	74	16	154	85	0	0	79	22	176	93	1	1	492
019	2	75	16	114	74	0	0	91	22	118	72	1	2	425
020	2	75	16	119	70	0	0	83	22	130	84	1	0	392
021	2	69	16	110	64	0	0	69	22	134	87	1	0	326
022	2	91	16	124	78	0	0	102	22	116	73	1	1	346
023	2	57	16	116	67	0	0	62	22	111	54	1	1	366
024	1	96	16	114	79	0	0	91	22	117	74	1	1	352
025	2	86	16	121	83	0	0	90	22	110	79	0	0	60
026	2	74	16	158	84	0	0	68	22	140	81	1	0	371
027	1	91	16	158	100	0	0	116	24	176	115	1	2	103
028	1	80	16	148	80	0	0	86	22	140	101	1	1	336
029	1	71	16	103	66	0	0	81	22	106	71	1	1	387
030	2	79	16	104	69	0	0	95	22	124	86	2	1	199

031	2	83	16	117	73	0	0	84	24	120	80	1	2	274
032	1	88	16	168	100	0	0	84	22	179	104	0	1	274
033	1	96	16	114	80	0	0	123	22	121	67	1	1	392
034	2	87	16	88	53	0	0	94	24	96	68	2	3	259
035	1	77	16	144	98	0	0	97	24	150	112	2	3	285
036	2	104	18	135	98	0	0	134	24	114	77	1	2	246
037	1	74	16	124	78	0	0	75	22	126	74	1	1	330
038	1	75	16	118	42	0	0	79	22	109	63	0	1	350
039	2	66	16	124	74	0	0	71	22	115	71	1	0	408
040	1	87	16	133	84	0	0	83	22	118	90	1	1	299
041	2	100	16	133	73	0	0	109	22	119	72	1	0	359
042	1	85	16	92	54	0	0	89	22	93	58	1	1	455
043	2	83	16	127	92	0	0	83	22	132	82	1	1	242
044	1	88	16	83	51	0	0	98	22	83	46	1	1	349
045	1													
046	2	82	16	127	82	0	0	99	24	153	93	1	2	157
047	2	95	16	104	69	0	0	102	24	113	73	1	1	83
048	2	80	16	120	80	0	0	79	22	153	108	0	1	288
049	1	73	16	113	83	0	0	75	22	129	92	0	1	321
050	1	66	16	141	87	0	0	69	22	136	83	1	1	306
051	2	72	16	101	76	0	0	75	22	118	82	0	1	361
052	2	72	16	120	80	0	0	78	22	168	22	0	1	295
053	2													
054	1	74	16	151	95	0	0	82	24	132	84	1	2	275
055	2	102	16	120	69	0	0	88	22	123	80	1	1	265
056	1	88	16	147	83	0	0	86	22	130	87	1	1	285
057	2	79	16	119	83	0	0	95	22	135	86	1	1	385
058	2	77	16	134	67	0	0	75	22	143	71	1	1	334
059	1	72	16	123	76	0	0	74	22	132	90	1	1	398
060	2													
061	2	90	16	175	90	0	0	99	24	190	94	1	2	242
062	2	66	16	132	90	0	0	73	22	131	90	0	0	354
063	2	81	16	111	67	0	0	78	22	115	73	1	1	330

064	1		72	16	151	88	0	0	68	22	158	88	1	1	319
065	2		73	16	127	70	0	0	68	22	115	78	1	1	353
066	2		50	16	163	90	0	0	59	22	168	92	0	0	493
067	2		77	16	101	75	0	0	79	22	105	71	1	1	371
068	2		62	16	151	83	0	0	67	22	165	84	0	0	388
069	1		66	16	147	92	0	0	77	22	117	78	1	0	322
070	1														
071	2		71	18	122	84	1	0	77	24	142	83	4	3	302
072	2														
073	1														
074	1		70	16	121	79	0	0	84	20	138	83	1	1	421
075	2														
076	1		91	16	129	84	0	0	104	24	98	79	1	2	318

1 = intervention group; 2 = control group

Red = participants who did not attend post-intervention testing

Staff Training Schedule and Description

Training provider: Saul Cobbing (qualified Physiotherapist and Biokineticist)

Training venue: Study hospital (seminar room and hall for practical sessions)

Dates provided: Four consecutive weeks (January – February 2015).

Attendees: The five CCWs who conducted pre and post-intervention testing (here named S1, S2, S3, S4 and S5) and the four CCWs who implemented the study HBR intervention (here named S6, S7, S8 and S9).

Week 1:

Topic covered: Study description and research ethics

Attendees: All

Topic covered: Theory and practical application of four study outcome measures

Attendees: S1, S2, S3, S4 and S5

Week 2:

Topic covered: Basic human anatomy and physiology

Attendees: S6, S7, S8 and S9

Week 3:

Topic covered: Aerobic rehabilitation and provision of walking aids (theory and practice)

Attendees: S6, S7, S8 and S9

Week 4:

Topic covered: Strength and functional rehabilitation (theory and practice)

Attendees: S6, S7, S8 and S9

Information and consent form for home-based rehabilitation workers

Title of Study: A home-based rehabilitation intervention for people living with HIV and disability in a resource-poor community, KwaZulu-Natal

Investigators:

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Dr. Jill Hanass-Hancock, HEARD University of KwaZulu-Natal
Dr. Hellen Myezwa, WITS University, Johannesburg

Funders: National Research Foundation (NRF) Thuthuka Programme

Why are we undertaking this research?

You have been involved in this study as a home-based rehabilitation worker. We would like to interview you in order for us to better understand the benefits and challenges of the home-based rehabilitation intervention for both yourself and the participants in the intervention. To assist you in deciding whether to participate in this interview, you should understand its risks and benefits to be able to make an informed decision. Make sure that all your questions have been addressed before agreeing to participate.

What is involved if I agree to participate?

In this interview you will be asked questions about the challenges you faced being involved in this intervention, as well as the benefits you perceive to have gained from this involvement. A voice recorder will be used to record your responses. This information is purely for research purposes. The information will not in any way be used to monitor your performance.

What risks and benefits are there?

There are no risks involved in providing this information to the researchers. The benefit of this research is that it will help reveal the benefits and challenges related to this intervention, in order to improve similar interventions in the future.

How will we make sure that your information remains confidential?

All information shared will be kept confidential. No names will be included in any written notes, publications or presentations. After the data is entered, electronic copies of the data will be kept on a password protected computer and paper copies will be kept in a locked cabinet in the lead researcher's office in the Department of Physiotherapy, UKZN.

If you have any questions about your rights as a participant in this project you can contact Saul Cobbing on 031 260 8147. You can also contact the UKZN Biomedical Research Ethics Committee 031 260 4769 e-mail: BREC@ukzn.ac.za with any concerns or complaints you may have regarding this study.

Can I withdraw from the study?

The study is voluntary and you are free to withdraw from it at any time.

HBR Worker's Consent Form

I…………….. ………………………………………………(full names of participant) hereby confirm that I understand the nature of the research project, and I consent to participating in this study.

I consent to my interview being audio recorded. ☐

I understand that I can withdraw from the project at any time, should I so desire.

HBR worker's signature Date

______________________________ ______________

Mina..(amagama aphelele ophendulayo) ngiyaqinisekisa ukuthi ngiqonda kahle okudingwa yilolucwaningo. Ngalokho-ke ngiyavuma ukuzibandakanya kulolucwaningo.

Ngiyavuma ukuba lemibuzo engibuzwa yona iqoshwe. ☐

Ngiyaqonda futhi ukuthi ngingayikhipha lemvume kulolucwaningo nganoma isiphi isikhathi uma ngithanda.

Kusayina Obuzwayo Usuku

....

COMMUNITY HEATHCARE WORKERS: Semi-structured interview Guide

1. Can you describe the experience you have had while being a part of this study? (Lived experience)
2. What were some of the challenges or barriers you experienced while doing your work on this study?
3. What were some of the things that helped you and encouraged you to do your work on this study?
4. What do you understand about disability? (Introduce ICF questions here, environment etc.)
5. What is your understanding of using exercises to help people living with HIV?
6. What has been the highlight of working with the people in the community who were part of the study?
7. Where there any changes in the way you have felt over time as the study progressed? (Emotions? Feelings? Attitude)
8. What are some of your reservations or concerns now that the study intervention in completed?
9. Given your experiences, how would you change the implementation of this home-based exercise programme, if you were to be involved in this work in the future?
10. If programmes like the one you have worked on are to be implemented on a wider scale, is there any advice you could give to researchers/funders/hospital staff to make sure that they are successful?

POSITION PAPER: THE ESSENTIAL ROLE OF PHYSIOTHERAPISTS IN PROVIDING REHABILITATION SERVICES TO PEOPLE LIVING WITH HIV IN SOUTH AFRICA

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ABSTRACT: *Despite increased access to highly active anti-retroviral therapy (HAART) in South Africa, there remains a high risk of people living with HIV (PLHIV) developing a wide range of disabilities. Physiotherapists are trained to rehabilitate individuals with the disabilities related to HIV. Not only can South African physiotherapists play a significant role in improving the lives of PLHIV, but by responding proactively to the HIV epidemic they can reinforce the relevance and value of the profession in this country at a time when many newly qualified therapists are unable to secure employment. This paper offers recommendations that may help to fuel this response. These ideas include enhancing HIV curricula at a tertiary level, designing and attending continuing education courses on HIV and researching Southern African rehabilitation interventions for HIV at all levels of practice. Furthermore, it is vital that physiotherapists are at the forefront of directing multi-disciplinary responses to the rehabilitation of PLHIV in order to influence stakeholders who are responsible for health policy formulation. It is hoped that this paper stimulates discussion and further ideas amongst physiotherapists and other health professionals in order to improve the quality and access to care available to PLHIV in South Africa.*

KEY WORDS: *HIV, PHYSIOTHERAPY, REHABILITATION, RESEARCH, RESPONSE.*

Sub-Saharan Africa bears an inordinate share of the worldwide HIV burden, with an estimated 11.3 million people living with HIV (PLHIV) in 2009 (UNAIDS 2010). AIDS-related deaths have fallen in this region from 1.4 million in 2001 to 1.3 million in 2009 and this trend looks set to continue with the more widespread availability and uptake of highly active anti-retroviral therapy (HAART) (UNAIDS 2010). The statistics above tell a story. Ultimately there will be more and more people living with HIV and consequently far more people living with disabilities as a result of their HIV infection (Myezwa et al, 2011, Nixon 2011). Physiotherapy as a profession can play a key role in assisting PLHIV manage these disabilities and improve their holistic participation in the occupational, social and recreational aspects of their lives.

The changing nature of the local HIV epidemic coincides with an important time in the evolution of the profession of physiotherapy in South Africa. The occupational specific dispensation (OSD) negotiations for physiotherapy were completed in 2010, and resulted in salary increases for public sector physiotherapists; primarily at Grade 1 level (NPSWU, 2010). Despite this development, many qualified physiotherapists perceive that the profession remains undervalued, both in a remunerative sense and in terms of an understanding of what physiotherapists actually do as first line practitioners (SASP, 2009). This is highlighted by the shortage of physiotherapy posts at a number of state institutions and the difficulty facing some newly-qualified physiotherapists in securing employment following their year of community service. Despite these job shortages, the number of physiotherapists being trained at South African tertiary institutions continues to increase, in line with specific government directives to train

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more health professionals (DOH, 2011). For example, the annual first year intake at the physiotherapy department at the University of KwaZulu-Natal (UKZN) has increased from approximately 30 students to more than 50 students in the past decade.

The demand for any medical service, such as physiotherapy, is determined by a country's burden of disease. It is to be noted that the disease burden is described by Disability Adjusted Life Years (DALYs), a composite measure which incorporates both the number of years lost to mortality and the number of years lived with disability (Murray, 1996). According to the proposed National Health Insurance (NHI), South Africa faces a quadruple burden of disease, with the mortality and morbidity related to HIV/AIDS second only to non-communicable diseases, resulting in this country having a burden of disease almost double that of other developing countries (Econex, 2009). A correct analysis of this burden of disease is crucial in the allocation of resources and the forecasting of demand for specific medical services. In April 2012, the Department of Health began piloting the NHI in 10 selected districts (DOH, 2012).

In order to enhance the relevance and value of the profession, South African physiotherapists working in all sectors need to respond proactively and energetically to the HIV epidemic (Myezwa and Stewart 2012, Nixon 2011). This is particularly important in ensuring that physiotherapy is not forgotten when any revised resource allocation occurs under the NHI. This task should not be borne solely by state physiotherapists, but should be supported by physiotherapists working in the private sector as well as in tertiary education, all of whom stand to benefit from an increased understanding of the abilities and skills of physiotherapists. Furthermore, it is important that physiotherapists work closely with other allied health professionals, such as occupational therapists and speech therapists, in achieving these goals. Interdisciplinary teams of healthcare professionals involved in rehabilitation can offer a range of rehabilitative services through a comprehensive, coordinated and collaborated programme (Jelsma et al, 2002).

As experts in exercise, physiotherapists are ideally placed to offer services to PLHIV, via the development of well-planned and progressive rehabilitation and exercise programmes. While physiotherapists may be well aware of this, it was encouraging to note that a recent newspaper article in a national publication (Malan, 2012) outlined the crucial role physiotherapists and other health care professionals play in the function and well-being of PLHIV, while at the same time highlighting the fact that this role is often not acknowledged. The effects of exercise on the physical and mental well-being of PLHIV have been explored in a number of studies, many of which have been conducted in the high income countries. These studies are well summarised in two systematic reviews by O'Brien et al (2009 and 2010) on the effects of resistance exercise and aerobic exercise interventions on PLHIV. The conclusions were that there were positive effects of exercise including improvements in cardiopulmonary fitness, muscle strength and certain measures of psychological status as well as increases in body weight. Both forms of exercise were further found to be safe for PLHIV, incurring no additional health risks to participants. Overall, no significant changes in immunological status (as evidenced by CD4 count and viral load) were noted. Similarly, in a low income East African context, Mutimura (2008) found that exercise does not negatively affect CD4 count and improved several components of quality of life, body fat distribution and metabolic indices, which may in turn have positive effects on HAART adherence and other treatment initiatives. More research, however, is required regarding the physiological and psychological effects of exercise and therapy on PLHIV in a relatively under-funded Southern African public sector context.

South Africa has taken a leading role in producing research pertaining to the rehabilitation of PLHIV and disability. Myezwa et al (2009) conducted a study to assess eighty HIV in-patients at the Chris Hani Baragwanath Hospital in Gauteng province, South Africa. Using the ICF checklist (WHO, 2003) to assess the impairments, activity limitations and participation restrictions experienced by these patients, the researchers found that over 70% of the participants in this study reported impairments related to digestive, neuromuscular, respiratory and sensory function as well as emotional and mental problems and decreased energy levels and sleep quality. These impairments led to activity limitations such as reduced mobility and problems with self-care as well as participation restrictions, including the ability to engage fully in community, social and civil life. Other physiotherapist-led studies found similar impairments to be present in contrasting settings (Jelsma et al, 2006, Van As et al, 2008, Myezwa 2011). Ferguson and Jelsma (2009) and Potterton et al (2010) highlighted the motor and cognitive developmental challenges facing HIV infected children and the positive influence of a home stimulation programme.

Other disciplines have also revealed data showing that impairments such as HIV dementia (Joska 2010, Lawler 2010, Lawler 2011) neuropathy (Maritz 2010), depression and anxiety (Brandt 2009, Freeman 2007), changes in body function such as pain (Friend-du Preez et al, 2010, Nair and Muthukrishna 2009), fatigue (Nair and Muthukrishna 2009, Gerntholtz et al, 2006), emotional challenges, sensory problems (Maritz 2010) as well as activity problems particular in the area of mobility (Nair and Muthukrishna 2009, Patel 2009) and self-care (Oketch 2011) are prevalent in a significant amount of people living with HIV (many of whom have access to treatment). Not only do these studies reveal the myriad of problems that PLHIV face, but they further underscore the urgent need for increased therapy resources in the area of HIV management.

Physiotherapy as a profession can play a major role in improving both the health and quality of lives of PLHIV. Here, we offer recommendations on the way forward and hope to encourage discussion about possible solutions to enhance future rehabilitation interventions for PLHIV.

PHYSIOTHERAPY TRAINING PROGRAMMES TO ENHANCE HIV CURRICULA:

An audit of physiotherapy curricula in South African universities (Myezwa, 2008) revealed many gaps in the teaching of HIV-related material to physiotherapy students. It is therefore necessary that these tertiary institutions examine their curricula to ensure that relevant and up-to-date teaching on HIV is included. Ideally, academics from the various training institutions could collaborate in the design and development of a comprehensive curriculum (Myezwa and Stewart, 2012). In an effort towards realising this goal, a survey of 58 physiotherapy academic staff at eight South African universities was recently conducted (Myezwa et al, 2012). This survey found a high level of consensus (above 80 percent) amongst these academics as to which HIV-related topics should be taught in their individual programmes. These topics included HIV pathophysiology, anti-retroviral therapy, HIV-related disorders and teaching on HIV and disability. This theoretical grounding should be reinforced and developed by ensuring that students have frequent opportunities to treat and rehabilitate PLHIV during their clinical placements. The challenge now for individual institutions is to ensure that these topics are mainstreamed into their curricula.

CONTINUING EDUCATION ON HIV FOR ALL PRACTICING PHYSIOTHERAPISTS:

Secondly, private and public sector physiotherapists should be encouraged to attend seminars or workshops on topics pertinent to the physiotherapy management of HIV. This would enable physiotherapists interested in this clinical area to update their knowledge in this ever-evolving field. It might even be suggested that, just as resuscitation and ethics CPD points are required for reregistration with the HPSCA, a course in HIV should be included as an additional requirement. In order to both highlight the value that physiotherapists as a profession can offer as well as encourage multi-disciplinary collaboration, it would be opportune to invite other health care professionals to these training events. An example of such a workshop is currently being piloted by a collaboration between the Health Economics and HIV/AIDS Research Division (HEARD) and the UKZN. (HEARD, 2012). The material for the workshop will be available in 2013.

MORE RESEARCH IS REQUIRED ON REHABILITATION IN THE CONTEXT OF HIV IN SOUTH AFRICA:

Thirdly, there is a dearth of evidence for interventions in HIV within a Southern African context and it would be prudent for the profession to accelerate and facilitate the production of evidence to inform physiotherapy practice and education, and to contribute to HIV policy. A pilot study conducted recently by HEARD (Hanass-Hancock et al, 2012) indicates that HIV-related disability might not only influence adherence but might also be closely linked to issues around mental health and coping. Research should also explore the role of rehabilitation, and physiotherapy specifically, in improving adherence to ART and other aspects so crucial to the HIV epidemic.

PHYSIOTHERAPISTS NEED TO BE PROACTIVE IN CLINICAL CARE:

Fourthly, it is important that physiotherapists take an active leadership role in initiating and directing multi-disciplinary responses to the rehabilitation of PLHIV, rather than wait patiently for referrals which may never appear (Myezwa et al, 2009). This proactive approach needs to be taken with an understanding of the South African Department of Health (DOH) vision of public health care delivery in South Africa moving towards community-based care (CBR) and home-based care (HBC) models. In addition the first line practitioner status that physiotherapists enjoy should encourage an approach to screen assess and treat relevant problems among HIV patients. According to the South African Department of Health, (DOH 2001) these models promote the treatment of people in or near their homes and encourage participation by people, responds to the needs of people, encourages traditional community life and creates responsibilities.

PHYSIOTHERAPISTS SHOULD BE AT THE HIV DECISION-MAKING TABLE:

Finally, in the longer term, it is crucial that in the interests of the profession, all physiotherapists are involved in demonstrating the value that they can add in both the public and private sectors to stakeholders who are responsible for policy formulation and decision-making. This is obviously not limited to PLHIV but in an ever-competitive resource-poor South African context, physiotherapy should ensure that they are in the vanguard of the response to HIV-related disability and impairments. In order for our profession to grow and thrive it is not good enough for physiotherapists to merely know what they themselves can do, it is vital that they let others at all levels of health delivery know of the positive impact they can have on PLHIV.

To conclude, physiotherapists should be key role players in providing rehabilitation to PLHIV in the era of HAART. The need for rehabilitation services will increase as PLHIV live longer lives. The onus lies on all physiotherapists to seize this opportunity to promote the critical role that the profession should be playing in response to the HIV epidemic in this country. With improved training and research in this area, proactive clinical intervention and the building of collaborative relationships with other health professionals, physiotherapists can add significant value to the lives of PLHIV, while at the same time strengthening the standing of the profession in South Africa.

REFERENCES

Brandt R 2009 The mental health of people living with HIV/AIDS in Africa: a systematic review. African Journal of AIDS Research. 8(2): 123–133

Department of Health (DOH) 2001 National guideline on home-base care/community-based care. Available at:<http://www.doh.gov.za/docs/factsheets/guidelines/homecare/> [Accessed November 2012]

Department of Health (DOH 2011) Human Resources for Health: South Africa 2030. Available at:< http://www.info.gov.za/view/DownloadFileAction?id=152426>[Accessed September 2012]

Department of Health (DOH 2012) National Health Insurance. Available at:< http://www.doh.gov.za/list.php?pageNum_rsList=1&totalRows_rsList=53&type=National%20Health%20Insurance> [Accessed September 2012]

Econex 2009 South Africa's burden of disease. Available at:< http://www.mediclinic.co.za/about/Documents/ECONEX%20NHI%20note%202.pdf> [Accessed September 2012]

Ferguson G and Jelsma J 2009 The prevalence of motor delay among HIV infected children living in Cape Town. International Journal of Rehabilitation Research, 32(2): 108-114

Freeman M 2007 Factors associated with prevalence of mental disorder in people living with HIV/AIDS in South Africa. AIDS Care, 19(10):1201-9

Friend-du Preez N and Peltzer K 2010 HIV symptoms and health-related quality of life prior to initiation of HAART in a sample of HIV-positive South Africans. AIDS and Behavior 14(6):1437-47

Gerntholtz TE, Goetsch SJ, and Katz 2006 HIV-related nephropathy: a South African perspective. Kidney International 69(10):1885-91

Hanass-Hancock J, Nixon, S, Myezwa H, Van Eggerat L, and Gibbs A 2012. 'Nathi Singabantu" an exploratory study of HIV related Disability in KwaZulu-Natal. Durban: HEARD.

Health Economics and HIV/AIDS Research Division (HEARD 2012) Disability Research and Advocacy Projects. Available at:< http://www.heard.org.za/african-leadership/disability/projects> [Accessed September 2012]

Jelsma J, Mielke J, Powell G, De Weerdt W and De Cock P 2002 Disability in an urban black community in Zimbabwe. Disability and Rehabilitation 24 (16): 851-859

Jelsma J, Brauer N, Hahn C, Snoek A and Sykes I (2006) A pilot study to investigate the use of the ICF in documenting levels of function and disability in people living with HIV. South African Journal of Physiotherapy 62(1): 7-13

Joska JA 2010 Clinical correlates of HIV-associated neurocognitive disorders in South Africa. AIDS and Behavior, 14(2): 371-378

Lawler K 2010 Neurocognitive impairment among HIV-positive individuals in Botswana: a pilot study. Journal of the International AIDS Society, 13-15

Lawler K 2011 Neurobehavioral effects in HIV-positive individuals receiving highly active anti-retroviral therapy (HAART) in Gaborone, Botswana. PLoS One, 6(2),17233

Malan M 2012 Healing touch helps HIV patients. The Mail & Guardian.17-23 Feb

Maritz J 2010 HIV neuropathy in South Africans: frequency, characteristics, and risk factors. Muscle Nerve, 41(5): 599-606

Murray CJL (1996) Rethinking DALYs, in the global burden of disease, pp 1-89, Harvard School of Public Health, Cambridge

Mutimura E, Stewart A, Crowther NJ, Yarasheski KE and Todd Cade W 2008 The effects of exercise training on quality of life in HAART-treated HIV-positive Rwandan subjects with body fat redistribution. Quality of Life Research, 17:377–385

Myezwa H 2008 Mainstreaming HIV/AIDS in physiotherapy education and practice. Unpublished doctoral dissertation, University of Witwatersrand, Johannesburg, South Africa.

Myezwa H, Stewart A, Musenge E and Nesara P 2009 Assessment of HIV-positive in-patients using the International Classification Of Functioning, Disability and Health (ICF), at Chris Hani Baragwanath Hospital, Johannesburg African Journal of AIDS Research 8(1): 93-106

Myezwa H, Buchalla C, Jelsma J and Stewart A 2011 HIV/AIDS: use of the ICF in Brazil and South Africa– comparative data from four cross-sectional studies. Physiotherapy 97: 17-25

Myezwa H, and Stewart A 2012 HIV/AIDS in physiotherapy Education – Mainstreaming UN principles. South African Journal of Physiotherapy 68(1): 35-41

Myezwa H, Stewart A, Solomon P and Becker P Topics on HIV/AIDS for Inclusion Into a Physical Therapy Curriculum: Consensus Through a Modified Delphi Technique. Journal of Physical Therapy Education 26(2): 50-56

Nair KM and Muthukrishna N 2009 Psychological Well-Being and Health Related Quality of Life among a Group of Low-Income Women Living with HIV/AIDS in South Africa. Journal of Psychology in Africa19(4): 517-529

National Public Service Workers Union (NPSWU) 2010 Occupational specific dispensation for therapeutic, diagnostic and related allied health professionals. Available at:<http://npswu.org/docs/Res_2_of_2010_5.pdf> [Accessed May 2012]

Nixon S 2011 Rehabilitation: A crucial component in the future of HIV care and support. South African Journal of HIV Medicine June 12-16

Nixon S 2011 The Increasing Chronicity of HIV in Sub-Saharan Africa: Re-thinking "HIV as a Long-Wave Event" in the Era of Widespread Access to ART. Globalisation and Health 7:41

O'Brien K, Nixon S, Glazier R. and Tynan A 2009 Progressive resistive exercise interventions for adults living with HIV/AIDS (Review). The Cochrane Library, Issue 1. Available at: <http://www.thecochranelibrary.com> [Accessed November 2012]

O'Brien K, Nixon S, Tynan AM and Glazier R 2010 Aerobic exercise interventions for adults living with HIV/AIDS (Review).The Cochrane Library, Issue 8 Available at: <http://www.thecochranelibrary.com> [Accessed November 2012]

Oketch JA 2011 Too little, too late: comparison of nutritional status and quality of life of nutrition care and support recipient and non-recipients among HIV-positive adults in KwaZulu-Natal, South Africa. Health Policy 99(3): 267-76

Patel R 2009 Quality of life, psychosocial health, and antiretroviral therapy among HIV-positive women in Zimbabwe. AIDS Care 21(12): 1517-27

Potterton J, Stewart A, Cooper P and Becker P 2010 The effect of a basic home stimulation programme on the development of young children infected with HIV. Developmental Medicine and Child Neurology, 52(6): 547-551

South African Society of Physiotherapy (SASP) 2009. Occupation specific dispensation - The SA Society of Physiotherapy report. Available at:<http://www.physiosa.org.za/?q=node/848> [Accessed November 2012]

UNAIDS, 2010. Report on the global AIDS epidemic. Available at: <http://www.unaids.org/globalreport/Global_report.htm>[Accessed November 2012]

Van As M, Myezwa H, Stewart A, Maleka D and Musenge E 2009 The International Classification of Function Disability and Health (ICF) in adults visiting the HIV outpatient clinic at a regional hospital in Johannesburg, South Africa. AIDS Care, 21(1): 50-58

World Health Organization (WHO) 2001 International Classification of Functioning Disability and Health.Available at: <http://www.who.int/classifications/icf/en/>[Accessed November 2012]

World Health Organisation (WHO) 2003 ICF checklist: version 2.1a, clinician form. Available at: <http://www.who.int/classifications/icf/training/icfchecklist.pdf> [Accessed November 2012]

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RESEARCH PAPER

Physiotherapy rehabilitation in the context of HIV and disability in KwaZulu-Natal, South Africa

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Abstract

Purpose: The purpose of this study was to describe the experiences of people living with HIV (PLHIV) who had undergone a physiotherapy-led rehabilitation programme, with the aim of informing and improving future rehabilitation. *Methods*: The study population included patients living with HIV who were referred for physiotherapy rehabilitation at a public-funded KwaZulu-Natal hospital. Eight participants were considered for final analysis in the study. A qualitative research design was adopted using in-depth interviews to explore their experiences of their rehabilitation programme. Additionally all eligible participants were requested to complete the World Health Organisation Disability Assessment Schedule. *Results*: Participants presented varying activity-related challenges with mobility, self-care and life activities being the most severely affected areas. Participants showed little understanding of their health conditions, prescribed medication and in some cases therapy. HIV and disability impacted their daily lives, adversely affecting work and domestic activities. Although participants reflected positively on the rehabilitation experience they faced a number of barriers to accessing continued rehabilitation. *Conclusion*: PLHIV who experience disability are affected in major life areas but the current model of delivering rehabilitation provides a number of barriers to patients. A more accessible approach of delivering HIV-care and rehabilitation needs to be developed.

Keywords

Access, barriers, HIV, ICF, South Africa

History

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➤ Implications for Rehabilitation

- Physiotherapists and other rehabilitation professionals, particularly those working in the South African public sector, need to consider developing and implementing home-based rehabilitation interventions for patients living with HIV and disability. This will counter some of the barriers these patients face in accessing hospital-based therapy.
- With the increasing incidence of HIV-related disabilities as PLHIV live longer lives, rehabilitation professionals working with this patient population should keep up to date with recent literature and practical training courses related to the disease and its management.

Introduction

Sub Saharan Africa bears an inordinate share of the worldwide HIV burden, with an estimated 11.3 million people living with HIV (PLHIV) in 2009. Annual AIDS related deaths have fallen in this region from 1.4 million in 2001 to 1.3 million in 2009 and this trend looks set to continue with the more widespread availability and uptake of highly active antiretroviral therapy or HAART [1]. Data show that in Sub Saharan Africa the access to HAART has increased from 2 to 27% in the period of 2002 to 2009/10. According to a recently published report by the Actuarial Society of South Africa [2] an estimated 5.5 million people are currently living with HIV in South Africa, more than in any other single country in the world. Within South Africa itself, KwaZulu Natal has the highest HIV prevalence of all the nine provinces, with 14.8% of the province's inhabitants living with HIV, as compared to the Western Cape, which has the lowest prevalence of 5%. The report estimates that the annual number of AIDS deaths in South Africa decreased from 257 000 in 2005 to 194 000 in 2010. These statistics indicate that there will be more and more people living with, rather than dying of, HIV in South Africa and more specifically in the province of KwaZulu Natal. This is, of course, a positive development, but this increased longevity has been mirrored by an increase in the prevalence and impact of disability experienced by this population [3,4].

Literature also indicates that the effects of the increased burden of diseases particularly in the eastern and southern African region may also contribute to the increased disability prevalence [5]. Depending on the source, between 12% and 24% of the South African population is considered to have a disability which is above the world average and one of the highest in Africa [6]. A recent scoping review [4] indicates that the disabling effects of HIV, its opportunistic infections and the treatment of both affects

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a large number of people PLHIV including those on long term treatment. The review, which focuses on hyper endemic countries, summarises a wide range of research papers including a number of health conditions (e.g. depression, lipodystrophy, peripheral neuropathy, HIV dementia) that have the potential to develop into disability. Some of these challenges can be addressed by biomedical interventions. Others, however, need a more comprehensive approach that includes rehabilitation.

Physiotherapy, as a profession, can play a key role in assisting PLHIV to prevent and manage disability and therefore enable holistic participation in the occupational, social and recreational aspects of life [7,8]. The profession of physiotherapy is concerned with the assessment and treatment of people challenged with a wide array of neurological, musculoskeletal and respiratory conditions. PLHIV are prone to opportunistic infections that have the potential to damage one or all of the above physiological systems [9]. Physiotherapists are therefore involved in the rehabilitation of these patients [7].

In resource rich settings, this reality has been recognised for a number of years [10]. Two comprehensive systematic reviews have demonstrated that aerobic and resistance exercise interventions are not only safe for PLHIV, but confer a wide range of physical and physiological benefits to these individuals [11,12]. Very little, however, is known about physiotherapy led rehabilitation for PLHIV in countries with a widespread epidemic of HIV, all of which are in resource poor settings. As a result there is limited knowledge about PLHIVs' experiences of, and access to, rehabilitation in the context of HIV in southern Africa and it is not understood which model of care is suitable in an epidemic country with limited resources.

This study aimed to explore and describe the experiences of patients living with HIV who participated in a rehabilitation programme in a public funded KwaZulu Natal hospital. It aims to present information on the participants experience with impairment activity limitations and participation restrictions as well as the rehabilitation they received. Disability in this study was framed through the International Classification of Function, Disability and Health (ICF) [13]. The ICF adopts a bio psychosocial approach that views impairments, activity limitations and participation restrictions in relation to associated contextual factors, which are further divided into environmental and personal influences [14]. This allows disability to be defined beyond the medical model and places emphasis on the experience of disability in a socially constructed realm dependent on interrelated social, environmental and personal factors.

Methodology

In order to describe the experiences of PLHIV who experience disability, a qualitative research design approach was applied in this study. As this study was interested in the how the individual participants interpret the physiotherapy led rehabilitation, a phenomenological design was adopted. Phenomenological research is an approach that examines ''lived experiences'' and how the individual reacts to and makes meaning of the experience [15]. The study conducted semi structured in depth interviews after a period of rehabilitation, designed and supervised by physiotherapists and conducted in the physiotherapy clinic or on the medical wards of the research institution. The development of the interview schedule was guided by the ICF framework [13]. This interview consisted of 14 open ended questions prompting responses to health condition and the experiences of receiving rehabilitation. In addition, information about the patients' health condition and degree of disability was obtained from the patient files as well as the World Health Organisation Disability Assessment Schedule (WHODAS 2.0) [16].

Research setting

The study was located at a public funded hospital in a semi urban area of KwaZulu Natal, South Africa. The hospital is a 200 bed facility, serving a population of 750 000 people. The hospital provides a service for 4500 registered PLHIV many of those on HAART [17]. The hospital includes a physiotherapy unit which is staffed with one physiotherapist and two assistants. The hospital lacks the financial means to support any type of occupational therapy, speech therapy or mental health interventions. The hospital works in cooperation with the Community Outreach Center (a local NGO), which provides home based care (HBC) services to the local community and complements the health services from the hospital.

Study population and sample

The study approached all PLHIV who were referred to the physiotherapy department at the study hospital during a randomly selected five week period in July and August 2012. Individuals were excluded if they were unable to communicate with, or understand the researcher (e.g. due to advanced HIV dementia) or were unwilling to participate in the study. The study used a convenient sampling method dependent on who was referred to the physiotherapy department during the period of the study. The sample therefore includes participants just after an acute period of illness as well as patients that were already clinically stable. In line with phenomenological tradition, the study targeted to recruit between 8 and 15 participants [18]. At baseline, 14 participants volunteered for the study and completed the WHODAS 2.0. Four participants completed their rehabilitation, but were lost to follow up as they did not return for the post rehabilitation interview nor were they contactable through the telephone numbers recorded in their patient files. One participant had passed away since being discharged from the hospital, while another participant did not arrive for the interview after already having missed a number of scheduled appointments. Thus, a total of eight participants, who completed both the WHODAS 2.0 and the interview, were considered for discussion in this study.

Data collection

Participants received rehabilitation over the course of a 5 week clinical block at the hospital. Each participant received an individualised rehabilitation programme, designed and supervised by their designated physiotherapist. Participants filled in the WHODAS 2.0 before beginning their rehabilitation. On completion of their period of rehabilitation, individual participants participated in an interview with the principal investigator and, where necessary, a research assistant who was fluent in isiZulu.

Data analysis

Recorded data from participant interviews were transcribed and translated where necessary. A second researcher crosschecked the transcriptions and translations in order to improve the validity of the reviewed data. The analysis was guided by thematic content analysis, in order to identify any common categories and themes that emerged from the data. This process was facilitated by the use of NVIVO 10 software (QSR International, Doncaster, Australia). The analysis process coded emerging issues first as taken from the data and later submerged emerging issues into themes.

Ethical considerations

Permission to conduct the study was granted by the chief executive officer of the hospital. Ethical approval was obtained from the UKZN Human and Social Sciences Research Ethics Committee. Participants were given an information sheet outlining the nature and requirements of the study, with the right to withdraw at any point during the study and then asked to sign a consent form. Participation was voluntary and a patient's refusal to participate in the study did not influence their ongoing treatment. Participants were assigned codes in order to maintain anonymity. No information regarding the participants' involvement in this study was divulged at any point.

Results

Participants' description

Participants in this study included four men and four women ranging between the ages of 26 and 48 years and presenting different types of health conditions. Table 1 provides a brief summary of participants' demographic and diagnostic information. This information was extracted from both the WHODAS 2.0 forms as well as the medical and physiotherapy notes in their individual patient files.

The WHODAS 2.0 form was completed by each patient in order to assess their level of physical and cognitive functioning as well as their ability to participate fully in society. Table 2 shows the scores of all eight participants for each of the six WHODAS 2.0 domains. This information was obtained prior to the commencement of rehabilitation. A score of 1 indicates that the patient has no difficulty at all with the task or activity assessed in each question. A score of 2 indicates mild difficulties, 3 moderate difficulties, 4 severe difficulties, while a score of 5 indicates extreme difficulties or an inability to do the specified task. The score given for each domain in Table 2 is an average of the scores given for the questions asked for each of the six domains.

The domain scores from Table 2 indicate that participants presented with varying degrees of disability and activity levels. Six participants recorded low scores for the questions in the cognitive domain. The mobility domain shows considerably higher scores, with five of the participants scoring between 3 (moderate difficulty) and 5 (extreme difficulty or an inability to perform the specific task). The self care domain focuses on activities such as washing, getting dressed, eating and living on their own. The scores reflect a wide range in the ability of participants to look after themselves. The fourth domain questions participants' ability to get along with other people. The participants in this study recorded generally low scores for this domain. The life activities domain questions participants on household activities, such as cooking and cleaning, as well as work or school activities such as the ability to get all their work tasks done well and in time. Five of the participants showed very high average scores in this domain. Finally, the participation domain explores their ability to participate fully in society, including community activities, as well as their ability to be able to relax and live with dignity. Scores for this domain varied considerably for all eight participants. The challenges illustrated by the WHODAS 2.0 scores were further elaborated upon by the individual participants in their interviews.

Table 1. Individual participant data.

Code	Gender	Age	Education[a]	Marital status	Work status	Health condition
P1	Male	40	14	Married	Volunteer	Hemiparesis
P2	Male	35	12	Never	Unemployed	Hemiparesis
P3	Male	31	12	Never	Paid work	PTB
P4	Female	35	12	Never	Unemployed	PTB
P5	Female	48	8	Married	Self employed	PN
P6	Male	45	3	Never	Unemployed	PTB
P7	Female	26	9	Married	Paid work	Body Pain
P8	Female	40	3	Separated	Unemployed	PTB

[a] Total years of school and post school studies; PTB, pulmonary tuberculosis; PN, peripheral neuropathy.

Table 2. WHODAS 2.0 domain scores.

Code	Cognition	Mobility	Self care	Getting along	Life activities	Participation
P1	2.7	4.8	3.5	3.0	5.0	4.9
P2	1.2	5.0	4.3	1.8	5.0	2.6
P3	1.7	4.2	2.8	1.2	4.5	3.3
P4	1.3	2.2	4.0	2.8	2.9	1.9
P5	1.3	1.6	1.0	1.4	1.6	1.3
P6	3.8	4.6	2.8	1.8	5.0	4.1
P7	1.2	1.2	1.3	1.2	2.5	2.0
P8	1.5	3.2	1.8	1.0	4.5	2.5

Interview data

The emergent themes from the eight interviews reflect repeated participant responses. Participants elaborated on three main themes: the understanding of their health condition, their activity limitations and participation restrictions and their experiences with rehabilitation. These themes are discussed in more detail below.

Understanding of health condition and impairment

Only one of the eight participants indicated that they fully understood the reason for their admission to the hospital. For instance a female patient (participant 8) who was referred for pulmonary tuberculosis (PTB) and experienced high degrees of disablement in the mobility and life activity domains revealed:

> ''I was ill and I did not know what was wrong with me.'' (Participant 8)

Although participants agreed to the researcher accessing their patient files and information only three participants alluded to their HIV status, with only one of the participants, Participant 5, directly referring to the disease.

> ''Then I started my AIDS''. (Participant 5)

In contrast to the relative silence regarding their HIV status, most of the participants readily discussed issues relating to their prescribed medication, although only two participants actually mentioned the phrase ''ARVs'' or a similar term. This is despite the fact that all of the participants, with the exception of Participant 1, had, according to their patient files, been initiated on ARVs at the time of the interviews. This silence might point towards learnt behaviour: trying to avoid HIV disclosure through identifying medications as ARVs.

Beside the lack of understanding their health conditions and silences around HIV all eight of the participants in this study described a wide range of issues on the body function level, of both a physical and cognitive nature. Pain was a common theme emerging from the data. For instance Participant 7, a female patient, referred to the hospital for non specific ''body pain'' describes her experience below:

> ''Yes, my body is also itchy. It's my bones, my bones are painful. They get painful especially if I have been too cold, they get painful''.

Fatigue and tiredness was another theme described by the patients. Participant 8, diagnosed with PTB, described how her illness left her without energy:

> ''I got ill in such a way I did not have power''. (Participant 8)

Similarly, patients discussed other changes in their sensation. Some participants described signs of peripheral neuropathy, a condition in which the individual feels severe irritation on the hands and feet. Participant 6, also diagnosed with PTB, described this sensation in the following way:

> ''The illness got me when I was in the hospital … my feet were shocked where I felt pins and needles underneath my feet and toes. Then my legs got shocked''. (Participant 6)

Similar to their HIV diagnosis, these comments show that participants were able to describe symptoms but not able to actually label their health condition which was the reason for their referral in the first place. Again, this might point towards a lack of understanding of the actual health condition that the patients were referred to for physiotherapy.

Activity limitations and participation restrictions

A number of participants recorded very high average scores in the mobility and self care domains of the WHODAS 2.0 prior to their rehabilitation. Participant 1, a male patient who reported extreme difficulty or an inability to do any of the tasks outlined in the mobility domain and moderate to severe difficulty in the self care domain, gave the following response which illustrates how severely activity limitations can affect a participant's domestic life in a period of acute illness:

> ''I was confined to my bed, I could not do things for myself. I had to be helped. Even to the toilet, even to take my baths in the morning. Some people had to come and bath me on the bed, you can imagine. Such an experience, I have never had it in my life''. (Participant 1)

However, disability was still prevalent in the patients even after a period of acute illness had ended. The above participant, for instance, revealed how his loss in mobility affected his working and social life long time after his acute illness:

> ''I tell people I was not working before and now I am not able to go around for evangelism the way I used to before''. (Participant 1)

For this individual, the fact that he could not walk for long distances was a severe set back, reducing his participation in his community and impacting on his spiritual life.

The interviews also revealed other long term effects on the participants' lives. In particular the ability to work was discussed by a number of the participants. Similar to the quote above, Participant 3 described how his illness and his loss of activity continues to limit his ability to secure and retain paid employment. In the interview he described how he was not able to keep up with the standards requested at work:

> ''No, it's because when I got them [work opportunities] I couldn't reach the expected work levels when I was employed''. (Participant 3)

Participants' description of the rehabilitation experience

The interview responses by the eight participants included both positive and negative experiences of the rehabilitation process. Five of the participants described how rehabilitation had benefitted them with respect to specific activity limitations such as self care and domestic activities. For instance, Participant 4 discussed his improved ability to perform self care, an area which is particularly important to patients as it may improve their dignity and also reduce reliance on other household members, who can then focus on providing an income instead of care:

> ''Yes it helped me. I now can wake up and walk to the toilet. I couldn't walk at all before''. (Participant 4)

While there were no reports reflecting negative effects of the rehabilitation, one participant reported that despite the intervention his loss in body function was so severe that he felt as if he was dying.

> ''No it [physiotherapy] has not helped me because I am still dying''. (Participant 6)

This response may also indicate a lack of hope and a possible link to mental health and experiences of depression. It is possible that his therapy package needed some additional support such as a support group or mental health intervention. His experience also speaks to the comments by other participants who provided a more positive testimony in regards to rehabilitation. These participants also reflected on positive attitudes or mental strength being a key factor in the success of their rehabilitation progress. For instance participant 3, who was diagnosed with PTB, elaborated on the reasons that he attributed to the improvement of his condition. He identified his own commitment during the rehabilitation process as crucial for this process:

> ''It was commitment… Yes I would [come back for treatment], since all that I want is to be better''. (Participant 3)

Unfortunately a number of participants revealed that they were unclear about the purpose of the rehabilitative sessions that they received. The responses of three participants (Participants 3, 7 and 8) revealed that the participants were unaware of having received any rehabilitation at all. For instance, Participant 7 reported that she had not received any therapy, beside the fact that her patient chart indicated that she participated in at least three individual rehabilitation sessions.

> ''There was a lady who came to me and asked questions then wrote down but she never showed me anything. She said she would come back but never came back''. (Participant 3)

This lack of understanding could be associated with a lack of quality of care or a lack of knowledge around the purpose of rehabilitation with regards to improving the patient's health condition. It could also be associated with a degrading ability to memorise and comprehend important information. All are plausible explanations that this study could not explore further.

The above responses demonstrate that despite receiving similar rehabilitation, individual patients will have very different experiences and opinions of the value of receiving this care. Therefore this study also highlighted the challenges associated with providing this care.

Barriers to rehabilitation

Issues around barriers and obstacles emerged throughout each of the eight interviews. Each of the participants faced challenges while accessing rehabilitation and healthcare services. All eight participants reported financial barriers. This is mirrored by the difficulties the researcher had calling the participants for interviews, in most cases having to phone family members or friends of the participants to arrange a suitable date and time to meet. The cost of making a phone call was beyond many of these participants' means and therefore they probably used pay as you go cards when they were able to afford them. As a result, the ability to contact participants via phone fluctuated. For all participants, their poverty was compounded by their difficulties in returning to work. Most participants reflected that they had difficulties in paying for transport and getting to and from the hospital. None of the participants owned a car or other type of transport and therefore used the common South African taxi transport system. For instance, Participant 5 described the financial cost of her attending one rehabilitation session:

> ‘‘When I come, I pay $4 for physio. Then I [also] pay for the taxi. It's $1 to come here, $1 to go back, you see?’’ (Participant 5)

Transport cost is an issue for many people in South Africa, who will therefore choose to walk. However, for these participants walking was a challenge as a result of their mobility limitations. Participant 6 described that even walking a short distance of about 50 m from the outpatient department (OPD), where the local transport drops them, to the physiotherapy department at the hospital was a considerable challenge.

> ‘‘I easily get out of breath and I have no power, walking from OPD to here I was in trouble’’. (Participant 6)

Seven of the eight participants discussed the possibility of receiving rehabilitation in their homes as a positive alternative, due to the difficulty they had in getting to the hospital for treatment. Participant 2, for instance, elaborated on this:

> ‘‘I don't have it [transport], but if the physiotherapy can have it, they can reach that home. Then I will be glad for them to come’’. (Participant 2)

Issues around transport were mentioned by most participants and were either related to financial issues or the ability to use the transport and cope with a smaller walking distance that still needed to be overcome.

Discussion

Increasing knowledge of health condition and medication

Both HIV and PTB are very prevalent conditions in South Africa [9] and patients need to understand these conditions in order to conduct the appropriate health seeking behaviour. It is, therefore, alarming that the data indicates that some of the participants did not fully understand their conditions, the medication and therapy associated with it. This is despite the fact that the patients had seen several health care professionals. It is possible that this phenomenon is related to a lack of education in this population as well as the memory loss associated with HIV [19]. Ideally, an institution's multi-disciplinary team should work in concert to educate patients. The reality, at this institution (and many other South African public sector hospitals) is that they do not have the financial resources to employ the necessary numbers and diversity of health professionals to give the required assistance and education to the very high numbers of PLHIV. The multi-disciplinary team at the study setting is limited to doctors and nurses and one qualified physiotherapist, with no psychologist, occupational therapist or speech therapist employed at this hospital, a relatively large facility serving a huge population [17]. This lack of knowledge therefore may be seen as a failure of the health system in many respects, rather than the fault of individual patients. A recent study targeting health care workers in the same setting indicated that nursing and other non-therapy staff exclusively used referral systems in cases of disablements in their patients living with HIV [20]. The study also revealed that these health care workers were not aware of what happened with these referrals and what kind of additional intervention or therapy their patients were taking up. This indicates a lack of communication between the multi-disciplinary team in this setting. However, one also needs to understand that this setting includes a number of structural challenges. For instance any patients requiring therapy separate from physiotherapy interventions will be referred to other health facilities with little room for staff interactions, apart from written communication.

In contrast to the above reality at the study setting, literature indicates that inter-disciplinary teams of healthcare professionals involved in rehabilitation can offer a range of rehabilitative services through a comprehensive, coordinated and collaborated programme [21]. As members of the multi-disciplinary health care team, physiotherapists spend a considerable time with patients and have ample opportunities to educate patients about their condition. Lack of communication within the multi-disciplinary team can influence quality of care for the patients [22]. It is thus vital that physiotherapists find out the exact nature of each of their patient's diagnosis from the attending doctor or nurse, so as to assist in reinforcing patients' knowledge of their health conditions beyond rehabilitation and in so doing improve treatment outcomes. Information needs to be provided both to and from the rehabilitation staff. Based on this information, it may also be of value to integrate written and graphic material (in simplified formats) on common health conditions related to HIV within the physiotherapy treatment environment. This could be posted on clinic and ward noticeboards and provided to patients throughout the rehabilitation process.

Tackling stigma

Most participants were evasive around the topic of HIV with only one participant referring directly to his HIV status. This is despite all participants having been counselled regarding their positive HIV status (confirmed by their medical files). The silence surrounding one's HIV status is common amongst PLHIV throughout the world [23] and may be further fuelled in South Africa by the prevailing stigmatisation of PLHIV in their own communities [24–26]. The stigma associated with HIV and AIDS is further compounded by the stigma of disability [20,27]. From their interview responses, it would appear that the participants were far more comfortable talking about the symptoms, impairments and activity limitations associated with HIV than they were discussing the disease itself. Being aware of, and sensitive to, issues of denial and stigma when treating PLHIV may enable therapists to better gain patients' trust and further improve the effectiveness of prescribed treatments. This awareness can be attained and retained by regular staff training in the form of multi-disciplinary workshops and individual professional development activities.

While physiotherapists are not involved in prescribing or dispensing medication, they should be aware of the potential side effects of HAART medication, which can raise further issues of stigma and negatively affect adherence [7]. Physiotherapists can also play a key role, as members of the wider multi-disciplinary team, in reinforcing and encouraging PLHIV to adhere to taking their tablets on time every day. Non adherence to HAART is a major concern as it leads to faster disease progression as well as the development of resistant strains of HIV [28]. Particularly in an HIV endemic country, a review of the undergraduate physiotherapy training curriculum may be required to ensure that all qualifying physiotherapists are informed of the indications and side effects of HAART medication as well as knowledge related to opportunistic infections. Postgraduate training and multidisciplinary workshops can ensure that qualified physiotherapists are able to update their knowledge in this area.

Overcoming impairments, activity limitations and participation restrictions

Some of the health conditions and physical impairments related to HIV are documented and include weakness or paralysis of muscles [29], peripheral neuropathy [30], inflammatory joint conditions [31], impaired lung function [30] and the widespread prevalence of pain [20]. Physiotherapists are directly concerned with treating the impairments related to the neurological, musculoskeletal and respiratory complications of HIV infection, as well as providing rehabilitation to counter the activity limitations and participation restrictions related to these impairments. The participants' responses in this study highlighted the close inter relationship between impairment (e.g. weakness) and activities (e.g. going to the toilet and bathing), thus confirming the value of considering a patient's overall health holistically via the use of the ICF framework [13]. It is vital that physiotherapists identify all levels of disability that patients may experience with regard to their participation in school, work or community pursuits. Physiotherapists could use the WHODAS 2.0 instrument to collect this information. This tool has been found to be a valid measure of disability across different populations [32,33].

It is vital that physiotherapists are involved in the design and development of rehabilitation interventions that address the various impairments, activity limitations and participation restrictions facing PLHIV. These should involve the wider multidisciplinary team, patients' families and most importantly each individual patient. In this context it is imperative that alternative rehabilitation interventions or approaches (e.g. to overcome financial barriers or communication barriers within the rehabilitation team) are explored in the South African public health sector.

In addition to the above, physiotherapists and other rehabilitation professionals need to be closely involved in the development and provision of assistive devices. Patients may need support with mobility or with self care at home that goes beyond rehabilitation sessions. However, the cost of these assistive devices, such as walking aids and wheelchairs, often exceeds the budgets of public service rehabilitation services and is certainly out of reach of many patients themselves. Novel, low cost solutions need to be researched and developed and where appropriate, the use of these devices must be incorporated into the education of physiotherapists and other rehabilitation professionals.

A significant challenge to physiotherapists is the frequent presence of cognitive deficits and mental health conditions related to HIV [4]. These deficits may include loss of concentration, poor memory and social withdrawal [28]. A systematic review of the mental health of PLHIV in Africa indicates a prevalence of 44 55% of psychiatric disorders in PLHIV with a psychiatric morbidity of 75% noted in one Zimbabwean study [34]. Anxiety or depression are the most common mental health problems with 20 30% of PLHIV being diagnosed with depression and 30 64% of PLHIV experiencing symptoms of depression [34]. Studies suggest that aerobic exercise and resistance exercise interventions, which are both routinely included in physiotherapy led rehabilitation programmes, are linked to improvements in the psychological status of PLHIV [11,12]. This again points to the importance of the multi disciplinary team working together, in this case the professions of physiotherapy and psychology, in an effort to improve both physical and cognitive treatment outcomes. Although physiotherapists are not qualified to give psychological counselling, they are able to engage with the patient in regards to his mental wellbeing and are able to provide referrals where necessary. Consequently, physiotherapists need to engage with mental health professionals in their local area and discuss the appropriate screening tools as well as indications for referral.

Rehabilitation experience and structural barriers

Five of the eight participants reported how the rehabilitation helped them overcome their activity limitations and participate more fully in life situations. By employing a combination of resistance and aerobic exercise interventions, rehabilitation had a largely positive impact on these participants. This supports the evidence revealed by two systematic reviews outlining the positive effects of exercise for PLHIV [11,12]. Not all the interview responses, however, were positive regarding individual experiences of rehabilitation, with three participants reporting that they did not receive any treatment from a physiotherapist. These responses are directly contradicted by information contained within these participants' patient files, which contain written evidence that all three of them were in fact treated by the physiotherapist on two or more occasions. It is possible that participants simply forgot that they had received any rehabilitation, which in some cases was a month before the interviews took place. Alternatively, this memory loss may indicate possible HIV related cognitive deficit. Research conducted in a southern African context [35 37] has outlined the neurocognitive deficits related to HIV, which include problems with memory. Whatever the explanation for this apparent anomaly, the onus rests on physiotherapists to continually educate patients with regard to both a wider explanation of the profession itself as well as the specific goals of each individual rehabilitation programme. Where possible, caregivers should also be included in this education process, to aid patient recall and adherence to their rehabilitation. Simplified information material might also be helpful to the patients and enable them to self administer therapeutic exercises where appropriate and in doing so reinforce their understanding of their conditions as well as increasing activities related to the improvements of this condition.

Participants reported a number of barriers that limited their ability to access continued rehabilitation. All interviews indicated that the financial and physical challenges of getting to the hospital for treatment are significant factors dissuading patients from returning for further care. These barriers were mainly related to transport costs and long ways to the physiotherapy department (even within the hospital premises). The fact that 6 out of the 14 patients were also lost to follow up indicates an accumulation of barriers to access services as well. Patients at the hospital are requested to pay a nominal amount of $4 for each physiotherapy treatment session. This may seem a small amount of money, compared to private physiotherapy rates, which can be 10 times that amount, depending on the type of treatment provided [38]. However, $4 is still beyond the means of a large number of unemployed South Africans, who do not necessarily receive any unemployment benefit. These financial difficulties were further exacerbated, in some cases, by the physical difficulties that participants had in walking from their home to a taxi and from where the taxi dropped them to the hospital. Home visits might also be a feasible option for this setting as the community outreach programme of this hospital is already visiting homes in its home based care service. However, at the time of investigation, the community health care workers at the study site were not trained to perform any type of rehabilitation for these patients.

The barriers discussed by the eight participants in this study reflect a reality that appears contrary to the guidelines written by the South African Department of Health (DOH) in 2001 that promote the treatment of people in or near their homes, in order to respond to the needs of people and encourage traditional community life [39]. Now, 12 years later, this study indicates that in this semi rural KwaZulu Natal hospital patients still have to commute considerable distances, at great financial and physical cost, in order to access the rehabilitation they require. To the researchers' knowledge, of the 200 community rehabilitation facilitators working in over 100 communities in South Africa [40], none of them work in the geographical area served by the study hospital, an area with a population of over 750 000 people [17].

People living in the Western World have improved access to rehabilitation professionals, as compared to their southern African counterparts, simply as a result of there being significantly more qualified rehabilitation professionals in the West, per head of population as well as more accessible and affordable public transport. Recent World Health Organisation statistics reveal that there are more than 20 physiotherapists per 10 000 population in Finland as compared to less than two physiotherapists per 10 000 population in South Africa [41]. Denmark has approximately 11 occupational therapists, compared to less than one occupational therapist in South Africa, per 10 000 population. Those responsible for the allocation of funding and resources may argue that the South African government cannot afford to train and place more rehabilitation professionals. However, Green et al. [42] argue that improving the delivery of services to PLHIV not only makes clinical sense, it also has the potential to save healthcare systems money they would have otherwise spent on hospitalisation due to acute illness and the provision of second and third line HAART regimens. Thus, by improving rehabilitation for PLHIV it may be possible to decrease the number of hospital visits that PLHIV are required to make due to exacerbation of any of their physical impairments. It may also hold potential to improve adherence to HAART, as people are less likely to continue to experience severe side effects. To paraphrase, Nixon et al. [7], while medicine (in the form of HAART) may add years to the life of PLHIV, it is rehabilitation that can add life to years.

Study limitations

Of the 14 individuals who satisfied the inclusion criteria for this study and completed the WHODAS 2.0, only eight participants were able to attend the post rehabilitation interviews. This study explores the experience of these eight participants and is not representative of all PLHIV in South Africa. Thus, more value may have been added to the findings had it been possible to interview more participants. Five of the eight participants were interviewed by the isiZulu speaking research assistant. While the principal investigator was present at all five of these interviews and participated in the asking of questions, via translation, it is possible that some of the meaning may have been lost in the translation and transcription of the interview data. Although this was unavoidable due to the language barrier between the researcher and the participants, it should be noted as a limitation to this study. To attenuate this potential limitation, the research assistant received thorough prior training to help ensure the quality of the interview delivery.

Conclusion

While the majority of participants found the rehabilitation they received to be beneficial, they also reported a number of barriers that they faced with regards to receiving continued rehabilitation. These barriers included a lack of transport to get to their nearest hospital, a lack of money to pay for transport and continued rehabilitation, physical difficulties in accessing rehabilitation services as well as a dependence on others to enable them to access this care. In addition, participants experienced multiple forms of disability (such as pain, mobility restrictions, self care and mental health problems), which require a holistic approach to care. Mental health issues related to HIV were also identified in this study and may be a result of additional health conditions and influence adherence to treatment (HAART and rehabilitation) negatively.

This study suggests that an alternate model of delivering rehabilitation to PLHIV in South Africa, which addresses in particular structural and communication barriers, may need to be developed. This model should respond to the varying needs of this vulnerable population and be designed to promote increased and improved access to rehabilitation services. The adaptation and assessment of rehabilitation models for PLHIV in South Africa and the responsibility of implementing these models into practice should directly involve health professionals within in the field of rehabilitation, working together with the wider multi disciplinary healthcare team.

Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the article.

References

1. UNAIDS. 2010. Report on the global AIDS epidemic. Available from: http://www.unaids.org/globalreport/Global report.htm [last accessed Mar 2013].
2. Actuarial Society of South Africa. 2011. ASSA 2008 model. Available from: http://aids.actuarialsociety.org.za/404.asp?pageid 3480 [last accessed Mar 2013].
3. Rusch M, Nixon S, Schilder A, et al. Prevalence of activity limitation among persons living with HIV/AIDS in British Columbia. Can J Pub Health 2004;95:437 40.
4. Hanass Hancock J, Regondi I, van Egeraat L, Nixon S. HIV related disability in HIV hyper endemic countries: a scoping review. World J AIDS 2013;3:257 79.
5. Hanass Hancock J, Regondi I, Naidoo K. What drives the interrelationship between disability and HIV in Eastern and Southern Africa (ESA)? AJOD 2013;2:1 6.
6. WHO. 2011. World report on disability. Available from: http://whqlibdoc.who.int/publications/2011/9789240685215 eng.pdf [last accessed Mar 2013].
7. Nixon S, Forman L, Hanass Hancock J, et al. Rehabilitation: a crucial component in the future of HIV care and support. SA J HIV Med 2011;6:12 17.
8. Myezwa H, Stewart A, Solomon P, Becker, P. Topics on HIV/AIDS for inclusion into a physical therapy curriculum: consensus through a modified Delphi technique. J Phys Ther Edu 2012;26:50 6.
9. Jenkins SK. AIDS: education and prevention. Indiana (IN): Author House; 2009.
10. Hanass Hancock J, Nixon S. The fields of HIV and disability: past, present and future. J Int AIDS Soc 2009;12:28.
11. O'Brien K, Nixon S, Glazier R, Tynan AM. Progressive resistive exercise interventions for adults living with HIV/AIDS (Review). The Cochrane Library. 2009. Available from: http://www.thecochranelibrary.com [last accessed Mar 2013].
12. O'Brien K, Nixon S, Tynan AM, Glazier R. Aerobic exercise interventions for adults living with HIV/AIDS (Review). The Cochrane Library. 2010. Available from: http://www.thecochranelibrary.com [last accessed Mar 2013].

13. WHO. 2001. International Classification of Functioning Disability and Health. Available from: http://www.who.int/classifications/icf/en/index.html [last accessed Mar 2013].
14. Van As M, Myezwa H, Stewart A, et al. The International Classification of Function Disability and Health (ICF) in adults visiting the HIV outpatient clinic at a regional hospital in Johannesburg, South Africa. Aids Care 2009;21:50 8.
15. Smith DW, Thomasson AL. Phenomenology and philosophy of mind. New York (NY): Oxford University Press; 2005.
16. WHO. 2010. WHO disability assessment schedule 2.0. Available from: http://www.who.int/classifications/icf/whodasii/en/index.html [last accessed Mar 2013].
17. St. Mary's Hospital. 2012 About us. Available from: http://www.stmarys.co.za/pages/40327 aboutus.htm [last accessed Mar 2013].
18. Cresswell JW. Qualitative inquiry and research design: choosing among five traditions. London: Sage; 1998.
19. Rackstraw S. HIV related neurocognitive impairment a review. Psychol, Health Med 2011;16:548 63.
20. Van Egeraat L. HIV related disabilities: an extra burden to HIV and AIDS health care? Final Report. University of Amsterdam, Amsterdam.
21. Jelsma J, Mielke J, Powell G, et al. Disability in an urban black community in Zimbabwe. Disabil Rehabil 2002;24: 851 9.
22. Atwal A, Caldwell, K. Do all health and social care professionals interact equally: a study of interactions in multidisciplinary teams in the United Kingdom. Scand J Caring Sci 2005; 19:268 73.
23. Parker R Aggleton P. HIV and AIDS related stigma and discrimination: a conceptual framework and implications for action. Soc Sci Med 2003;57:13 24.
24. Kalichman SC, Simbayi LC. HIV testing attitudes, AIDS stigma, and voluntary HIV counselling and testing in a black township in Cape Town, South Africa. Sex Trans Infect 2003;79: 442 7.
25. Visser MJ, Makin JD, Lehobye K. Stigmatizing attitudes of the community towards people living with HIV/AIDS. J Comm Appl Soc Psych 2006;16:42 58.
26. Campbell C, Nair Y, Maimane S, Nicholson J. 'Dying twice': a multi level model of the roots of AIDS stigma in two South African communities. J Health Psych 2007;12:403 16.
27. Rohleder P, Braathen SH, Swartz L, Eide AH. HIV/AIDS and disability in Southern Africa: a review of relevant literature. Disabil Rehabil 2009;31:51 9.
28. Dudgeon WD, Phillips KD, Bopp CM, Hand GA. Physiological and psychological effects of exercise interventions in HIV disease. AIDS Pat Care STDs 2004;18:81 97.
29. Nixon S, Cott C. Shifting perspectives: reconceptualizing HIV disease in a rehabilitation framework. Physio Can 2000;52:189 207.
30. Myezwa H, Stewart A, Mbambo N, Nesara P. Status of referral to physiotherapy among HIV positive patients at Chris Hani Baragwaneth Hospital Johannesburg South Africa. SA J Physio 2007;63:27 31.
31. Tehranzadeh J, Ter Oganesyan R, Steinbach LS. Musculoskeletal disorders associated with HIV infection and AIDS. Skel Radiol 2004;33:249 59.
32. Garin O, Ayuso Mateos J, Almansa J, et al. Validation of the ''World Health Organization Disability Assessment Schedule, WHODAS 2'' in patients with chronic diseases. Health Qual Life Outcomes 2010;8:1 15.
33. Ustun TB, Chatterji S, Konstanjsek N, et al. Developing the World Health Organization Disability Assessment Schedule 2.0. Bulletin of the World Health Organisation 2010;88:815 23.
34. Brandt R. The mental health of people living with HIV/AIDS in Africa: a systematic review. African J AIDS Res 2009;8:123 33.
35. Joska JA. Clinical correlates of HIV associated neurocognitive disorders in South Africa. AIDS Behav 2010;14:371 8.
36. Lawler K. Neurocognitive impairment among HIV positive individuals in Botswana: a pilot study. J Int AIDS Soc 2010;13:15. doi: 10.1186/1758 2652 13 15.
37. Lawler K. Neurobehavioral effects in HIV positive individuals receiving highly active antiretroviral therapy (HAART) in Gaborone, Botswana. PLoS One 2011;6:17 33.
38. HealthMan. 2012. Physiotherapy costing guide 2012. Available from: http://www.mm3admin.co.za/documents/docmanager/419AE5A4 F8C7 11D4 9FB7 0090279A6A88/00023508.pdf [last accessed Mar 2013].
39. Department of Health. 2001. National guideline on home base care/community based care. Available from: http://www.doh.gov.za/docs/factsheets/guidelines/homecare [last accessed Mar 2013].
40. Chappell P, Johannsmeier C. The impact of community based rehabilitation as implemented by community rehabilitation facilitators on people with disabilities, their families and communities within South Africa. Disabil Rehabil 2009;31:7 13.
41. WHO. 2011. World report on disability. Available from: http://whqlibdoc.who.int/publications/2011/9789240685215 eng.pdf. [last accessed March 2013].
42. Green K, Dix O, Mwangi Powell F, et al. Where's the care in the post ART era? Africa Health 2012;34:19 21.